

MENTAL HEALTH

Understanding the Psychological Effects of Childhood Cancer

We must do more to help

By Hilary Marusak on July 24, 2018



Credit: Getty Images

Many forms of childhood cancers have gone from being a death sentence to a curable disease. Thanks to advances in treatments, the overall survival rate for childhood cancers has increased from 10% a few decades ago to nearly 90% today. This means that by the year 2020, an estimated half a million survivors of childhood cancer will be living in the U.S. With more children surviving, though, it has become increasingly clear that cancer and the subsequent treatments, such as chemo or radiation therapy, can have long-term negative effects that extend beyond physical problems such as hair loss, pain, and physical disability. Indeed, similar to “chemo brain” in adults, childhood cancer and its treatment may have harmful effects on brain development, causing problems with attention, memory, and language, and also leading to

depression and anxiety. Based on studies using neuroimaging to examine brain structure and function also suggest that the treatments that are needed to save children's lives can also be harmful to neural development.

However, cancer and its treatment may not be the only damaging factors to consider. Childhood cancer is extremely stressful, for the patient and for the whole family. Stress begins at the time of diagnosis, when families are confronted by the tremendous burden of understanding the disease and medical terms, and facing the possibility of the child's death at a young age. Family life is disrupted as families struggle with a 'new normal' that consists of frequent hospital visits, overwhelming medical bills, and a questionable future. And then there are the stressful and sometimes painful medical procedures. Treatment for childhood cancers is often more intensive than for adult cancers, in part because the disease is more rapidly progressing than adult cancers, but also because children's bodies can tolerate more than adults can. This means that the side effects of treatment—nausea, fatigue, diarrhea, vomiting, and hair loss—can also be more severe.

The transition into survivorship brings its own set of challenges as families readjust to home and family life, and children re-enter school and social settings. Children may be years behind in school, and faced with the challenge of lasting attentional and memory problems, as well as hearing loss and other physical limitations. There is a constant fear of relapse which leaves families on guard—is that headache normal? We should not only consider the effects of cancer treatments on brain development but also the impact of childhood cancer as a stressful and potentially traumatic experience.

The long-term psychological effects of intensive cancer treatments in children have been a topic of study since the 1980's. As a group, childhood cancer patients cope psychologically well with the experience, but still, many report anxiety, depression, and even posttraumatic stress. Among children with cancer, research suggests that specific posttraumatic stress symptoms occur more frequently than the full spectrum of posttraumatic stress disorder (PTSD) and may affect nearly 75% of youth during or after treatment. There is substantial variability, with some studies suggesting that perceived life threat or clinically-related factors (e.g., length of hospital stays, reoccurrence, treatment intensity) are associated with more severe posttraumatic stress symptoms. Posttraumatic stress symptoms may include nightmares or flashbacks, a desire to avoid people, places, or things associated with the experience, a difficulty in feeling emotions, feeling helpless, distant, or cut off from others, and feeling anxious or easily startled. These symptoms may be experienced by children and their parents as well as siblings.

Although the psychological effects of cancer have been recognized for several decades, how the stressful and potentially traumatic aspects of childhood cancer affect brain development has been largely ignored. This is despite compelling evidence that stress

and trauma experienced during childhood can significantly alter the developing nervous system. Changes in neural development may be lifelong, and increase risk for a range of physical and mental health problems throughout the lifespan. Indeed, in the landmark Adverse Childhood Experiences (ACES) study, published in the late 1990's, it was demonstrated that childhood trauma (e.g., violence, abuse, neglect) is extremely common, with more than 50% of adults reporting exposure to one or more forms. The study also identified childhood trauma as major risk factor for physical and mental health problems including cancer, heart disease, depression, and suicidality. These are major causes of death and disability around the globe.

Neuroscience research has shown that certain brain regions may be more susceptible to stress and trauma during childhood. Previous research by our group and others demonstrates that brain regions such as the hippocampus (involved in learning and memory), the amygdala (involved in emotion-related functioning) and the prefrontal cortex (involved in attention and other higher-order executive functions) are altered in individuals exposed to childhood trauma. Because these brain regions continue to develop across childhood, they may be particularly sensitive to insults such as stress, trauma, or chemotherapy. Therefore, we must consider the 'double hit' of cancer treatments and the stressful and potentially traumatic aspects of the experience on brain development.

We must recognize that childhood cancer is not only a physical disease but also a mental one. Helping families to cope with these stressful experiences should be a priority during treatment. However, strained for time and resources, psychological support from social workers, therapists, or Child Life advocates is sometimes inadequate in hospitals. These psychosocial support staff are not in every hospital, and may only see the families once during the course of treatment, if at all. Families have also reported that the support they receive drops off tremendously when the child completes treatment, leaving them with few resources to deal with the new stressors that adjusting back to normal life brings. In addition to pushing for cures for cancer, we should also advocate for psychological support as a standard of care for childhood cancer. This means having social workers, therapists, and Child Life advocates as a part of the treatment team, and with the family every step of the way.

We must push for new ways to prevent long-term damage. We need research to find evidence-based ways to build more healthy and resilient brains for children. For example, our research group at Wayne State University is currently performing neuroimaging studies to test whether a martial arts therapy, Kids Kicking Cancer, can reduce pain and promote healthy brain development. Because the brain is more plastic during development, it is not only more sensitive to cancer treatments and stress, but may also be more receptive to all the help we can provide.

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