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Metastatic Cancer Patients -- Looking Good but not Feeling Better

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I have been providing metastatic breast cancer retreats now for nearly eight years. We hold them twice a year. They are not limited to Johns Hopkins patients either. So I have a window into the world of patients with advanced breast cancer from all parts of the country, all ages, are walks of life and all points of progression toward reaching end of life. I learn something new from these patients and the loved ones who accompanies them and I am always surprised by this new knowledge. I try to incorporate this new knowledge when seeing and getting acquainted with a newly diagnosed patient with stage IV breast cancer.

Our metastatic cancer patients spend a great deal of their time trying to look better than they feel. They may spend hours preparing for their visit with us. Cosmetics on just right, eyelashes glued in place, wig freshly washed and styled, clothes that make them look brighter, and a smile to top off the disguise. Their goal? For us to acknowledge that they "look great" and in doing so imply to them that they must be physically doing great too, from a cancer perspective. No need for scans because how their cancer could be progressing when they look so good. In turn, we are relieved to see them looking well. Relieved that we don't have to embark on a dark conversation today. They go home and crawl back into bed, wig on the bureau and clothes on the floor.

Is this enabling behavior? Yes. Is it buffering behavior? Definitely. But it is not what we should be allowing to continue to happen. The factor of the matter is that our ill patient who is traveling incognito is getting sicker resulting in a delay in important conversations that need to take place. And granted, a patient may choose to get dressed up as to not draw attention to herself when seen out in public (or at the cancer center). That patient also needs to feel comfortable, however, in letting us know what is happening underneath the disguise.

I believe this may best be addressed by establishing an agreement up front at the first encounter we have with that patient and her family. We need our patients to agree to be open and honest with us regarding how they are feeling and what their concerns are. It won't be the only conversation like this either. Over a relatively short period of time we need to enable this patient to trust us in knowing how she really feels, what her hopes are, what her fears are, and what her goals and expectations of us are. This may require us to take off our disguise too—the white coat. The desk that is positioned between ourselves and our patients, and to not glance at our watch in the middle of such a conversation.

Research studies have shown that we may not be very good at predicting when our patients will most likely be forced to succumb to their disease. Our predictions are for a longer period of time than what reality dictates. I have wondered if part of this inaccuracy is caused by our patients dressing up for us so that the denial of impending death can continue for a while longer. When this happens however the patient and their family are left with little time to prepare for their loved one's death. This causes chaos, and decisions being made in haste that may not be what the patient would have chosen for herself. It creates emotional turmoil for all and emotional upheaval in some cases even for us. We are witnessing the family chaos and wondering why we thought the patient would live longer based on our best educated forecast.

So I have started a new opening statement when I greet a patient with metastatic (breast) cancer. "Hello. You look great. Look at you today with your pretty hair on, makeup, gee you even have eyelashes. No one would guess you were dealing with a serious illness. So now that we agree that you look great, tell me how you are really feeling—physically and emotionally." -- Now I am in a better position to support my patient and address her needs as well as perhaps predict what lies ahead for her and her family.

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