



“It’s always something”: the health and functional complexities of late effects in long-term cancer survivors

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As most of you are well aware by now, I was diagnosed with a malignant brain tumor at the age of 53, 19 years ago in 2003. I am thankful for the life I have been given, but I did feel the need to write this editorial in an effort to remind those involved in research and practice that some late effects in long-term cancer survivors are indeed complex. Learning more about these complexities will influence both physical and functional health and is essential for optimal long-term survivorship. Sure, exacerbation of these late effects may in part be the consequence of aging, but nevertheless, their longer-term impact and the need for effective solutions remain an enigma.

There is a need to improve our understanding of the biological and bio-behavioral effects of such complexities and to develop enhanced evaluation and management of these challenges. My recent experience with one such late effect has motivated me to write this editorial. Understanding the subtle, yet important, consequences of the complexities involved in certain late effects and the impact they can have on health and functional outcomes in longer term cancer survivors is an important pursuit.

As with most survivors of brain tumors, my hearing was affected by the treatment I received for the glioma I was diagnosed with. At the time, the chemotherapy that was selected (Temadar) did minimize side effects. However, the radiation I was given did impact my hearing. Sure enough, I experienced bilateral high-frequency hearing loss that necessitated the use of hearing aids. The hearing aids at first allowed me to hear in public.

This accommodation did assist with work and allowed me to effectively interact with others. However, several years later, it was concluded that fluid in my eustachian tube, probably a late effect of the radiation I received, was the source

of my prolonged pain and pressure in and around my right ear. Eventually, the fluid broke through my right ear drum relieving the pressure and pain but contributing to bacterial and fungal infections. These were “treated” with different ear drops.

The ENT exam and audiogram confirmed an opening in the eardrum and a major loss in my hearing. Although I retired from my university career, the attenuation in hearing began to negatively affect my social functioning. It became harder and harder to understand the speech of others. Eventually, my right ear drum closed for a brief time, and while my hearing partially returned, it has never returned to where it was prior to my brain tumor treatment. I continue to experience major loss in hearing during conversations. My subjective assessment was again supported by a recent audiogram. The pressure and pain returned until once again, the pressure and fluid forced a reopening of my right ear drum and while the pressure and pain disappeared; the fluid and hearing loss reappeared. I still can not hear anything in my right ear, even with a hearing aid!

It seems that this “vicious cycle” was triggered once again by the build-up of fluid. The opening of my ear drum, a result of the fluid accumulating behind it, and the temporary solution of ear drops were once again prescribed. While this ongoing late effect was the result of exposure to radiation along with aging, nevertheless, it has resulted in recurrent hearing loss and problems in verbal communication with the consequence of limiting human interaction. While this hearing loss may be considered mild in comparison to many life-threatening late effects (e.g., cardiovascular effects, it has resulted in isolation and reduced social interaction. Anecdotal evidence suggests that both survivors and clinicians are faced with similar examples of such complexities at one time or another.

While there has been considerable research on the most prevalent late effects for years, there is very little empirical information on the incidence of these idiosyncratic problems for which, at present, there just is no adequate solution.

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These complexities can lead to longer term challenges to optimal health and function. Identifying, understanding, and developing effective clinical solutions to such problems represents an important area for future research. A focus on the incidence of these problems and their impact on function is essential to optimize cancer survivorship over the long term. It is time that the management of these types of late effects go beyond the need to simply “live” with these challenges.

To improve long-term outcomes, researchers and practitioners need to direct greater attention to the epidemiology (descriptive and clinical), potential mechanisms, and the development of evidence-based clinical management of these phenomena. The *Journal of Cancer Survivorship* stands ready to publish research on the occurrence of such manifestations and how these late effects can inadvertently reduce function and negatively impact overall quality of life. Studies on more effective solutions to these types of clinical problems are also welcome.

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Declarations

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