

Guest Editorial

Survivorship: Let's reclaim a hijacked agenda!

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The 10th anniversary of the *Journal of Radiotherapy in Practice* offers us a time to reflect on changes that have taken place in health care, our role in making those changes, our reactions to them and the implications for our practice in the future.

The past decade has seen unprecedented improvement in cancer survival rates. Patients are living longer and longer after treatment which in turn is putting significant pressure on the cancer system to meet their long-term health needs. The fundamental structure of the formal cancer system is predicated on planning services for the new case, leaving cancer survivors relatively underserved. These patients leave our treatment programs ill-equipped to deal with a host of persistent and late effects that affect them physically, emotionally, socially, and spiritually. Many report feeling abandoned by our overburdened system of cancer care. Moreover, we as health-care providers feel ill-equipped to address these previously unrecognized consequences of treatment, should we remain involved in their post-treatment care.

These pressures have been building for some time. In 2005, the Institute of Medicine (IOM) of the National Academies published an extensive national consultation on cancer survivorship called *Lost in Transition*, which was co-sponsored by the American Society of Clinical Oncology.¹ The ten recommendations from this consultation have driven the survivorship agenda in North America with a sub-

sequent “medicalization” of the term survivorship, seemingly limiting its application to the post-treatment phase of the cancer control continuum¹. The components of survivorship care are then grouped into two main categories. The first deals with medical surveillance after treatment for prevention and early detection of recurrent disease and second primary cancers. The second concerns itself with surveillance to identify, prevent and treat persistent and late effects of cancer treatment. This framework has generated much debate from various professional groups as to who should take ownership and has resulted in calls to develop survivorship programs, models of survivorship care and research into survivorship.

However, there is not a great deal of clarity in the cancer community about what survivorship research entails. There is significant overlap with existing programs that explore the impact of treatment on quality of life, functional, and patient reported outcomes. This information is already collected, albeit not often systematically or for long enough, and then iterated back to help tailor treatment approaches to improve the therapeutic ratio. Supportive care and cancer rehabilitation research is traditionally the domain of psychosocial oncology, rehabilitation sciences and now regenerative medicine.

¹ The cancer control continuum is a way of organizing population based cancer services and is generally composed of several components that can include prevention, screening, diagnosis, treatment, “survivorship”, end of life care and so on.

One might question the wisdom of creating a new construct called survivorship, as opposed to broadening the reach, composition and research directions of comprehensive clinical and supportive care programs.

But let us explore this concept of survivorship a bit further. The name survivor and the idea of survivorship was coined by a cancer patient-physician Fitzhugh Mullan who published his experience with cancer in the *New England Journal of Medicine* in 1985. He described it as journey with three distinct seasons—acute, extended and permanent, each posing unique challenges.² He experienced a woefully inadequate medical approach that was inordinately focused on the cancer. This prompted him to found the National Coalition of Cancer Survivorship to empower patients through education, peer support and advocacy. Their definition of cancer survivor is simple and inclusive, has broad community support and is endorsed by the US National Cancer Institute. A cancer survivor is anyone with a personal history of cancer. You become one when you hear the words “you have cancer” and remain one for the balance of your life. Because a cancer diagnosis has broad reaching consequences to the individual and those close to them, the definition embraces family members and caregivers.

This patient-centred concept was apparent in the themes that came out of the IOM stakeholder interviews of over 200 cancer patients. The most important themes were the need for cancer patients to be partners in care, to be heard, to be part of a responsive system of care that is integrated and coordinated, one that takes a holistic approach to care from the point of diagnosis through to death. There was strong messaging on the need to develop strategies help patients develop the skills to self manage their cancer journey in the long term, with appropriate self management support.

Successful chronic disease management is predicated on developing productive partnerships between activated, empowered patients and prepared, proactive team members.³ Education, support and supportive environments are

the fundamental prerequisites of empowerment. There is a growing body of literature on the benefits of patient education to the individual, the organization and the health-care system. Hospital program standards have been established and research is ongoing on how to help us maximize our patient education skills.^{4–6} We can all support the survivorship agenda by helping our patients navigate our complex health-care system, by coaching and mentoring them to become expert in managing their condition, by advocating for change on their behalf, and empowering ourselves to lead change initiatives.

The Princess Margaret Hospital Survivorship Program was established in 2005 in response to community advocacy and a major fundraising initiative called the Weekend to End Breast Cancer. The Program provides information, education, tools and support to engage and empower self management activities along the continuum of care. Our interdisciplinary team partners with patients and clinicians to address challenges in the physical, emotional and practical domains. To extend our reach to a geographically disperse population we have a blended model of live and virtual programs. This program is supported by ELLICSR: the Collaborative Centre for Health Wellness and Cancer Survivorship Research. ELLICSR houses researchers and self-management research facilities and provides an innovative physical base for the Princess Margaret Hospital Cancer Survivorship research program. By leveraging the intellectual and human resource capital of the survivors themselves, the goal for ELLICSR is to make new discoveries in cancer survivorship, innovate clinical processes, and investigate new models of survivorship care delivery. Key to this will be fostering collaboration between researchers, clinicians, and survivors, and enabling all stakeholders to engage with each other with appropriate clinical guidance.

The implications of adopting the patient-as-partner concept are huge, and would result in transformative changes to our provider-centric processes and systems. What would that look like? You just need to imagine what

level of information, access to quality services, coordination of care and system responsiveness we would demand for ourselves as patients, and then make it the standard for all. We are trying to build this vision of cancer care at ELLCSR starting with a networked community of clinicians, researchers, survivors and community cancer organizations dedicated to revolutionizing the cancer experience. Come and join us at www.ellicsr.ca. Let's work with survivors and reclaim the survivorship agenda!

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