Quality of Life for Brain Tumor Survivors: A Grand Opportunity for Service

By Scott Norris, brain tumor survivor

Quality of life by definition means all aspects of living – physical, psychological, and social – and to focus solely on one in the treatment of brain tumor survivors, such as palliative care or symptom management, drastically misses the mark.

The psychological and social aspects of care are so important that the Institute of Medicine went so far as to point out in their 2007 report brief, “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs," that, "The failure to address the very real psychosocial health needs of patients and their caregivers is a failure to effectively treat that patient’s cancer, plain and simple. … After all, cancer treatment is intended both to extend life and to improve the patients’ quality of life. … [W]e need our health care professionals to do a better job recognizing a patient’s needs and connecting them to the right services – each and every time, for each and every patient."

A 2009 study by the National Brain Tumor Society (NBTS),

Scott Norris is an artist and brain cancer survivor. He and his wife Cheryl live in San Jose, CA. "Factors Influencing Quality of Life for Brain Tumor Survivors: A Practical Tool for Navigating Survivorship" is available for download in PDF form on the About Scott page of scottnorrisartstudio.com and free copies are available in booklet form by contacting Scott at scottnorris2@mac.com.
In a nutshell, the paper provides easy to use diagrams that can be taken directly to doctors during appointments to identify and point out concerns in the areas of communication, social support, coordination of care, access, advocacy, mobility, and inclusion. The diagrams not only help – and make it easy for – survivors and caregivers to focus in on their specific needs, but they also place the onus squarely on their medical team to respond across specialties and institutions with ideas, recommendations, and actions to fulfill those needs (something that both the Institute of Medicine and the NBTS indicate needs to happen more often).

“A Needs Assessment of Brain Tumor Patients, Survivors and Loved Ones,” parallels the Institute of Medicine report brief when it states, “Many of our findings highlight the need to re-examine what it means to live with a brain tumor diagnosis. The concept of brain tumor survivorship is expanding to include not only quantity of life but also quality of life for people with a brain tumor. ... There is a need for more routine assessments and services that go beyond standard treatment regimes and holistically address the spectrum of cognitive, physical and psychosocial needs of brain tumor survivors.”

As a brain cancer survivor I wholeheartedly agree with the conclusions of the Institute of Medicine and the NBTS. The modern medical system is very good at assaulting you with the big things – the “standard treatment regimes” that will hopefully keep you alive like the left frontal craniotomies, radiation, chemo, and Gamma Knife procedures that I’m all too familiar with. Don’t get me wrong, I’m eternally grateful for those things – without them I probably wouldn’t be here today.

But while you’re being dragged through the mud – while they’re busy pounding you with all the big things (and even long after they’re done) – it’s left up to you and your caregivers to find ways to deal with your "very real psychosocial health needs."

Having long recognized the gap between mere descriptions of the issues and shortcomings surrounding quality of life and an actual practical implementation, I decided to write a paper called, "Factors Influencing Quality of Life for Brain Tumor Survivors: A Practical Tool for Navigating Survivorship." The paper goes one step further than other quality of life efforts by actually offering an innovative and practical solution for addressing the psychosocial needs of survivors and their caregivers.

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The paper has received great feedback from caregivers and survivors, nurses and doctors, support group leaders, representatives of brain tumor and brain injury organizations, and the editor of the Journal of Cancer Survivorship.

Efforts must continue to address the issues surrounding quality of life for brain tumor survivors and their loved ones. Much work still needs to be done and there remains a grand opportunity for service in the field. However, that opportunity can only be taken advantage of if we expand our vision and definition of what constitutes quality of life. And it’s high time we did so because, as the Institute of Medicine points out, "Patients and caregivers deserve no less."