Supporting a Person with Cancer

Cancer patients often end up feeling isolated and no one should have to face cancer alone. I have no direct experience with cancer, but I am aware that interaction is one of the simplest ways to support a person with cancer, and one of the most significant. My premise for writing this paper is that I know there are many people out there who want to support a cancer patient, but steer clear of communicating with them because they don't know what to say and they don't want to tell them some platitude like "I'm here for you" or "Let me know if you need anything". I had a conversation with Patti in class the other day, an adviser in the HBHS department at Cornell University and a pancreatic cancer survivor. She said that dealing with cancer is a full-time job, and no cancer patient wants to be a volunteer manager as well. It can be more of a burden for cancer patients to reach out to people who promise to be there than it is for them to just do certain tasks themselves. Even if a cancer patient can do things like errands, a friend reaching out and offering to do a specific errand would give them one less thing to do, and one less thing to think about.

Cancer may seem like a one-victim situation, but it isn't. Friends, family, co-workers, and even healthcare providers may have the best intentions, but be reluctant to involve themselves in the life of someone with cancer. They may fear facing the same mental challenges as the person with cancer, they may be uncomfortable with not knowing what to talk about, or they may just feel powerless over such a complex disease. For these reasons and others, people may end up avoiding communication and interaction in general. This can lead to a person with cancer feeling isolated which is absolutely not what anyone would ever intend. I think a lot of people overlook having a casual conversation with someone with cancer because they think they have to contribute some kind of advice, or have a deeply emotional conversation about cancer and the chance of dying, or sign up to be their assistant on a regular basis, etc. Patti mentioned another very interesting point: she doesn't want her life to be about cancer in other peoples' eyes. She wants to be seen as Patti, the person she was before cancer, and the person she still is. From my experiences so far, I have learned that simple communication and human interaction is supportive on its own. Even if the person with cancer doesn't directly need support, who doesn't enjoy a nice conversation with a nice person?

Things to Not Do

Some people have preconceived notions of what they are supposed to say to someone with cancer. This usually takes the form of offering guidance, advice, false hope, or just feeling sorry for the person with cancer. I read an article on huffingtonpost.com called "10 Things Not to Say to Someone with Cancer" written by Dr. Nikhil Joshi. According to this article, "the most important thing to say to someone with cancer is anything at all… Because the isolation from cancer is sometimes the worst part of the disease" (Joshi 2014). However, there are some well-intentioned but awkward phrases to avoid such as "How are you feeling", "Have you heard from…", "You can beat this. You're strong", "You'll be fine". They have cancer, they feel amazing. Sarcasm. Another article titled "What Not to Say to a Cancer Patient", written by Jane E. Brody, from the New York Times goes into a little more detail on why to avoid asking "How are you" in general. Brody gives an example of a family member asking: "How are you really?", in response to "I'm fine" the first time. This is more intrusive than it is caring; if she wasn't

okay she wouldn't have wanted to delve into potentially bad news, and she probably didn't want to be reminded of cancer at what was supposed to be a fun event.

Cancer patients tend to receive unwanted advice from just about everyone. These platitudes do not actually help and usually have an opposite effect for both the giver and the receiver. If a person does not see a positive effect from their efforts, they tend to withdraw from the situation (Brody 2016). Or alternatively, they ask questions that they do not really want an honest answer to (Rosenbaum 2005). "Don't worry, everything will be fine", or "You'll feel better in just a little while", really means, "Don't tell me how you actually feel because this is too scary; just say you're feeling okay." Unfortunately, dealing with cancer is not something we are programmed to cope with. Even without the assistance of our parents, human babies would eventually learn how to walk, feed themselves, and communicate. These events and milestones are innate to our species. However, dealing with cancer is not innate. Like calculus, it must be taught. No one can truly understand what a cancer patient is going through and every patient's experience is unique.

Why Isolation is a Problem

Cancer patients also feel isolation and abandonment due to a withdrawal of the support of family and friends. Overall, one out of every four patients diagnosed with cancer will lack the support of their family and friends throughout their treatment and recovery (Devane 2013). There is no doubt that some of this lack of support may be due to the reluctance of the cancer patient to share their medical information with family and friends. For some, cancer needs to remain a secret affliction that they fight alone. However, the majority of these cancer patients report that they did share their diagnosis and still received little or no support. The explanation for this abandonment can be derived from several factors (Jeong 2016). Cancer is considered a threat to the quality of life and ultimately to life itself. It is a disease where the treatment is frequently worse than the disease itself. It is an invasion of the body and the psyche. The result is to cause fear, anxiety and depression, not only in the person diagnosed with cancer but also in their family members. This causes a withdrawal and lack of communication regarding the diagnosis in an attempt to suppress the worry and apprehension experienced by all those involved with the patient. The notion is - if it is not discussed and confronted, then it is not real. There may also be cultural factors that discourage discussion and support. For example, many Asians feel the topic of cancer is taboo and off-limits for discussion, and, thus, open communication is discouraged. Another explanation is an overall ignorance and poor understanding by our society as to how to cope with the diagnosis of cancer. Although this is an explanation, it is a poor excuse. A google search for something as simple as "how to talk with a patient with cancer" produces over 58 million hits. While not perfect, at least such help is a starting point. And yet, we frequently do not avail ourselves of any of these resources. This lack of support is especially true as time progresses and the interval after the diagnosis increases. Treatment for cancers such as breast, prostate, and colon cancer can last for many months. Some patients with breast cancer or leukemia stay on chemotherapy for years. Even after the treatment is completed, cancer survivors often continue to need care from multiple specialists to manage the long-term consequences of their illness and its therapy (Adler 2008). Unfortunately, both a decrease in the availability of support, as well as the perceived quality, was noted by cancer patients as their disease evolved (Arora 2007). Over time, caretakers themselves may experience "burnout". Family and friends withdraw and begin to limit their involvement solely

to crucial events or critical times when they believe the patient has the greatest need for them. They may be ignorant of the many networks and support systems available to these caregivers, intended to elicit outside help and reduce their potential for burnout. There may also be a misperception that the needs of a cancer patient diminish over time. However, this has been shown not to be the case. Although their needs and types of support may change as the disease, treatments and prognosis changes, the overall need for support does not diminish. Consequently, this sense of isolation and abandonment can have a devastating effect on a cancer patient's recovery. Patients frequently skip meals, miss needed medical appointments and, at times, even give up and decline necessary treatments completely due to a lack of support (Devane 2013). This has a deleterious effect on the cancer's patient's physical and mental outlook. Many investigators have shown a positive correlation between the support a cancer patient receives and the quality and duration of their lives (Arora 2007). This isolation and abandonment displayed by the family and friends of cancer patients is a form of ableism with devastating consequences. There is no doubt that the support and hope given to a patient who is ill provides an essential component of the will to live (Rosenbaum 2005). Dr. William Osler, one of the great founders of modern medicine once said, "to heal sometimes, to relieve often and to console always." Being confined to a hospital or house should not result in isolation and abandonment. There should always be friends and family ready to console, at all junctures along the way.

Ableism in the Workplace

Cancer patients face a great deal of ableism in the workplace resulting in not only adverse physical effects, but tremendous psychological and financial effects as well. Work represents an important part of an adult's identity. Consequently, a diagnosis of cancer can affect a person's career in many ways (Van Hoey 2017). For the period of time they are undergoing treatment, some patients may be able to continue working, while others may be physically unable to go to work. Thankfully, most cancer patients are able to return to work after their treatment ends. This can be psychologically beneficial. Work helps provide a social connection and is a distraction that allows a person to regain a sense of normality and control of their lives. Unfortunately, many cancer patients experience some subtle, or not so subtle, instances of workplace discrimination. Supervisors inappropriately assume they will be less productive as a result of their cancer. They may be demoted without a clear explanation, passed over for a new position or promotion, or not receive a well-deserved pay raise. They may also encounter a lack of flexibility when they request time off for necessary medical appointments. The result is that many patients fear being fired from their jobs with loss of income, as well as health insurance, at a time in their lives when they need it the most. The Americans with Disabilities Act (ADA), is a federal law that bars discrimination against individuals with a variety of disabilities. "Individuals with disabilities include those who have impairments that substantially limit a major life activity, have a record (or history) of a substantially limiting impairment, or are regarded as having a disability" (Questions & Answers about Cancer in the Workplace and the Americans with Disabilities Act). People who currently have cancer, or are in remission from their cancer, are protected by the ADA. This is an important safeguard for cancer patients, since statistics show that seventy-three percent are able to return to work within one year of their diagnosis and eighty-four percent return to work within the first four years (Hoffman 2008). Despite the increased numbers of cancer patients in the workforce and laws to safeguard their rights, difficulties are still encountered that potentially hinder a smooth existence at work. While the

ADA addresses specific work-related or treatment-related obstacles in the workforce, the damaging emotional perceptions experienced by cancer patients from fellow coworkers and employers can make returning to work stressful and unpleasant (Tiedtke 2009). For example, cancer and its treatment frequently affects a person's physical appearance. They lose hair, have changes in their weight, alterations in their skin, have new scars and even the visible loss of body parts. Returning to work can increase a patient's perception of these physical shortcoming, making them acutely aware of the before cancer and after cancer differences in the way they look. This can result in embarrassment and a sense of inadequacy that can be escalated by the behavior and attitudes of coworkers. It is not surprising that many women who return to work after cancer treatment choose to change jobs, perhaps in an attempt to avoid having changes in their appearance be a noticeable reminder to their colleagues. Other studies have shown unrealistic expectations and perceptions on the part of employers (Nowrouzi 2009). Some employers perceive the limitations of cancer patients as more significant than the actual reality of those limitations. Paradoxically, other employers expect that these employees can work harder than they are physically able to. Undoubtable, cancer and the workplace is a "sensitive, personal, and individualized issue for employees …its implications are widespread and often involve employers, colleagues, co-workers, and personal relationships with family and friends" (Nowrouzi 2009). Research indicates that when work modifications are targeted to meet the needs of employees with cancer, those employees are most likely to continue working (Tiedtke 2009). The typical fifty-year-old has spent almost two-thirds of their life either preparing for or working in their chosen careers. A job can be more than just a source of income. It represents who you are as a person. Cancer management and education for employers and their employees is necessary to prevent workplace discrimination and allow cancer patients another means of returning to a normal life through their careers.

Physicians Need to Avoid Using Too Much Terminology

Throughout their treatment, cancer patients look towards their physicians to disseminate information, provide care, and support their physical and psychological needs. It is surprising that many physicians find it difficult to effectively and empathetically communicate with cancer patients. Such communications frequently involve the delivering of "bad news" to the patient. This is a complex task that could involve communicating the original diagnosis, the spread of the disease, treatment failures, adverse side effects of the therapy, and issues of hospice care or desire for resuscitation at the end of life (Bailea 2000). Physicians may fail to strike an appropriate balance between medical honesty with the patient about the diagnosis to allow for important decision making, and the need to provide emotional support and hope to that patient.

Physicians might be uncomfortable when they must discuss an unfavorable diagnosis or outcome. There may be "uncertainty about the patient's expectations, fear of destroying the patient's hope, fear of their own inadequacy in the face of uncontrollable disease, not feeling prepared to manage the patient's anticipated emotional reactions, and sometimes embarrassment at having previously painted too optimistic a picture for the patient" (Bailea 2000). Nevertheless, physicians remain the primary source of medical information for cancer patients. Patients rely on them to discuss prognosis, treatment options, associated side effects, risks, benefits, etc. (Arora 2003). Studies that evaluate the quality and comprehension of the information received by cancer patients during interactions with their physicians show cancer patient to be left "confused and unsure" about many aspects of their disease and its treatment.

Physicians frequently underestimate their patient's need for information and overestimate the quantity and quality of the information they have imparted to the patient. They use complex medical terms too often, and are frequently unresponsive to the patients concerns and questions. Studies demonstrate that psychological morbidity experienced by cancer patients go unrecognized and therefore untreated by health care professionals (Fallowfield 2001). This communication is also hampered by a reluctance by the patient to discuss emotional issues, as well as an unwillingness of the health care professional to probe these areas adequately. Studies that have taped the interactions between cancer patients and their oncologists show the time used to address psychological issues to be very small percentage of the visit. Oncologists kept primarily to a medical agenda and dismissed emotional symptoms as a "normal consequence" of the patient's cancer. It is surprising and distressing to realize that health care professions, who should be better equipped and trained to support cancer patients, also fall short of desired expectations. There is no doubt that positive support behavior from physicians and other medical staff can produce significant health benefits to cancer patients. Unfortunately, many health care professionals do no better in achieving these goals than family and friends. Their role is not simply orchestrating therapies and providing pain medication. In reality, they play one of the most important roles in affording the patient the honesty and respect they deserve to optimize their outcomes. They enable the patient to have some control over the remainder of their lives. A caring and compassionate physician can significantly add to the quality of a cancer patient's life by relieving fear, anxiety and stress. They can allow the patient to regain some of the control the cancer, and its treatment, has taken away.

Conclusion

We are all an important part of the cancer team because we have the potential to support people diagnosed with cancer. The easiest thing you can do to support someone you know with cancer is to talk to them, about anything other than cancer. The diagnosis of cancer should not diminish friendships and families, it should strengthen them. A cancer survivor wrote, "Yes this year with cancer has been full of trips to the hospital, dealing with treatments, etc. but those are not the memories I hold onto…. I only remember and cherish the good times. Our camping trip, the many birthday celebrations, the outings with friends and family...those memories are important to me and made a big difference." (McNabb 2013). Cancer patients need love, support, and understanding to help them face the physical and psychological challenges they will encounter. The bottom line is, talk to people you know with cancer and be willing to listen and show support.

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