

# Quality of life for patients surviving cancer: are we moving ahead?

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Much has changed in the United States and worldwide since Richard Nixon signed the U.S. National Cancer Act of 1971. An awareness of prevention, earlier detection and newer treatments, rehabilitation, and more recently, the aggressive management of symptoms, have all contributed significantly to an improvement in survival rates for patients with earlier stages of disease. Since 2015, with the introduction of immunotherapy, an improvement in the survival of patients with metastatic disease is now the new norm, and clinicians are no longer as sure as previously about when patients are entering into their final days or weeks of life.

The growth of the cancer patient population and the lack of parallel growth in the supply of physicians and other allied health care professionals caring for patients, as well as inadequately funded health care services in many countries, could mean that many patients who survive cancer will be living with a higher risk of a second cancer and the side effects from treatments that can physically and emotionally scar patients and families. Who will be looking after the needs of cancer survivors?

The medical and psychological needs and concerns of cancer survivors were well described in a 2005 report from the U.S. Institute of Medicine<sup>1</sup>. They include effects on quality of life—specifically, effects on physical, psychological, social, and spiritual well-being—and the long-term and late effects of the cancer and its treatment. In addition, patients experience the uncertainty and vulnerability related to a possible relapse. Those needs, unmet, correlate closely with quality of life<sup>2,3</sup>. The “unmet needs” increase as patients transition through the continuum of diagnosis, treatment, survival, and relapse, possibly as a result of declining social support and increasing information hunger. Inquiries increase about prognosis; rehabilitation; disease surveillance; and social, financial, and other legal factors. Body changes and sexuality are high-priority questions initially, but can change during the transitions to various phases of survivorship. A frequent query is “What is the new normal and how will it affect my quality of life?”

Although many patients continue to see their oncologists after active anticancer treatments are completed, others want to return to the family physician for support and help with their various other medical issues. However, reports have demonstrated that many family physicians lack expertise in this area and are not able to meet the survivor’s

needs<sup>4,5</sup>. Many patients therefore find themselves feeling hopeless, helpless, and abandoned. Lack of communication—including physicians not being copied on all reports, medical transcriptions being delayed, and difficulties between specialists and family physicians in accessing patient information, particularly during care transitions—is also cited as a cause of distress for survivors<sup>6</sup>. Coordination of care is therefore vital in any care plan. If the needs are not anticipated at the beginning of treatment, then addressing them at a later time could be difficult.

The escalating cost of health care appears unsustainable. Canada spends approximately 11% of its gross domestic product on health care<sup>7</sup>. According to the 16th Annual National Report Card on Health Care, more than 70% of Canadians believe that existing health care services are in need of reform<sup>8</sup>. To have a transformative effect, explorations of ways to accurately measure costs and compare them with outcomes are an urgent need. Emphasis should be placed on the survivorship care planning process and the way plans are delivered. Aspects of the process include interdisciplinary care; integrated care (the family physician and the oncology team communicating to support the survivor); rehabilitation (promoting a return to functional capacity); and a fostering of patient self-management.

Building capacity with family physicians to manage patients in the survivorship phase will lead to cost-effective and high-value care for patients. Several models of survivorship care exist, but none has been properly tested. The levels of confidence between providers significantly differ with respect to their abilities to suspect and test for recurrence and to address the physical and psychological effects of cancer and its treatment. There is also discordance in the levels of trust between oncologists and family physicians. Given that many survivors have other chronic comorbid conditions, most family physicians will opt for a shared-care model.

The 2013 U.S. Institute of Medicine report identified increased needs for survivorship and palliative care in addition to the need for better coordination and organization of the delivery of cancer care<sup>9</sup>. All survivorship programs must include the promotion of emotional health and attention to quality of life, provision of information, and arrangement of access to resources that can address the unmet needs. Over the cancer care trajectory, the responsibility

for a healthy lifestyle and psychological care will shift to family and community. Self-management interventions will be needed to achieve the full provision of required support because the supply of health care professionals and the demands from cancer survivors will not be able to keep pace by 2025<sup>10</sup>. The future therefore dictates effective and timely identification of the needs of cancer survivors, integration of interdisciplinary care planning, coordination with community resources, and more efficient communication between health care providers.

#### CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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