REFLECTION

How Giving and Receiving Information Has Shaped My Cancer Journey

Mary E. Burman, *PhD, BSN, RN*

Fay W. Whitney School of Nursing,
University of Wyoming, Laramie, Wyoming

ABSTRACT

I have been a nurse for 40 years and I now have metastatic breast cancer. I have learned a lot, especially about giving bad news, disclosing the diagnosis to others, and using the hospital's patient portal. First, how bad news is given to patients is important and should provide clear next steps for follow-up and treatment. Second, telling family, friends, and colleagues about a new cancer diagnosis is more challenging than you might expect. It is emotionally draining and time consuming, and support by primary care clinicians (PCCs) could make a difference. Finally, patient portals can be very beneficial, but their use in a complex diagnostic process like metastatic cancer can be problematic. Primary care clinicians should explicitly discuss use of portals with patients so that they receive the information they need in the way they want.

Ann Fam Med 2020;18:555-557. https://doi.org/10.1370/afm.2588.

As I exited the CT scan room, a radiology technician, with evident pride, told me that my results would be available on the patient portal that evening. I drew in a sharp breath and my heart pounded thinking about what the results were likely to show. As a nurse with a history of breast cancer, I suspected that it would be metastatic breast cancer. When I woke up the next morning, there, as expected, was an e-mail notifying me that I had "new results" in the portal. My mind reeled even though I had expected the e-mail. I emphatically answered "No" to my husband's question about whether I wanted to see the results. I needed to be with my primary care clinician (PCC) when I heard the results. By the time I was at work, I had an appointment set up for later that day. Although I dreaded it, having the results given to me and my husband by my PCC was a relief.

Although learning of my diagnosis was particularly stressful, it was just the beginning of a decision-making process involving numerous diagnostic tests, appointments, and procedures. Throughout the course of dealing with metastatic disease, I have gained valuable insights that I didn't really want, but, upon reflection, may help PCCs as they work with patients who are facing bad news, disclosing their diagnosis to their family and friends, and using the portal as part of their care.

My Story

My saga with breast cancer started in 2010 when I felt a small lump in my left breast. I saw my PCC within a few days and a biopsy shortly afterwards showed a Stage II ductal carcinoma. However, in the recovery room after my lumpectomy, I found out that it was actually a Stage III lobular carcinoma with multiple lymph nodes involved. Lobular carcinomas are famous for not showing up on mammograms resulting in diagnosis at later stages.

After the lumpectomy, I was treated with chemotherapy and radiation, which I completed in 2011, followed by tamoxifen. Since then I have felt good despite the intermittent worry about if and when the cancer would return. I continue to work and have found much time to enjoy life.

Conflicts of interest: author reports none.

CORRESPONDING AUTHOR

Mary E. Burman, PhD, BSN, RN
1000 E. University Avenue
Department 3065
Laramie, WY 82071
mburman@uwyo.edu

Indeed, I hiked up to 16 miles a day for a week with my family in Scotland in May 2018.

In June 2018, I presented to my PCC with achy chest wall pain that didn't fit any diagnostic framework that I could imagine. Like many people who have experienced cancer, symptoms that can't be easily classified led me to the inevitable angst of "Is the cancer back?" I could tell by the PCC's response that she was concerned, and this led to scans which showed fairly widespread lesions in my ribs, spine, and pelvis.

The PCC delivered the news sensitively. She sat down looking directly at my husband and me. She quickly got to the point that the scan showed "metastatic breast cancer," specifically using those words. She ended with a plan for next steps and then hugged me as I left the room. My PCC had already talked to my oncologist before the appointment and he was on standby ready to call me to start the process for further workup, which he did about 30 minutes later.

The 2 months between the diagnosis and start of treatment was chaotic and mind-numbing with plenty of time to stew about the diagnosis (Table 1). Each of the multiple follow-up appointments and tests was another occasion in which I revisited, reconsidered, and pondered the diagnosis. For example, when I signed the consent for chemotherapy, the pharmacist, who was caring and concerned, highlighted that the chemotherapy was for palliative treatment and specifically pointed out that the "palliative treatment" box was checked, not the box which focused on "cure." Intellectually, I knew that my treatment was not focused on cure but hadn't thought about it as "palliative," and although this didn't change anything about my treatment, it led to deeper realization of the gravity my situation, which, although uncertain, was also somewhat encouraging because I only have bone metastasis at this point.

Telling People About My New Diagnosis

Most challenging for me was deciding what to tell my family, friends, and colleagues about my metastatic disease. Multiple personal and professional relationships complicated this process. I live and work in a community of about 30,000 people where I was born and raised. As a dean of a school of nursing, nonprofit board member, and active church member at the time of my diagnosis, I am well known in my community and state. I knew that once I started to tell people I needed to be able to get the word out accurately and quickly to lots of people. I did not want rumors, nor did I want to put people in the position of having to keep the information confidential. With metastatic disease, I was also concerned that people would assume the worst and word would get out that I was terminally ill and not expected to live long.

Outside of immediate family, key colleagues at work, and a few friends, I made the decision to not tell others until I knew the details of my treatment. I chose to wait to tell my mother mostly because I just wasn't sure I could do it. Two of my siblings died as young adults and another was very disabled and nearing the end of his life at the time of my diagnosis. She is a strong woman, but I worried greatly about the impact on her emotional and physical health.

For me, telling others was an emotionally draining process. I found myself hating the words "metastatic breast cancer" and yet I was unwilling to not use those

Table 1. Diagnosis to Treatment Timeline

June 29	Appointment with family nurse practitioner for chest wall pain
July 5	Bone X-rays series
July 6	Phone call from PCC reporting abnormalities in ribs and pelvis. Recommended CT scan.
July 12	CT scan
July 13	Appointment with PCC. Results of CT scan show rib fractures and metastatic breast cancer in ribs, pelvis, and cervico-thoracic spine. Phone call from general oncologist recommending bone scan and follow-up appointment.
July 15	Told brother and daughter
Week of July 16	Told key colleagues at work, 2 close friends and other 2 brothers
July 18	Bone scan
July 25	Appointment with general oncologist. Recommended seeing his colleague, an oncologist who specializes in breast cancer.
July 2	First appointment with physical therapist
July 27	Told mother
July 31	Bone biopsy
Week of August 6	Began to tell more extended family members
August	Brain MRI for recurrent headaches
August	First appointment with breast cancer oncologist. Recommends molecular profiling of cancer cells from bone biopsy and starting Zometa to prevent further "bone events."
August 17	Dental evaluation before starting Zometa
August 28	First infusion of Zometa
August 30	Scheduled follow-up appointment with breast cancer oncologist, but canceled and rescheduled (after several phone calls) to next day because molecular profiling results not back
August 31	Follow-up appointment with breast cancer oncologist. Decision to start carboplatin after reviewing lots of treatment options. Also met with genetic counselor.
Week of September 3	Informed faculty and staff in my units. Informed college deans/directors. Also told colleagues in the community, eg, hospital board members.
September 7	Pre-op appointment with surgeon for port placement
September 10	Port placement
September 11	Chemotherapy education with pharmacist
September 12	First chemotherapy

CT = computed tomography; PCC = primary care clinician; MRI = magnetic resonance imaging.

words; it would have been easier to say that "my breast cancer had returned." I didn't want pity, but I did want people to understand the seriousness and uncertainty of the situation. I also felt vulnerable, given the escalation of chest wall pain over the summer, in a way I had never felt before, which compounded the stress of disclosing my diagnosis.

Moreover, I had to respond to others' reactions upon their learning of my diagnosis. Fortunately, people generally responded in a supportive and caring manner, but at other times, the conversations required me to respond to the individual's anguish ("Oh this is bad… you've got a battle in front of you!") or address platitudes ("You'll beat this!"). Ultimately, through this process of disclosure I had to confront a new self-identity not as the person I always thought myself to be who could strap on a backpack to hike through the wilderness, but as a physically fragile woman with metastatic cancer who could break a rib in the normal course of life.

Practice Implications

This experience has provided me, as a patient and nurse, with the opportunity to inform primary care practice in 3 ways. First, the way PCCs give bad news is important, as I found in my experience. Salander emphasizes the importance of relationships in giving bad news, emphasizing "the significance of togetherness at diagnosis, of a supportive atmosphere, of being welcomed and acknowledged, of being spared from waiting and of being given a new appointment time immediately."[1] It made such a difference to me to be told of the new diagnosis in a comforting environment by my PCC who had a clear plan for next steps.

Second, the stress of disclosure of my diagnosis to friends, family, and colleagues was not addressed by any of the clinicians that I saw in the several months after my diagnosis. Yet it was very taxing for me, and research results related to disclosure ring true with my experience. People with cancer describe getting bad news as a "longitudinal, multi-sited search process culminating in a news-telling and realization event."[2] People report that telling family and friends about their diagnosis of cancer was difficult because they felt guilty for causing pain in their loved ones.[3] Participants delayed telling those loved ones who they perceived to be vulnerable. Those with a cancer diagnosis tend to have strong ownership of the diagnosis.[4] Consequently, disclosing the new diagnosis involves strategic decision making, eg, who they tell, and what, when, and how information will be shared.[5] Primary care clinicians are in a position, given their ongoing relationships with patients and their families, to discuss the disclosure process initially and to ask about it at follow-up visits. Simply inquiring could make a significant difference.

Finally, because electronic access to health information is growing, PCCs must help patients decide how they want to use their portal, especially for a work-up that might result in a life-changing diagnosis. Patients report that receiving abnormal results through a portal can be anxiety-producing[6] and they prefer to receive results with high emotional impact during an office visit.[7] For me, the portal is very helpful as a way to keep track of appointments, laboratory results, and prescriptions and to communicate with my oncologist. However, finding out my diagnosis via the portal was repugnant to me, although may not be to others. Access to clinical information should not be restricted; however, patients need to be guided to decide how they want to use the portal so that they can receive information in way that is comfortable to them, especially in the context of a serious diagnosis.

As a nurse of many years and a member of a family with other significant health issues, I thought I understood a lot about the experience of chronic disease. My experience with metastatic breast cancer, however, has given me a much deeper, even visceral, appreciation of living with a disease that is chronic and advanced. I hope that by sharing my experiences I can help other primary care clinicians deepen their understanding of life with metastatic cancer so they can sensitively give patients diagnostic and treatment information and support their patients as they receive that information and share it with others.

To read or post commentaries in response to this article, see it online at https://www.AnnFamMed.org/content/18/6/555.

Key words: metastatic breast cancer; diagnosis; disclosure; patient portals

Submitted November 20, 2019; submitted, revised, March 17, 2020; accepted April 7, 2020.

References

1. Salander P. Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients. *Soc Sci Med*. 2002;55(5):721-732.
2. Schaepe KS. Bad news and first impressions: patient and family caregiver accounts of learning the cancer diagnosis. *Soc Sci Med*. 2011;73(6):912-921.
3. Hilton S, Emslie C, Hunt K, Chapple A, Ziebland S. Disclosing a cancer diagnosis to friends and family: a gendered analysis of young men's and women's experiences. *Qual Health Res*. 2009;19(6):744-754.
4. Ngwenya N, Farquhar M, Ewing G. Sharing bad news of a lung cancer diagnosis: understanding through communication privacy management theory. *Psychooncology*. 2016;25(8):913-918.
5. Ewing G, Ngwenya N, Benson J, et al. Sharing news of a lung cancer diagnosis with adult family members and friends: a qualitative study to inform a supportive intervention. *Patient Educ Couns*. 2016; 99(3):378-385.
6. Giardina TD, Baldwin J, Nystrom DT, Sittig DF, Singh H. Patient perceptions of receiving test results via online portals: a mixed-methods study. *J Am Med Inform Assoc*. 2018;25(4):440-446.
7. Shultz SK, Wu R, Matelski JJ, Lu X, Cram P. Patient preferences for test results notification. *J Gen Intern Med*. 2015;30(11):1651-1656.