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Sarah Harris

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Sarah Harris

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“Chemobrain: Addressing mental health concerns in cancer patients”

Mental health is difficult for even healthy patients to manage. It becomes an even greater challenge in a population with a life-threatening illness such as cancer. For this reason Healthy People 2020 stated that it should be a priority to “ increase the mental and physical health-related quality of life of cancer survivors.”¹ There are many issues that need to be addressed when considering the mental health of a cancer survivor. Some of these include depression, anxiety, guilt, fear, financial and physical limitations as well as grief and cognitive impairment. Cognitive impairment is such a large issue in cancer care that it has become a frequently discussed topic among cancer support groups and cancer support organizations. The phenomenon known as “chemobrain” by patients, is referred to in the literature most commonly as chemotherapy induced cognitive impairment (CICI) or cancer related cognitive impairment (CRCI). This addresses the fact that chemotherapy often plays a role, but cognitive impairment can occur in conjunction with cancer in the absence of chemotherapy. Cognitive impairment in cancer survivors can take many forms including decline in cognitive abilities, decreased memory, difficulty with daily tasks and increased mental fatigue. Studies report a wide range of occurrence of CRCI, between 13-75% of cancer patients.²

Addressing the issue of chemobrain or cancer related cognitive impairment is in line with the Healthy People Objectives because CRCI is among the most prevalent mental health concerns of cancer survivors.³ It has been demonstrated that reduced cognitive functioning in cancer patients reduces social involvement and general quality of life.⁴ Up to 13% of cancer

survivors report discontinuing work due to “cancer related reasons” many owing to cognitive decline.⁴ Cognitive decline was reported to be a significant stressor with equal frequency as dealing with death and mortality one month following chemotherapy.⁵ For this reason, increasing awareness of CRCI and educating on coping strategies will increase the mental health of cancer survivors.

An important aspect of addressing CRCI with survivors, is explaining that this decline isn't something that they are making up; it's a real pathophysiologic process that we can understand and address. Often, knowing that there is an explainable, physiologic reason for the changes they are experiencing, makes coping with the decline a bit easier. Recent research has suggested that a multi-sided attack on the brain is responsible for the cognitive decline experienced by so many cancer survivors. Some of these underlying etiologies include damaged cerebral cells and vasculature, increased cytokine release and inflammation coupled with decreased neurotransmitter release.⁶ Oxidative stress, damage to cellular proliferation processes and myelin sheath degeneration have also been implicated.² Given this level of toxicity, the neurotoxic complications of chemotherapy can lead to limitations on dosing of medications that could otherwise be given at higher doses.⁷ These processes are all induced by chemotherapy and some can be induced by the tumor itself regardless of location. Animal studies have demonstrated that the presence of the solid tumor, even one outside of the brain, can lead to reduced hippocampal cell proliferation.² This multifaceted attack on the processing ability of the brain leads to the feeling of a subjective inability to complete tasks and the feeling of overall mental fatigue and decline in those facing cancer.

Imaging studies have shown that after chemotherapy, there is an actual reduction in both grey and white matter in the brains of survivors.⁵ This same study demonstrated that patients are

able to compensate for this by activating more areas of their brain than their healthy counterparts which may help explain why patients report higher levels of cognitive fatigue and decline than can be measured objectively.⁶ For this reason, it has been difficult to objectively study cognitive decline in cancer patients. It is difficult to study cognition, harder to test subjective complaints and even hard to research patients coming in at different stages of diagnosis, with different types of cancer receiving different treatments and starting from a different neurologic baseline. However, attempts have been made to create a standard definition for cognitive impairment. Most studies reference a patient's performance relative to standard deviations below a population norm or a measured decline in the patient's personal performance relative to a baseline measure taken prior to treatment.⁴ While these are important for documentation purposes, it is most important to listen to a patient's own subjective complaints of decline as these are most reflective of the impact that CRCI is having on their mental health.

For some, the ability to acknowledge that the "fogginess" that they are feeling is a normal reaction to cancer and chemotherapy will be enough to improve their mental health. Others will be able to take solace in the fact that most studies show that the majority of patients no longer show signs of cognitive impairment by 3.5 years after treatment.⁵ Once well enough, many survivors will want to take active steps to combat CRCI. Some interventions that have been proven to help patients include cognitive rehabilitation, activities such as Luminosity, yoga, tai chi and other physical activity as well as antioxidants and some supplements.^{2,4} Feeling validated in their experience, assured that their current state won't likely last forever and empowered that there are changes that they can make to hasten recovery should make strides towards improving at least one aspect of a cancer survivor's mental health.

While CRCI affects many parts of a community, friends, family, employers included, those most affected are the cancer survivors and their caregivers. A cancer survivor is defined as anyone that has been diagnosed with cancer. From the moment of diagnosis, regardless of prognosis or place in the treatment process, that patient is now a cancer survivor.⁸ For this reason, an audience of survivors and caregivers is a reasonable group to present this information to. The Klamath Falls “Finding Your Joy Cancer Support Group” is open to all individuals affected by cancer. This group spends its weekly meetings talking about physical, emotional, financial and psychosocial challenges faced by survivors and those around them. One study showed that discussing chemotherapy related concerns, like CRCI in a support group online, generally helps the survivor feel better.³

Support groups are often open to anyone affected by cancer, not just those with an active diagnosis, because cancer is a far-reaching illness. It is estimated that as of January 1st 2016 there were 195,790 survivors in Oregon.⁸ At this time, there were an estimated 3,560,570 breast cancer survivors in the United States making breast cancer the most common malignancy in females. Of these breast cancer patients, nearly 60% receive chemotherapy at some point in their treatment.⁸ As one of the mainstays of cancer treatment, this high percentage of chemotherapy utilization in breast cancer is reflective of treatment for many types of cancers. This illustrates the point that a large segment of the population will be diagnosed with cancer at some point, and a large subset of these patients will be at even further risk for developing CRCI through exposure to chemotherapy. When considering family members, friends, coworkers and loved ones, nearly everyone will be touched by cancer at some point in their lives.

Though it is required as a part of the rural health program, it is fitting that this presentation will be given in a rural community. Rural communities lead to close ties. This

means that the experience of cancer for one patient touches the lives of many. Though ties are close, medical care is often far. Rural patients will often not have the access to as many high-level providers trained in cognitive decline as their counterparts in large cities. They won't have as much access to therapists that are trained in cognitive rehabilitation. They may not even have their oncologist nearby. The Department of Health and Human Services has categorized Klamath County as a healthcare shortage area for mental health providers.⁹ It is also designated as a Medically Underserved Area by the same organization. This means that there are not enough primary care or mental health providers to meet the needs of those living in this rural community. It is for this reason that it is so important that this population in Klamath Falls understand why they might be experiencing chemobrain, how to talk to their providers and what they can do about it at home.

In addition to the interventions listed above, it will be valuable for cancer survivors, particularly in a rural healthcare shortage area, to know that there are tools to address their mental health concerns online. There are websites that are dedicated to providing access to oncology social workers to those that can't access them in person. Oncology social workers are key to addressing non-treatment based services that cancer survivors may need.¹⁰ One such resource that CRCI afflicted individuals might need is help with dealing with employment issues. As mentioned above, cognitive decline can be a major reason for cancer survivors to leave the workplace. The National Coalition for Cancer Survivorship is a great resource of survivors and one of the many resources that they have available includes a document on employment rights for cancer survivors.¹¹

Another resource available in person, or by remote access, is the American Cancer Society. The American Cancer Society is a cancer advocacy group with a large impact on cancer

care. Their recommendations and research are used by providers to guide aspects of clinical care. They also have a large public presence. In addition to funding research, they also provide support to cancer survivors through outreach and education. They have produced a document on their website intended to educate patients about chemo brain.¹² It covers much of what is in this paper but on a less scientific level. This will help patients as they explain CRCI to their loved ones or as they look back to refresh on the information that they learned during the presentation. In addition to information on this specific topic, the American Cancer Society is also able to help connect survivors into support groups, connect them with financial and physical aid and promote a community among survivors and their loved ones. Helping patients find the support they need and easing the burden of cancer in their life, related to cognitive impairment or otherwise, is a good step towards improving their mental health.

All of these virtual resources are relevant to present to a rural community. These can be accessed through the internet which can be accessed at a local library if a patient doesn't have access at home. The only barrier to these resources would be literacy. A patient with low literacy would be best served by working with an oncology social worker as mentioned above. For those that want to take an active approach to improving their cognitive function in a rural community, speaking to their provider is certainly a good place to start. Practicing how to speak to a provider about the struggles they are having with CRCI will be an important intervention presented. In addition, appropriate at home interventions will be discussed such as online cognitive therapy like Luminosity and yoga. These are easily accessed regardless of rural or urban location. One intervention that will not be mentioned unless provoked by a question is the use of pharmaceuticals to combat CRCI. There is limited data showing the efficacy of any particular medication and would therefore not be helpful to present. However, if questioned, it will be

important to know that there have been animal studies that have showed the effectiveness of a medication called KU23 in reducing CRCI in mice.¹³ This is a limited study and has limited clinical relevance but it may be relevant to know that research on the pharmacologic management of CRCI is ongoing.

As mentioned several times throughout this paper, cancer affects all of us. A month after PA school started, I found out that one of my closest friends had been diagnosed with melanoma. She was twenty-four; an age that is supposed to make you impervious to things like cancer. Even though she was diagnosed at stage IV, she stayed positive. She was determined that one of the treatments would work. She was strong as could be and continued to work. She struggled to remain herself though. She would go home early from work because her brain was just so tired after a few hours. She would lash out at her fiancé which was wildly out of character for her. Her fiancé went to the ends of the earth to take amazing care of her. Her soon to be mother-in-law slept on the floor of her room to monitor her for seizures. As her life was ending, they turned theirs upside down to make sure she was getting everything that she needed. This is why I had to do something for a cancer support group; I had to try to give back to those that I know are going through so much. When I asked the leader of a cancer support group what they would most like to hear about, chemobrain was their answer.

This presentation won't lead to a drastically different outcome for a cancer survivor. It won't change the course of their disease and it won't solve all their mental health concerns. What it might do, is address one aspect of a survivor's struggle. It might help them better cope with one part of their daily struggle as they survive with cancer.

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