
There is nothing we can do?

When I entered the nurse's station, I immediately felt the typical business of a weekday morning. The morning rush during which everybody tries to get a handle on all the tasks for day was unfolding. One of the nurses looked at me briefly and said "good that you are here – something needs to happen – this patient has cancer from head to toe and the family is in denial. The patient is not a full code but there is nothing we can do." Sounds familiar?

Working as a palliative care nurse in a hospital is like no other nursing job.

My job is to look at the patient and their family in a holistic way, to look at the bigger picture and to address nursing needs or general care needs that are related to serious illness and frequently at the end of life. Nowadays, many of our patients in the hospital have specific needs related to serious illness and requires a different skill set. I carry around a small bag with papers and informational material – my stethoscope is neatly tucked in there as well – it lives in a zip lock bag ready for use together with all the information brochures and papers. My work outfit does not



include scrubs, I am mostly a conversation nurse, although there are times I do “hands on” nursing care.

The patient I was asked to see to assess for palliative care needs appeared very sick when I entered the room. Only half awake, the face sunken in, breathing shallow and faster than normal, the skin glowing in this yellow-greyish undertone that tells you right away something is wrong. A variety of drains and intravenous lines around him. His wife who sits next to him in the recliner chair is hesitant when I introduce myself. She agrees to talk with me and points out that her husband has been confused the last days and tried to pull out IV lines and the Foley catheter, which is the reason she stayed overnight.

My biggest and most important tool is listening – I have the luxury to provide “time” while patients and their families tell me their “story.” His wife tells me a typical story and tries to sum up neatly the last several years that have been consumed by the initial cancer diagnosis with all the usual tests, surgery, radiation, chemotherapy. Uncounted visits to the city teaching hospital close by that is known for expertise in cancer treatments. Many days sitting in the hospital and waiting for lab results to show up, waiting to hear from the oncologist, waiting to know what comes next. Months on end with frantic activity in which being a cancer patient’s wife turned into an unpaid full-time 24/7 caregiver job. True – there were also some months during the last years when things seemed better but life never returned back to where it was before he was found to have cancer in an advanced stage. Instead of traveling for fun, visiting family, and getting together with their group of friends to play cards, they were now experts in navigating the large hospital in the city, knew all the different times during which traffic is unbearable, developed preferences for one of the food courts and got to know the oncologist, nurses, aides, lab technicians, and the cashier at the food court.

His wife continues to paint the picture that reflects their journey for the last years. The change of identify from the “retired couple with grandchildren” to a member of the “cancer tribe” with specific rituals and unwritten rules. The many talks she had with other spouses in a room united in hope but also united in the unspoken fear and worries.

“We did everything they told us to do. Never missed an appointment, faithfully showed up for lab work, scans, check-ups.” The last two months, she noticed that things were changing. Granted, they had been going to the cancer center for years and were now very familiar with what it means when the doctor tells you “I have bad news – we found something on the scan that does not look good” or “I am afraid that the chemotherapy is not working.” It never meant to her that things might now be going into a different direction overall. To her, it meant that there will be “something they can do”, although she realized that the cancer was slowly taking over his body. “He is definitely much weaker now, he has not gotten out of bed in weeks, it was already very difficult at home the last weeks. I have to do everything for him, he sleeps a lot.” Her face gets sad and for a second I can feel the desperation when she continues to outline what has bothered her the most for the last weeks: “you know, you are good enough as long as they can treat you, while they are doing surgery, giving you chemo and radiation. But when there is nothing left and the cancer spreads they just throw you away. One day I called to talk to the new oncologist to tell that there were problems and that we had gone to the local emergency department because the city is too far for him now that he is so sick. I was told to talk to hospice. Just like that.”

We talked some more and she made it clear that she appreciated everything they were able to do for her husband. But it bothered her that there was no transitioning period, that the oncologist she had trusted and who was empathic had left the teaching hospital - she never connected with the next one. And she felt “passed off”, “thrown away” and obviously abandoned. They never had a

sit down about what would be important in case the illness progresses and spread further or what could lie ahead. “Of course they talked about do not resuscitate but you just don’t know what comes next or what to do.” It did not help when it was suggested to her to talk with hospice. “They want me let him die.” It also started a whole chain of other reactions and events all based on the sudden feeling of abandonment by the department and institution that had been their second home for the last years.

Obviously, there were many missed opportunities for conversations. When he became unable to tolerate food and TPN was started it was helpful but it was a milestone and would have been a good time to sit down. When they found metastasis after the extensive surgery that left him with a variety of bags and attachments it would have been a good time to talk about “what if” and “how much are you willing to go through for gaining more time.” The patient’s wife felt not prepared for what her husband had been knowing for a while. His continued functional decline and the continued unwell feelings including pain, nausea, vomiting and general discomfort were clear signs for him that he was not doing well and he became tired of being sick and unwell. For his spouse, his decline meant mostly more activity and more “things to do” but did not connect her with the fact that he was approaching the end of his life. When she realized, it was like the moving universe suddenly came to a full stop. Caring for him and taking care of all medical appointments, managing his illness and drains had moved her along like a conveyor belt where “you just keep going.” She pointed out that she was not in denial, she knew that death would come but it did not have much meaning until the physician said “hospice”. The constant activity shifted all her focus and thinking towards “doing” with no reflection about the bigger picture. When she was not busy with his 24/7 care and coordinating providers and treatments, she was so tired that she would just sleep or distract herself watching TV. Now that her main caregiver activity was to sit with him and talking to

his care team, her emotions and thinking were catching up. From non-stop activity to full-stop. Her mind and heart re-connecting what had been mostly an intellect based experience for her.

I validated her feelings and expressed sadness. As human beings, we want to feel connected and we want to know that the other person cares. People want to tell their story; they need to talk about how they feel and do not want to feel “thrown away.” Many transitions do not go well because conversations happen too late and do not include “what if” talks. I sometimes hear “come on – they must have realized he is dying” – but reality is that our society does not view dying as a normal part of living and physicians view their job mostly as “treating” and have a lot of discomfort when they need to talk about the fact that dying is not optional – which is why many tend to have conversations that are not effective or hurtful. “Your cancer is progressing despite the 3.line treatment – there is nothing else I have for you” and when the patient and family starts to show distress followed by “do not lose hope – there is always something new, it may be just around the corner and I will look into clinical trials” while knowing very well that all of this is not an option and this is the time to prepare and do ensure that the time that is left can be spend in the most meaningful way. Sounds familiar?

Physicians often feel that they are taking away hope - but what does that really mean? Often enough, the helplessness and the lack of skills to have a conversation that does not “turn bad” leads to passing the bucket to a different provider or the hope that “the family will realize.” Some providers have become skilled in avoiding a conversation and elevate the “having a purposefully vague conversation” to an art so they fool themselves and others that “I have put it out – they are not ready to hear what I am saying.”

Obviously, I am advocating for earlier and better conversations. It is not about “taking away hope” or “stop fighting.” When somebody has a serious illness that very well may turn terminal, it is important that the physician sits down and has a conversation that focuses on goals, values, preferences, trade-offs, strengths. It is important to stop the conveyor belt of “treatment” and to pause early on to reflect, build the relationship in a different way and guide patients and their families along. Thinking needs to shift from considering all treatments possible to pause and evaluate the benefits and if the treatments and care plans are actually congruent with the patient’s overall wishes and goals if “time left” is limited regardless of maximizing treatment. When death is not avoidable in the near future, we should focus on finding out how much the person is willing to go through and what are acceptable trade-offs for gaining more time. Those structured conversations do not have to be long, when done early on and regularly they are might be only 20 minutes long. It helps the family to understand what their loved one wants and opens the room to discuss what is important at a given time and which treatments and care plan match that goal. Instead of focusing on “what we cannot do” focusing on “what we can do” as a healthcare team.

There is actually a lot we can do when somebody approaches end of life: We can help you to find out which care plan and treatments match your needs and preferences. We can help you to maximize your comfort and allow you to spend the time that you have, however long that may be, with more quality especially when comfort and avoiding suffering is most important to you. We can still hope and fight – not for a cure or to maximize the lifespan – but for the most comfort and quality to make the time that is left most meaningful. We can give the gift of time and listen. We can care and sit with patients and their families throughout this time. We can re-assure them of their choices especially when they feel ambivalent about comfort care. There is actually a lot we can do!