

Cancer Survivorship Planning in an Era of Cost Consciousness

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Evaluating Survivorship Care Planning in the Era of Comparative Effectiveness

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As someone who has had four cancer-related diagnoses and who is thusly familiar with everything that having that many diagnoses and undergoing that much treatment involves, you'd think I would have expertise in survivorship care planning. But you'd be wrong. I do, however, have a lot of experience with it – not only mine, but that of the hundreds of people I have talked to about how they find and use health care in their effort to live for as well and as long as they can.

Julia Rowland's invitation to participate in today's discussion about evaluating survivorship planning at a time when concerns about evidence-based medicine and cost effectiveness are ascendant gave me the chance to reflect on those experiences. And it challenged me to use those experiences to illustrate some of the barriers that those of us who *believe* that survivorship planning is important, face in trying to *demonstrate* it.

Here's a little background on my perspective: I am the president of the Center for Advancing Health (CFAH), an independent, foundation-funded non-profit in Washington. We work on patient engagement, on the assumption that we will not benefit from the health care available to us unless we can participate knowledgeably and actively in it.

When I founded CFAH in 1992, we focused exclusively on how to ensure that the empirical literature on health behavior had an impact on public health and health care policy.

Then in 2003, I received my third cancer-related diagnosis and it really knocked my socks off – I was amazed, not only by how much diagnostic and treatment technologies had changed in the decades since my first diagnosis, but by how much I had to do if I was going to get good care and benefit from it. I really struggled while I was sick, and when I was better, I started asking people about their experiences responding to a serious diagnosis.

After listening to the stories of more than 200 people, I had heard an earful about just what new responsibilities fall to people and their loved ones at the beginning of an illness. I heard about what they expected from their care and what they found; where they felt they were on their own and where they felt supported. Those interviews became a book about how to get through the first couple of weeks following a serious diagnosis – *AfterShock* – whose 2nd edition came out last year. But these

interviews also led us to shift the focus of CFAH’s work to exploring patient engagement from the perspective of the patient; that is, what we must do to find good health care and get the most from it.

Since then, we have worked to identify the specific behaviors we and our loved ones must perform if we are going to benefit from our care. After many more interviews and reviews of various literatures and surveys, we developed a comprehensive list – the Engagement Behavior Framework – that lays out 42 complex behaviors we have to perform to ensure we get the most out of our care. You can find the framework and a description of the methodology we used to develop it on the [CFAH Website](#).

Those 42 behaviors fall into 10 categories of related actions:

Find safe, high-quality care	Participate in our treatment
Communicate with our doctors	Promote our health
Organize our health care	Get preventive care
Pay for our health care	Plan for end of life care
Make treatment decisions	Seek knowledge about our health

We believe that care is not patient-centered unless it guides and supports us in doing these behaviors and we advocate for care that does both.

I usually introduce myself and this perspective and then go on to address the topic at hand, but it seems to me I should stick with this framework for our discussion today, since we have to perform these behaviors as part of any survivorship plan designed to help us do the best we can after we have completed our treatment for cancer.

I will talk about what we – patients and our loved ones – must do to put together and execute a survivorship plan. I’ll raise questions about what must happen – what must be in place – to guide and support us in performing those actions and will comment on the measurement challenges they raise.

“Find safe high quality care”

Between my diagnosis of Hodgkin disease at age 20, and my referral to [Kevin Oeffinger](#), director of the Memorial Sloan-Kettering [Adult Long-Term Follow-Up Program](#) two years ago, I had no formal survivorship plan, despite a hysterectomy for severe cervical dysplasia and a hemicolectomy for adenomatous polyps. The short history of my informal survivorship plan includes an initial five years of denial, during which time I was seen by no physicians at all, the discovery of these two additional conditions in the course of routine screening and a long parade of site-specific oncologists, from whom I more than once heard things like “I have no idea about that – it’s not my body part,” and “What are you doing here? I have sick people to take care of. There’s nothing wrong with you.”

It seems to me that the precursor to finding the right provider to care for me after I have finished treatment is that I must understand my risks of recurrence and any long-term effects of my treatment that I need to watch out for.

Then I need to find a specialist or primary care provider to be my responsible professional partner who will hold onto, coordinate and update my survivorship plan. As we will undoubtedly discuss today, this is not only a question of which provider is *qualified* to do this, but also, which one is *willing* to take on this responsibility for which patients.

In my interviews with individuals and caregivers, I heard often about primary care providers who were unwilling to advise about treatment decisions or take on long-term follow-up after a cancer diagnosis because they were not confident that they knew enough to do so well. In the course of my travels, I heard from many primary care providers who want this responsibility and are comfortable with it.

We need some guidance on this issue – and so do clinicians: Which of us can be safely seen by a primary care clinician and which of us need to continue with specialty care? What are the criteria that support this decision? Which clinicians are willing to take survivorship care seriously and where can we find them?

These questions must be answered if we are to find safe, high-quality survivorship care.

“Make treatment decisions” and “Get preventive care”

After I started working at NCI in 1988, it occurred to me that research was being conducted that was relevant to watching out for late effects or recurrence for my previous cancers. So I would arrive at my oncology appointments clutching articles that I thought were relevant to my care long before Google and PubMed.

Depending which oncologist it was, he may or may not have seen the article before. But if I thought I should get a test more frequently or a different test, either one of my oncologists or primary care doc was compliant in ordering it. This continued until two years ago – but even with the addition of PubMed and advice from a group of same-age, same-diagnosis, same-treatment friends, I was never confident that I was on top of my informal program.

Since entering the Adult Survivors Program at Memorial Sloan-Kettering, I have learned I was right to doubt my efforts. Just getting the right tests scheduled at the right time requires considerable work – and that doesn't count the time I spend learning from my doctor about the evidence (and lack thereof) behind newly identified risks and changes in the periodicity of tests and other activities that could help me stay healthy – and then deciding together whether to pursue them or not.

Formulating a survivorship plan is something that takes place between the clinician and the patient. However, for this to take place:

Clinicians must have time to gather the information and to discuss it with us. And they need to be able to track changes in recommendations not only for people with more common cancers like breast and colorectal cancers, but for the less common cancers. This means that:

- Good consensus guidelines and evidence must exist, including, for example, exposure guidelines;
- Those guidelines and that evidence are reliably and authoritatively updated;
- Everyone – including PCPS and patients – can find it easily

All this must be in place if we are to make informed decisions and then follow through on preventive care.

Now I'm going to put three categories of behavior together under the heading of "In or Out." These are all behaviors we must do in order to optimally benefit from our care and to live well after cancer treatment ends...but it is not clear where these behaviors fit in an evaluable survivorship plan.

"Participate in our treatment"

While preventive maintenance is core to a survivorship plan, good health and functioning often require much more. Many of us take maintenance drugs of one sort or another; we make use of mental health and substance abuse services, peer support and family groups; some of us need physical and occupational rehabilitation programs; we may need help with financial planning.

The 2009 IOM Report [Cancer Care for the Whole Patient](#) spells out in detail the range of supports and services we may need during and after treatment. It is an intimidating list. One thing to remember here is that most of us don't need most of these services even during active treatment, and even fewer of us do as cancer recedes into the background of our lives.

- 1) Are all these services a part of a survivorship plan?
- 2) If so, is our need for this range of services assessed as part of our survivorship care and referral to them measured?
- 3) What outcomes can be expected if these services are part of the plan and if we participate in them?
- 4) How can this be measured?

"Promote our health"

We are talking diet, exercise, sleep, stress, smoking cessation, substance abuse – the usual stuff here. We need to know that these behaviors play a role in our health and we need to act on them to the extent we are able.

Nobody here would ever say these things are not important to our long-term quality of life and survival. Doctors and patients alike have been willing to let them slide during treatment. But today's discussion should address whether these elements are in or out of an evaluable survivorship plan.

"Plan for end of life care"

Advance directives and living wills also have a legitimate place in a survivorship plan. Most people have been prompted to complete one or the other in the course of their treatment, if only by the persistent nagging of the quality measure prompt for staff to ask whether we have one of these documents as part of any inpatient or emergency room encounter.

Our preferences will change over time, though, and revisiting those arrangements is probably a good idea. While it doesn't require much time to encourage us to review them, their recommended presence in the survivorship plan raises questions about what we expect to be different because they are included; and whether and how to evaluate the difference.

Participating in treatment and using psychosocial services may be important for some of us, but actively promoting our health and having an up-to-date end of life plan are activities that every former cancer patient must do. Does an evaluable survivorship plan address them?

"Organize our health care"

This refers to the administrative work of coordinating care which, in the absence of an interoperable electronic health record (EHR), remains a task that falls to patients and their families: scheduling appointments, obtaining records, schlepping them around and so on. Those of you working in big comprehensive cancer centers cannot *imagine* what this is like for patients who are not seen in such settings.

Here is an illustration. Until two years ago, this was my situation: I had seen 10 physicians in the course of that year, some of them working in the same academic medical center on adjacent floors. Not one of them had *ever* communicated with another. I was the sole adjudicator of who got which information about me. This was not good. Yet this is still common. I don't need to remind you where most cancer care is delivered in the United States, nor of (as CMS director Don Berwick calls it) "the majestic pace of change" toward implementation of EHRs.

But getting the right tests and then getting the results to the right doctor raises much more substantial questions. For example:

- Which tests are we getting and which results are we schlepping around?
- What are the standard data elements that constitute a survivorship care plan? The Quality Oncology Practice Initiative (QOPI) standards only require inclusion of a chemotherapy summary.

- Which and how much historical material is included in the plan? For example, does the treatment summary include a record of surgeries and radiation exposures?

There is probably some urgency to identifying this while vendors who are developing EHR platforms are still willing to consider including new elements and are establishing linkages to reliable, authoritative sources of guidelines and other consensus material.

Whether our physician uses an EHR or a paper record, we still need to know what elements should constitute our survivorship plan so that we can arrange for all of them to arrive there.

“Pay for our health care”

Even those of us who are fully insured must take actions to make sure that our health care doesn't bankrupt us. As pressure to cut costs rises for health systems, so does the price of care for us – both in financial terms and in terms of the time we have to devote to fiddling with payment concerns.

For example, everyone here knows that many tests ordered under the rubric of long-term follow-up for cancer treatment are not based on evidence or even consensus guidelines. In an era of evidence-based medicine, clinicians necessarily will face pressure to do less without good justification.

Cost-cutting measures by payers seem, for example, to make pre-certification something we have to watch out for. You cannot imagine the snags: people showing up for colonoscopies to find they weren't approved and having the choice of putting \$5K on the Amex or getting another prep another day. And we can expect that we will have to appeal more coverage decisions by our health plans as medical necessity shifts around.

The better the evidence base and the greater the consensus for long-term follow-up, the easier it will be for doctors to order and for insurance to pay for, and for more of us to benefit from, what constitutes good survivorship care.

Starting with the actions we patients must take in order to remain as healthy as we can after we have finished treatment for cancer, I have raised a number of questions about what evidence, arrangements and skills have to be in place to support us doing so.

Which *clinicians* should work with **which** *patients* to put together a plan that includes **which** *elements* that can be **organized** and **located** *where* so that we *patients* know **what** to do **when**?

The answers to these questions are powerfully shaped by who you are and what you need. For example, the 2004 President's Cancer Panel and the IOM *Lost in Translation* committee members were expansive but vague in answering these questions. Those who created the coalition of advocacy and professional organizations that developed "The Way Forward" were more specific but less comprehensive; the LiveStrong Guidebook is comprehensive but aimed only at patients.

Today, we sit here at the behest of the NCI Survivorship Program. Our charge is to advise them about whether it makes sense to evaluate the impact of survivorship plans, and if so, how. At various points in our discussion, the elements that have been identified through all these survivorship planning efforts will fade in and out of focus for practical, political, strategic and scientific reasons.

I hope that these two lessons I have learned about survivorship from my experiences as a person living with cancer will remain constant:

First: regardless of the excellence of the data, the promise of reimbursement and the skill of the physician, if I don't show up, discuss my risks and my options and then follow through on the decisions I make with my clinician, I will get no benefit from survivorship planning, nor from the tests and technologies that can be used to improve the quality and extend the length of my life.

These are the things only I can do.

And second: I know with complete certainty that regardless of how much expertise, experience, connections and energy I invest in developing and implementing a survivorship plan, I cannot do this alone.

An effective survivorship plan requires a partnership between a patient and his or her provider.

As we discuss various aspects of an evaluable survivorship plan in an era of cost consciousness, let's remember that we want to end up with a structure that enables solid partnerships between patients and clinicians that – despite the physical and emotional assault of cancer and its treatment – will help us live for as well as we can for as long as we can.