Survivorship 2.0
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Introduction
A plethora of reports1,2 and review articles3 admonish cancer health care systems and providers for not meeting the challenge of cancer survivorship. These worrying reports are made against a backdrop of remarkable success in cancer screening, diagnosis, treatment, and survivorship. This success, however, is now a double-edged sword: With more survivors of cancer, more cancer care is needed, not less. The challenge of cancer survivorship is great, the evidence for best care is scanty, and the capacity of the health care system is ever diminishing.4 Given these challenges, which were recently comprehensively reviewed,5 what tools and models of care can address them?

Several tools, such as survivorship care plans (SCPs), clinical practice guidelines (CPGs), and risk stratification approaches have been proposed to improve survivorship care. One of the most influential recommendations from the first Institute of Medicine report was that every patient be provided with an SCP.1 Despite spawning a new area of research, the evidence of benefit of SCPs for patient and/or health system outcomes is patchy.6 Similarly, CPGs for survivorship care are often too complex, make recommendations with a limited evidence base, or cannot be implemented because they require resources that are not available. For each of these tools, their promise and hope have exceeded the proven benefit. Jacobsen et al7 make several important methodologic recommendations for future SCP research. One of these recommendations is that SCPs—and, by extension, all other tools—be studied within a model of care that supports their implementation, and within an environment that can provide the resources and services recommended. The former is necessary for successful and sustained implementation, whereas the latter is necessary to have an effect on patient outcomes. For example, supportive care recommendations in CPGs that are then incorporated into SCPs are meaningless unless the appropriate supportive care resources are available. In the multilayered, multidimensional reality of health care,8 tools cannot stand alone but should be studied within the broader context of care models.

To this end, several reviews have synthesized the literature on models of survivorship care in the various environments in which these models7,11 and their implementation12 have been studied. These models can generally be grouped into those that are oncology led, primary care led, nurse led, or shared care. Each of these different models has advantages and disadvantages and must be assessed for goodness of fit according to the specifics of the individual settings.13 Although there are important lessons to be learned from each of these reviews about the limitations and benefits of the different models, three overarching conclusions can be drawn.

The first conclusion is that needs are complex and as varied as the many forms of cancer and cancer treatments. For example, one recent guideline on breast cancer survivorship intended for primary care physicians makes 27 different recommendations14—and this is just one cancer disease site! This demands multidisciplinary care as neither oncology nor primary care can comprehensively cover all of the guideline recommendations, if even for one cancer site. In some instances, it is within the scope of primary care, whereas in others more specialized care is needed.7 Multidisciplinary care must be individualized and founded on the principles of risk stratification and equity15: Those with the greatest needs should receive the greatest resources.

The second is that survivorship is about more than cancer. The holistic conceptualization of survivorship is visionary but challenging. Optimum survivorship care encompasses cancer-specific surveillance; supportive care for long-term and late effects; general medical care of multimorbidity in an aging survivor population16; general preventive care, including behavioral risk factors; and psychosocial supportive care.3,14 This is a tall order indeed!

The message here is that, to be meaningful, this approach to survivorship care—and the care models that must follow from it—can no longer isolate cancer care. Survivorship care must be integrated with all medical and preventive health care services.

One promising model that integrates cancer-specific surveillance and preventive care with preventive care for other chronic diseases in the primary care setting is currently being tested in a randomized trial.17 BETTERWISE builds on an effective approach to improve adherence to guideline-recommended preventive care that is personalized to the individual’s medical history,
family history, and lifestyle risk factors, such as diet, exercise, smoking, and weight control. This model has now been revised to meet the special concerns of survivors of cancer by incorporating cancer-specific surveillance and prevention recommendations into an evidence-based algorithm for prevention and screening for diabetes, heart disease, and other cancers. A health professional who is trained to be a prevention practitioner develops and counsels survivors in their personalized prevention prescription. Such a prevention expert could be a powerful adjunct to a primary care team that offers survivorship care.

The third overarching conclusion is that multidisciplinary teams are not a panacea. Whereas none of the ambitious goals articulated in reports and guidelines on survivorship care is feasible without the expertise that can be brought to bear through multidisciplinary care, there are risks of fragmentation of care, confusion over role responsibility, and poor communication and coordination. These are well-documented problems of all aspects of cancer care and can cause more harm than good.

Principles of the medical home or the medical neighborhood—as the institutional underpinning of multidisciplinary care—points the way toward overcoming the problems of communication and coordination. These institutional structures can enable multidisciplinary teams, already with a commitment to collaborate, to work together within an institutional framework with shared infrastructure, such as shared medical records, common referral patterns, shared access to laboratory and imaging data, and a patient portal that enables the patient and family to be a part of the medical team. For this to work, it is important to be mindful of team dynamics and to acknowledge the respective roles and responsibilities, referred to by team science as shared mental models.

Survivorship 1.0 was heralded by the report, From Cancer Patient to Cancer Survivor: Lost in Transition, which documented the importance of cancer survivorship. It is now time for Survivorship 2.0: a wider adoption of the best available institutional structures and information technology through medical neighborhoods to support multidisciplinary teams that encompass primary care, oncology care, management of multiple chronic conditions, and preventive care, as well as the specialized supportive care that many survivors need.

More than a decade of research, summarized by systematic reviews, has shown us that the way forward is neither straightforward nor easy. Researchers, health system managers, and research funders alike should consider more complex pragmatic study designs that take place within the real-world setting of the care model. Too often, trials have to create study-specific systems for the experimental tool or care model that do not fit organically within the institution’s structure. This can delay adoption if ultimately proven effective. Jacobsen et al discuss the advantages of such study designs as hybrid trials and cluster randomized trials. Other research designs can improve our understanding given the multilayered nature of health care. For example, factorial trial designs allow for testing of two factors, such as SCPs and a risk-stratification approach, to investigate whether one or the other is effective individually, if both are effective together, or if neither is effective. SCPs, CPGs, and risk-stratification criteria must be underpinned by foundational biomedical and clinical research that provides the evidence base for efficacy. Consequently, survivorship research must involve the entire translational pathway from basic biomedical to health system and policy research. Only then will the much-lamented gap between research and practice narrow.

Cancer statistics show that between one third and one half of us will develop cancer. These projections mean that, as providers, nearly all of us will encounter survivors of cancer. It also means that for nearly all of us, cancer will be more than professional—it will be personal, as is so poignantly described by Bishop in the article accompanying this work and others.

I’ve Looked at Life From Both Sides Now

Recently cancer became personal for me: My husband was diagnosed with stage IV cancer. After the shock, I realized the cruel irony that, for us, cancer survivorship would be a privilege we would never experience; chronic metastatic would be the best we could hope for. The things that I knew professionally, either through my clinical or academic work, I was now experiencing in the most dramatic personal way. Had I really profoundly and empathetically understood the things that I thought I understood? The answer is no.

I did not understand how completely one’s perspective changes. How the design of health care institutions gives only lip service to patient centeredness. Even details that might seem insignificant or inconsequential can turn into monumental problems for patients, adding anxiety and stress to an already difficult situation. Assurance of collaboration and communication among the health care team (the medical home)—who all have access to the same medical records—is core to patient centeredness and can go a long way to reduce patient anxiety. Similarly, information about tests and scheduling through a patient portal helps fulfill the promise of patient–caregiver engagement as the blockbuster drug of the future.

Like many researchers, I dutifully followed the principles of patient engagement. I designed studies with patients and caregivers as part of the research team. One of these studies developed a map of the cancer care system as a visual knowledge translation tool. This map is a linear image that is so complex and convoluted that it is difficult for providers within the system, let alone patients, to fully understand the process. The patient–caregiver members of the team objected, stating that the map did not

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reflect their experiences. A second map was thus developed that illustrates the patient and family at the center and the relationships that form around them. These two maps highlight the difference between the perspectives (and needs) of patients and caregivers and the way in which the cancer care system has been designed.

There is no one best model for survivorship care. Cancer care providers and managers must make careful choices to find the best model that fits their local circumstances. Central to the success of any model, however, is meaningful patient and family engagement to design systems that are truly patient–caregiver centered. It is critical that cancer care providers get this right—for all of us.

REFERENCES

16. BETTER: Building on existing tools to improve chronic disease prevention and screening. www.better-program.ca
AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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