



Addressing the Needs of Patients with Metastatic Breast Cancer

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Editorial

Though we know that more and more women are surviving breast cancer today, there continue to be approximately 39,000 who still succumb to this disease annually [1]. These patients were looking forward to a long life ahead of them filled with hopes and dreams for themselves and their families. This is the “space” I clinically work in and study. I do not conduct laboratory research or clinical trials comparing various chemotherapy regimens but instead am focused on the quality of life preservation and helping patients experience a good death.

For the last decade I have been conducting retreats for metastatic breast cancer patients semi-annually. One is for patients to bring with them their spouse or partner, known as the metastatic breast cancer couples retreat; the other is for patients not in a relationship and they bring a female caregiver who is commonly a mother, sister, daughter or even a best friend. These retreats are held at a spiritual center off campus from the Johns Hopkins Medical Institution and last for three days and two nights. They are free to attend and are funded by grants and through philanthropy. Our first one was nearly a decade ago. Though patients and their loved ones attend primarily for the purpose of networking with others who are in the same situation, they also have the opportunity to discuss their fears and hopes, and by the end of the third day have a working end of life plan, which they never imagined would be one of the outcomes of such a program. Pre and post retreat surveys are conducted with one of the most impactful questions being—I am fearful of my future. It is rare that a patient scores below the 50th percentile with the top of the scale being extremely fearful, however upon leaving and when surveyed again three months later (for those still surviving), it is unusual to see anyone above the 50th percentage mark. We believe this reaffirms that talking through scary issues such as fear of being in intractable pain, dying without dignity preserved, feeling no sense of a time line for their future, worrying about who will raise their young children and keep her memory alive as well as instill their mother’s values in them as they grow, have been adequately addressed so fear is converted into knowledge and with knowledge there is patient empowerment.

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Palliative care is a focused topic of discussion because it is misunderstood. It continues to be coupled with hospice care when it is designed and intended to be provided long before hospice is needed [2]. Time is devoted specifically to discussing what patients and their family members believe the purpose of palliative care is and when it should be implemented. So even if their doctor isn’t offering it a patient can be proactive for herself and request a consultation with the palliative care team. Knowing they are there for symptom management, are comfortable knowing that it is not just for end of life pain management, and having another member of the team appreciate the importance of quality of life preservation brings on a look of relief and content sighs. Even knowing that pain control doesn’t always mean heavy narcotic usage is a surprise.

Hospice care is also discussed and begins usually with a round robin discussion of what people believe it is for--- and most believe it is for those who are actively dying and no more treatments can be given so they are taken home or to a hospice facility where they are given heavy doses of narcotics and left alone to sleep until they pass away. Learning that hospice is intended to be given for six months nearly always amazes the attendees. However they are actually providing us their experience with hospice based on family members or friends who have received hospice care in the past, and died just days later.

A profound session occurs on day 2 of the couples retreat when the patients and their spouses/partners are separated into different rooms and candid discussions take place. The husbands have been trying to hide their emotions until then and finally in the privacy of being with a facilitator and just those who are in the same boat, someone soon to become a widower, they are able to let go. They cry, they express anger, talk about their fears, and are frustrated they cannot “fix” their illness.

They want time lines, what symptoms to watch for that the disease is progressing, advice how to talk with young children and teens, and how to cope with their own sadness [3]. And rather than say to their wives again, “you can’t die. I can’t raise our children without you”, they learn to say, “I can’t imagine our lives going on without you but I know they will. I will make sure that our children always know how much their mother loved and still loves them, instilling your values in them, and remind them of your hopes for their futures as they reach each milestone of their lives. I will recruit and accept help from others like your sister or mother when it is time to discuss things like menstrual periods that dads are clueless about. I love you.”

We have learned the implications of what can happen when communication doesn’t go as expected or assumed. This is not a time for silence but a time for more communication and clarity as well as helping to ensure everyone is on the same page. That means the goals of treatment need to be based on the patient’s goals—not the doctor’s and not the family members’. Because treatment for treatment sake is bad care.

Laughter should be part of the patient’s treatment. It is an effective stress reliever. Though dark humor may catch some friends or family members off guard when used by the patient, it still has its place and must be accepted rather than suppressed. We conduct the “Almost Newly Wed Game” on evening 2 that has virtually everyone rolling in their seats, no matter how will they are. For 2 hours no one has cancer.

Research currently happening at a national level is discussed by a Hopkins researcher, not for the purpose of providing hope that a cure is close at hand but instead to provide comfort that future generations will see an end to this disease. Clinical trials are discussed by a Hopkins medical oncologist and it is not unusual to have a retreat attendee to choose to pursue enrollment in a clinical trial that is presented.

Spirituality is also discussed, though religion per se is not brought up. Families of all faiths attend these retreats and it has been heartwarming to see that it doesn’t matter if they are catholic, Jewish, mormon, or non-denominational, everything agrees that spirituality is important to have because of its connection to hope.

The hardest part of orchestrating such events is not the creation of an agenda, because prior patients and family members have informed us during focus group discussions what they want to hear and experience. The hardest thing to tackle was finding the right venue for holding such an event. It requires open spaces, serene environment, an atmosphere of peace and of feeling safe to freely discuss anything.

Case Study – Rachel

A 30 year old woman with stage 4 breast cancer attended a metastatic couples retreat with her husband, age 31. She was diagnosed from the onset with metastatic disease. They have 2 sons, who were ages 1 and 2 at the time of her diagnosis. She had been undergoing active treatment for metastatic disease to the bones and liver for more than a year. When I asked her what her goals of treatment were she told me she had two goals---1) to receive treatment until her last breath so that her mother and husband could tell her children later in life that she fought to be with them; 2) that she wanted her boys to remember her and be old enough to remember her without having to always look at photos or be told stories about her by others. Though both goals sounded rational they in fact were not. If she received aggressive toxic treatment up until her last breath she would have likely less time with her children due to her needing to be hospitalized

and die sooner. If, however, she focused on quality of life preservation and spent this time at home as much as possible rather than being chronically readmitted to the hospital following 3rd line, 4th line, 5th line therapies, she would have more quality time with her boys creating memories that are everlasting[4]. So she changed her goals by deleting #1 and embracing #2.

She also learned at the retreat the elements of what makes up a good death experience. These include[5]:

Having purpose for living and feeling it was valued by at least one other person

Leaving a legacy that is not related to leaving money

Dying in an environment of the patient’s own choosing

Being pain free

Giving forgiveness and receiving forgiveness

Feeling confident she will be thought of kindly after she is gone

Feeling a connection spiritually to a higher power

Having legal and medical affairs in order

Leaving no financial debt for the family to pay associated with the patient’s cancer care

Such a list requires time to accomplish and cannot be done in a week or two. And this should be our goals as clinicians—to orchestrate a good death—to no longer say I am sorry because after all we knew that the patient was eventually going to die. Instead we need to take pride in orchestrating a good death.

This requires clearer and more effective communication, honesty, asking the patient key questions such as: What are you hoping for? What are you most worried about? What is important to you? What gives you joy or gave you joy before you became sicker [6].

Now back to Rachel in our case study. She is still living at the time of this editorial being written and is still making memories with her boys who are 4 and 5 years of age. Her cancer spread to her brain two years ago. Palliative care has provided her quality of life preservation, which after all is what it is intended to do – preserving it or restoring it. She knows her time is winding down and she is ready because she created her end of life plan at the retreat, which over time she has fine tuned. One of the elements in that end of life plan is having cards for her boys as they grow up. Cards to open for every milestone of their lives—birthdays, drivers’ licenses, communions, graduations, when they wed, even when they have their own first born and become dads themselves. Written in them are her words of wisdom, her love for them, and her values she wants them to remember and hold steadfast. She will still “be here” having her voice heard and her hopes for them expressed. (These cards are provided as in kind donations from many individuals as well as advocacy groups so the patients select and take home these cards, as well as recordable children’s books for those with very young children or women who won’t “be here” for a grandchild’s birth. The baby will hear its grandmother’s voice as she reads stories that are preserved to play for a lifetime).

For more information about the metastatic breast cancer retreats, send an email to shockli@jhmi.edu. A Metastatic breast cancer retreat program planning guide is available for free. Johns Hopkins has also launched these retreats for metastatic colorectal, advanced pancreatic and advanced gyn oncology patients and their spouses/partners. The

Johns Hopkins metastatic breast cancer retreats are not restricted to only being offered to Johns Hopkins patients. If you have a patient you believe would benefit, let us know. The retreat is free for patients and their loved ones to attend. The patient and family member only need to provide their own transportation.

You can also watch a short video clip at: <https://www.youtube.com/watch?v=Bg02G2a7uHo>

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