

Editorial

Making the Paradigm Shift from Saying “I’m Sorry” to Fulfilling Hope

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For decades, we have been trying hard to promote optimism, courage, and pray with our metastatic cancer patients and their families for a miracle to happen. Though newer drug therapies have extended lives, some with quality of life and some unfortunately without it, eventually the final outcome will be that they will die. We hope for a cure of their advanced cancer that has happened to them and without such a cure we know that this disease will dramatically in most cases shorten their lives. We discuss maintaining hope throughout the course of their care. Then, as treatments no longer are keeping the disease in check or the patient is too ill to endure more treatment, the next discussion begins with, “I’m sorry I couldn’t do more. It’s time to transfer you to hospice care”. Well, I became tired and frustrated a few years back regarding the issue of saying I am sorry. I am certainly sorry that my patient is going to die and sorry there is no cure, but frankly, I knew that from the first time I met the patient. And so do all of us.

We have been taught to treat the disease. It’s time we care for the patient, the whole patient, who is far more than their pathology. And time to stop saying we are “sorry”. Instead, our goals of treatment need to be what the patient says are her/his goals [1]. And we need to know what the patient’s life goals were and still are, whether they are here to personally fulfill them or not. When meeting with a newly diagnosed early stage breast cancer patient, I ask her to “tell me your life goals before you learned that you had breast cancer”. Though commonly the patient may say, “it doesn’t matter. Please just save my life”. I still tell them that we anticipate they will survive their disease and therefore we need to know her life goals so they can be factored into the treatment planning process. For example, is she planning to have a family or expand her family? This may require fertility preservation before chemo then. Though she works as a bank teller she is studying to become a concert pianist so being very selective in the chemo regimen chosen for her needs to factor in the need to avoid drugs that are known to cause peripheral neuropathy. Otherwise, she will forfeit her career goal and her passion for playing the piano to her cancer. Patients should never be forced to have to give cancer anymore time or give up future life goals because of our failure to ask these types of questions up front and incorporate them into the treatment planning process. She may be up for a promotion and therefore wants to demonstrate to her boss her commitment to

the corporation by working as much as she can during treatment. This would mean performing her lumpectomy on Friday instead of Tuesday and resting up over the weekend to be back at work the beginning of the week. Her radiation should be arranged for 7am instead of 1pm so she misses no time from work for this part of her adjuvant therapy.

So now let’s return to the patient with metastatic disease, in my world, that is metastatic breast cancer patients. What are her life goals? Some may be short term and can be achieved while she is still here on this earth, but other life goals may be way in the future and therefore must be fulfilling in alternative ways. It requires creativity. It requires having this thoughtful and profound discussion with the patient so that we can remain optimistic for as long as it is realistic, but always having an end of life plan in place which is there when needed including if she gets hit by a truck and dies in the middle of a street somewhere. Fulfilling hope in alternative ways is something I have done for a very long time. Below are examples of how this is accomplished:

Patients leaving behind young children: One of the greatest disappointments to a patient is that she won’t see her young children grow up. She won’t be here to instill her values in them. Let them know how much she loves them. How proud she is of them as they reach certain milestones in their lives growing up. She can however still be here, through the use of cards. Providing her cards to select from that are donated for this purpose (or having her select them at a local card store, though keep in mind they are expensive and she may not feel well enough to go). Birthdays, communion, getting his driver’s license, high school graduation, college, when she marries, when she has her first child - what does she want to tell her child on that specific day. By doing so, she is “still here” instilling her hopes, love, values, and advice in her children. A teenager seeing her mother’s handwriting and words of love and joy for her is very powerful. (I receive cards and phone calls from children who are now grown adults and they tell me how powerful and wonderful it has been over the decades to have cards from their mothers who died when they were young) [2].

Patients missing the birth of a grandchild: When a daughter or son is expecting a baby, the family is filled with joy and hopefulness for this little person who will be welcomed into this world in the coming months. The patient may be too ill to reach that milestone date, however which is a huge disappointment. Arranging for the patient to “meet” their grandchild in an alternative way can and has been accomplished by having them present when an ultrasound is done of the baby, even if the ultrasound needs to be arranged prior to the 5th month of pregnancy. The patient can “meet” her grandbaby, and perhaps even learn the sex of the child, find out the baby’s name from the parents-to-be, and write a letter to the baby about all of the things she hopes for in the future after this baby is born. Getting Hallmark

recordable books has been a great way to record the grandparent's voice reading these children's stories and keeping them permanently recorded for this baby as well as for other offspring in the future. The baby will come to know their grandmother's voice.

These are merely two examples of how we can fulfill the hopes for our patients. We need to stop saying we are sorry and instead address their hopes head on as well as do whatever we can to orchestrate a good death. This means being pain free, dying in the environment of their choosing preferable with hospice services in place, dying with dignity, having legal and financial affairs in order, giving forgiveness and receiving forgiveness, feeling confident they will be thought of fondly after they are gone, leaving a legacy unrelated to leaving money, leaving no financial debt for their children or spouse to pay associated with their cancer treatments, and feeling a spiritual connection to a higher power [3]. And by using this as a checklist in

our medical records, we can make sure the resources are provided to ensure each is accomplished, which takes time and good planning and cannot be done in a week. Then when we look back and reflect on the patient's experience with us, we can take pride in saying that we helped the patient fulfill their hopes and future goals in alternative ways and orchestrated a good death [2]. No more "I'm sorry".

References

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