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Thoughts of a palliative care nurse in times of pandemic

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Thoughts of a palliative care nurse in times of pandemic

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Abstract

This narrative presents a series of stories (interactions) lived by a palliative care nurse during the time of COVID-19, a time when we tirelessly prepare to help the services that need us, but we have little preparation of ourselves for the changes that we will have to face in the care of our patients and families. It shares the lived experiences, difficulties, emotions lived by me but shared by so many around the world. It also tries to show that despite the scarcity of physical presence, creativity and commitment to patients and families make us go beyond ourselves and continue to make a difference by saying we are here!

Keywords

COVID-19, palliative care, patient experience, patient communication, patient-centered, isolation, grief

Introduction

I bring you a personal narrative, deeply rooted in the present days that we live. A journey through a maze of different challenges and emotions. A journey, as a palliative care nurse during the time of COVID-19, often marked by doubt, anguish and restlessness with frequently asked questions, “Are we living? Are we allowing patients and families to live, or are we simply guaranteeing life?”. Times of strangeness, of complexity, of uncertainties but also times of surprise, solidarity, compassion, and gratitude.

General Narrative, A Synopsis of the Story Highlighting Relevant Moments

The pandemic was declared in mid-March, and from that moment on everything changed. I felt, like many of us since those early days, a mixture of emotions difficult to name. Fear and insecurity, for starters. An immense sadness, which was not just sadness, but without ceasing to be. An overwhelming anguish, which was not just anguish, but without ceasing to be. A feeling of limited possibilities, of no future existence, of emptiness, that was not just emptiness, but without ceasing to be. Grateful to David Kessler for making me realize that I was in grief. Not one, but several at the same time. And we do it in masse “...we're feeling a number of different griefs. We feel the world has changed, and it has. This is hitting us, and we're grieving. Collectively. We are not used to this kind of collective grief in the air... There is a storm coming. There's something bad out there. With a virus, this kind of grief is so confusing for people. Our primitive mind knows something bad is happening, but you can't see it.”¹

In those early days, in the middle of that unexpected grief, I never felt brave, certain, dependable, fearless, like a heroine, as the media and society in general portrayed us. Unlike other moments of grief, there was no time to stop.

I am a palliative care nurse in COVID-19's times. A time when teams were asked to make an important effort in supporting “COVID” services, with the number of national and international documents multiplying. We all work long hours to develop protocols, instruments, train and inform colleagues of good practices in distance communication and symptom management. And in this desire to help as much as possible the patients and families affected by COVID, we did not prepare ourselves. No one could have predicted the collateral devastating effects that the pandemic would have on our patients and families. Nobody warned us of what we would feel daily in palliative care services. Nobody advised us to try new coping strategies because the previous ones might not be available or would not work anymore. No one whispered to prepare ourselves because new forms of suffering, which we never imagined, would emerge. Nobody told us that every day our hearts would bleed deeply.

In these days, the bridge to another person is done most of the time by phone. First call is to a nursing home. I talk to my colleague about two elderly people we are following. She tells me they are “stable” and that she is deeply grateful for the call, “Thank you so much for calling, for caring about us,” she said. She tells me about the isolation they are subjected to, without any kind of external visit, the “mirror shifts” they adopted, the silence that flooded the institution, the sadness in which their residents plunged, and she confided in me, “Many will not survive this; they will not die from the virus; they will die feeling abandoned, not only by their family, but by all of us.” I feel what Jorge Sousa Braga

wrote, "Now it was the desert that settled among us,"² and I think how many lives we will lose while we try to maintain Life.

Next call is to the sister of a patient who died in the hospital last week. Two sisters who lived together for 35 years, who took care of their parents until they died. A sister, age 88, primary caregiver, who told me one week ago that when her sister died "she would be alone in this world." A tearful voice answers, "Oh my dear nurse..." and she goes on in uncontrollable crying. When she started talking, the immediate subject is the funeral rituals or their absence. "It was so sad, nurse. My little sister, dear to all, who helped so many people in her life, buried like a pauper, like an animal. There was me, her, poor thing in the coffin that wasn't even open, and a neighbor who didn't leave me and the priest. When it was finished, my neighbor went to one side and I to the other. Without a consolation, a hug, nothing. She didn't deserve it ... and neither did I. We didn't hurt anyone, nurse."

I do not know what will happen to all the mourners of COVID's time, but I know it will not be easy times for those of the future.

Dying is a solitary act. You die, as a general rule, when you do not want to. For reasons not imagined. In a place that was not chosen. In a way that, in almost everything, contradicts what was wanted. Sent to a filigree fragility that cannot be escaped. And despite the desire of all those who love us, and the way they accompany us, we die alone. But to die without being able to give a hand to the one you love or without having the right to a funeral without goodbyes and hugs, without the gratitude ceremony of those who insist on its presence, showing us recognition for having existed, and without people who like us can cry in each other's company reduces death to an aseptic imperative and to a sanitary urgency that humiliates us all.

Dying alone is sad; it is very sad! To disappear with only us and almost nobody else is to die twice. All at once.

And even worse is that the people who love us and who cannot be with us when we die because of the danger of contagion, and who cannot accompany us after dying so that our death does not infect them, die with us. Several times. Because they blame themselves for having "let" us die. Because they blame themselves for having "left" us to die without anyone. And because they blame themselves for not even saying goodbye to us. If the one who dies alone dies twice, the one who "lets" the other die like that is "contaminated" by a figure of death that torments, embarrasses and kills. Oftentimes. If losing someone precious is already the most unjust thing that exists, losing someone this way is, by itself, among everything else that hurts the most, the thing that is most contagious with death all our life.³

And maybe that's why some of our patients and families refuse admissions to the hospital and other institutions. I spoke to the wife of a patient who is waiting for admission to a long-term care facility "Oh, nurse, I was thinking, and I don't want him to go there." After a lot of talking about the

pros and cons of the decision, she confesses, "You know, it already costs me a lot to take care of him, but if he goes to the unit, I will be alone ... he is my only company." I asked if she needed anything else. She said, "Today I don't need anything; can you call tomorrow?" "Do you want me to call you tomorrow?" I asked. "If you could, I would be grateful. I don't talk to anyone else these days." I say "yes" that I will call the next day at 11 am. "Okay, that's fine. Now I know that the kind nurse calls every day at 11 am," she said. And so, it has been. Every day at 11 am the phone rings at someone's home just to ask, "Good morning, how are you today?"

Then I had to explain to a daughter (who I had never met) that her father's paraplegia, (he was admitted to the hospital and she has not seen him for two weeks), will not revert because it is a result of the process of metastasizing from the cancer. And this incredibly painful conversation was made by phone. When I hung up, I became aware of the number of people who are going to die in the hospital and the number of family members we talk to, some daily, who we will never meet. I realize I can no longer think clearly and draw on the empathetic statements I've become accustomed to using in conversations like these.⁴ In the end, to aggravate my anguish, they always repeat, "Thank you so much for worrying about us." In these times we feel, collectively, so humbled, My God.

Then we went to see a patient admitted to the emergency department. Not with COVID but with an advanced cancer. He is 65 years old, and when we talk about the depth of knowledge of the situation, I realize that he is complete and realistic. As he speaks, he cries and says to me, "It's all worse because of the princess." The princess is his granddaughter who turned 4 yesterday and who has not been physically with him for 4 weeks. He thinks he will not be able to see her anymore due to this isolation, because he feels very ill and may not live much longer. From what we understand from his clinical situation, I know he may be right, so I do not try to cheer him up or give him false hope. I listen to him and allow him to express his emotions and fears.

We created a holding space,⁵ and I realize that "temporary," proclaimed by the leaders of this world, does not have the same meaning for all of us. For all those who have a death announced, this "temporary" of today will become permanent, and this will be one of the saddest results of these times. A time of lives on hold. A time of interrupted life. I realize now that the idea conveyed by the media that we are all in the same situation is not at all true; we are, in fact, facing the same storm, but we aren't all in the same boat.

Return to the office for another phone call to someone who lives in a small village in the interior of this country. Far from everything. A difficult interior in times of

normality. An overwhelming interior in times of a pandemic.

“I called to see how you are doing, what the days have been like.” An elderly woman with a life-threatening disease in rapid progression with symptoms that don’t allow good days says, *“You know, nurse., it's this fatigue. This sick tiredness. I have no desire to do anything. I don't have any pain, no, sir. But this fatigue and seasickness. I would like to be able to eat something, but I don't want anything.”*

This will of not wanting anything caused by an advancing illness is lived within four walls of a humble, small house, but above all, without witnesses, because she lives completely alone.

“It has been hard, nurse, the son calls all the time... and cries, but what is there to do? It's this crazy bug. He wants me to go to Lisbon, but I want to stay here, in my little house.”

I asked if there was anyone else who supported her, but she said, *“None, nobody nurse, no one comes here, to this forgotten land of God. But do you know what hurts the most? You don't hear anything ... nothing at all. Antónia dos Currais used to come here every day, in the morning and in the afternoon when she went to take care of the vegetable garden. She would pass by the door and shout – ‘Oh Maria, are you better?’ And I would go to the gate and talk for a while. She doesn't pass anymore. Her son took her to Aveiro. Hermínia da Fonte, who passed here in front at lunch, I haven't even seen her. The windows have been closed for days. I don't even know if she left, if she went to the hospital, if she died. And that's how it is, they disappear, and no one is left ... even the priest stopped coming.”*

We talk a little more about how the day goes. *“... Wait! Someone is calling me from the gate?”*. I hear the slow steps in the distance, some imperceptible words and then, *“It was my ‘comadre,’ she had to go to the parish council and stopped here to leave me a custard tart. She says that she will be back next ~~the~~ week”* (a phrase that took a long time to be said due to evident fatigue). I ask if she is feeling short of breath. She tells me no, *“It is this sick tiredness. I'll be like this very quickly, but it will pass. Now I will lie down a little while and relieve it.”*

I ask if she was going to see or speak to anyone else today. *“Nobody. My son usually calls in the evening, my neighbor who used to come here after dinner, no longer comes ... no one leaves their house. I'll lie here resting”*

We talked about the possibility of some more formal support. *“No, not that. I will stay here in my house, and the nurse calls by phone...and that's enough. Thank you so much for the preoccupation you all have with me.”*

So, on days like today (unfortunately there are too many), I am not sure if we all will be OK. A future after these times in which many buried their loved ones alone, without witnesses, in which many grandfathers no longer embraced

their princesses, in which many parents do not caress their children's faces, in which many elderly couples resist together, but isolated, so many people will grieve deeply in this time that was not temporary; it was the last time.

And life, in these times, is made up of these different temporalities, a patchwork of what we were, what we are and what we will be after. Quoting Juliana Dantas, “I think that life lives in that place. The minute before everything changed. And the minute that everything changes. And, in the minutes that follow. In all, after all... the plans are no longer the same, we are no longer the same. Reinventing ourselves is solid ground - and also a tightrope.”⁶

But regardless of my soul that suffocates in a silent scream, as I write this reflection, I think of Emily Dickinson's poem, *Dying! Dying in the night!*

*Dying! Dying in the night!
Won't somebody bring the light
So I can see which way to go
Into the everlasting snow?*

And "Jesus"! Where is Jesus gone?
They said that Jesus — always came
Perhaps he doesn't know the House
This way, Jesus, Let him pass!

Somebody run to the great gate
And see if Dollie's coming! Wait!
I hear her feet upon the stair!
Death won't hurt — now Dollie's here!

Reflections/Recommendations Based on Experience

I feel, as in her poem, a path, a light, a hope, by thinking that maybe, just maybe, all of this is not so difficult, because we are here (now Dollie's here!). And as Sunita Puri said, “we cannot continue to be the professionals we want to be, but we will have to be the professionals that our patients need. We have to be there!”²

So, I don't know if I am on the front line, or in the back line, or in the middle line of this fight against this pandemic, but I know that for all the Maria's of this world, we are the only line that holds her to life in a world that has changed severely and isolated us. As Sheila Cassidy⁷ says, “We are here, walking “through the darkness” with all of them.”

A time that reinforced the presence in the relationship with the patient. A presence that does not just mean being there, but above all, it means being with.

And that is why tomorrow I am going to call again. And I will continue to do so, always afraid that someday no one will answer the phone.

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