
THE GW
CANCER INSTITUTE
THE GEORGE WASHINGTON UNIVERSITY

CENTER FOR THE ADVANCEMENT OF
CANCER SURVIVORSHIP, NAVIGATION AND POLICY

**Cancer Survivorship & Chronic Care Roundtable
Meeting Summary
December 5, 2011**

This event was made possible by support from the Pfizer Foundation and Pfizer Inc. through a grant to the George Washington University Cancer Institute's Center for the Advancement of Cancer Survivorship, Navigation and Policy funded by the Pfizer Global Health Partnerships Program.

This event was also supported by Cooperative Agreement number 1U50DP003054 from The Centers for Disease Control and Prevention. Its contents are solely the responsibility of the staff at the George Washington University Cancer Institute and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

Cancer Survivorship & Chronic Care Roundtable Meeting Summary

As the growing number of cancer survivors in this country transition into the post-treatment survivorship phase, many face physical, emotional, financial, social and practical challenges that are not well addressed in the current health care system.¹ The recognition that late and long-term effects require lifelong monitoring is leading to a change in the way cancer is being conceptualized; rather than being seen as an acute illness, cancer is increasingly being thought of as a disease that necessitates chronic care management in the post-treatment phase. New models of care have begun to be implemented, but many system barriers have slowed the incorporation of survivorship into the standard of care and no single model appears to be ideal for all settings and populations.² Consequently, there is still a great need to identify innovative models and methods for transforming the cancer care system across various settings to be responsive to survivors' post-treatment needs.

The components of the Chronic Care Model (CCM) clearly relate to the shifting perception of cancer and cancer care delivery. However, there is a need to better understand whether the chronic disease concept and the CCM are appropriate for cancer survivorship, how the CCM might be applied to drive cancer care changes, what can be leveraged in the current political climate to improve survivorship care and what the implications are of re-conceptualizing cancer as a chronic disease. To explore these important questions, the George Washington Cancer Institute (GWCI) Center for the Advancement of Cancer Survivorship, Navigation and Policy co-hosted a meeting on December 5, 2011 with The National Cancer Survivorship Resource Center (The Survivorship Center), a partnership with GWCI and the American Cancer Society (ACS) funded through cooperative agreement #1U55DP003054 with the Centers for Disease Control and Prevention (CDC). See Appendix A for the meeting Agenda. This report provides a description of the discussion and outcomes from the Cancer Survivorship & Chronic Care Roundtable meeting.

Defining the CCM

The CCM has driven health care system changes to improve outcomes for people with chronic diseases, such as depression, diabetes, heart disease and asthma.³ Although it has not been directly applied to cancer survivorship in the development of new care models, similarities between cancer and chronic diseases suggest that the CCM may be appropriate to guide improvements in post-treatment care. The CCM is a framework for guiding system changes to improve outcomes. Importantly, it recognizes the context within which health care occurs and seeks to create productive interactions between the patient and the practice team.³ In this model, patients are informed, activated and motivated and have the skills and confidence to engage in effective decision-making and health management. At the same time, the practice team has the requisite patient information, support for decision-making and resources for delivering high quality care.

In addition to the patient-provider interaction, the CCM focuses on health system and community changes to improve care.³ Changes needed at the health system level relate to self-management, delivery system design, decision support and clinical information systems. To achieve change with these components, health care organizations must visibly support improvement, especially at the leadership level, and actively promote effective improvement strategies. The community is

an important resource not only for patients but also for the health care system. Institutions should encourage patients to participate in effective programs as well as form partnerships with external organizations.

Methods

The Roundtable meeting agenda was developed by experts in survivorship and health policy. Experts on CCM, self-management, cancer survivorship and health policy were identified as speakers based on their expertise with the topics as recommended by the planning committee. Participants were recruited from different disciplines and backgrounds to provide diverse perspectives, and invitees included researchers in cancer and other chronic diseases, survivorship experts, clinicians, patient advocates, health policy experts and government representatives from the CDC and the National Cancer Institute (NCI). The Roundtable took place on December 5, 2011, and twenty-four individuals attended, representing the CDC, National Cancer Institute's Office of Cancer Survivorship, ACS, Group Health Research Institute, DC Cancer Consortium, Yale School of Nursing, Stanford University School of Medicine, National Coalition for Cancer Survivorship, LIVESTRONG, National Patient Advocate Foundation, GWCI, GW Medical Faculty Associates and the GW Department of Health Policy. See Appendix B for Attendee List. The one-day meeting included three focused discussion sessions and a final facilitated session to guide participants in discussing approaches to advancing cancer survivorship.

Discussion

The Roundtable discussion focused on four themes. First, is cancer really a chronic disease? Second, is the CCM applicable to cancer survivorship as a possible framework for transforming the cancer care delivery system? Third, what additional information needs to be collected and/or considered in the conversation about viewing cancer as a chronic disease? Finally, in the context of providing lifelong management for cancer survivors for the impacts of the disease and its treatment, how can the field move forward in changing the way cancer survivorship is described and discussed?

Is Cancer a Chronic Disease?

The answer to this fundamental question seems to be both yes and no. Participants noted that cancer survivorship shares many common characteristics with other chronic diseases. The risks, including obesity, nutrition and physical activity, are universal to chronic diseases, so management for many of these issues is similar and critical. Cancer survivorship and chronic disease also require lifelong management that necessitates collaboration between the providers and the patient to improve outcomes. Moreover, the role of the patient is elevated in survivorship and chronic diseases as they must take more responsibility for their health. With much of the general population facing at least one or more co-morbid illness, and often multiple co-morbidities, cancer survivors also face the need for ongoing management of co-morbid illnesses in the context of both their cancer and non-cancer follow-up care; care management for cancer and other chronic disease is not in isolation from other ongoing health issues.

Cancer survivorship, however, is distinct from other chronic diseases in several important ways. The group discussed that the intense psychological impact, stigma and fear of a cancer diagnosis are unique to cancer and are significant factors that distinguish the disease and its management from other diseases. Moreover, the management of the post-treatment cancer phase is very

different from managing other diseases. For example, patients with diabetes must continually address the diabetes itself and must live knowing they have the disease. Cancer survivors, on the other hand, need to address the *impacts* of the disease and its treatment and know that – oftentimes - they do not have the disease itself. In this sense, cancer as a disease itself is not chronic; rather, its effects need to be managed chronically. (The exception to this point is recurrent disease or disease that requires indefinite therapy where patients are on active treatment for long periods of time.) With so many different types of cancer that require very different treatments, the impacts can vary significantly such that chronic management for each person may be very different.

CCM and Cancer Survivorship

The CCM is a framework for changing the care delivery system that includes many of the same components that have already been applied to cancer survivorship care delivery and coordination as new care models have been developed and implemented. Much focus has been placed on improving survivor-provider interactions, and the Survivorship Care Plan (SCP) has been recommended by the Institute of Medicine and others as a tool to improve communication and care coordination while educating both the patient and non-oncology health care providers. Simultaneously, national policy initiatives are pushing toward productive interactions in cancer survivorship. For instance, the Comprehensive Cancer Care Improvement Act would provide Medicare reimbursement for physicians to develop SCPs, which would offer additional resources to support providers during survivor interactions.

Meeting attendees also indicated that focus has been placed at the system level and is evidenced by newly applied interventions and care models. *Self-management* interventions have been used across the cancer continuum, including the survivorship phase. One example presented is the expansion of Stanford University's self-tailored Chronic Disease Self-Management Program to cancer survivors through a study with the University of Hawaii and the Department of Defense. This six-week web-based program allows survivors to set self-tailored goals with support and information, and preliminary data indicates it may be an effective intervention in this population. *Delivery system re-designing* is occurring as new models of care are being implemented, such as multi-disciplinary clinics, disease/treatment specific clinics, consultative services and integrated care models.² The models incorporate better *decision support* through integrating specialist and primary care expertise and sharing of information with patients so they can be more active in their survivorship care. They also lead to improved *clinical information systems* where individual care planning takes place and information is shared not only with the patient but also across providers.

While CCM is applicable, several challenges to applying the CCM to cancer survivorship were identified. Perhaps the biggest challenge is the paucity of evidence needed to develop post-treatment care guidelines. This data would be useful both as the foundation for delivering evidence-based care, a central component of both the CCM and high-quality health care, and as an incentive for providers and institutions to change practice. Without it, many important stakeholders are unable or unwilling to make decisions that would improve survivorship care. Participants discussed that other incentives are also needed for system change, such as financial incentives, quality measurement and feedback. New incentives and incentives successfully applied in other disease areas should be explored and aligned to promote improved care.

Providers and systems are not the only audiences that need incentives; patients need to be incentivized to take more control of their survivorship care as well. However, before incentives can be fully utilized, the group pointed out that a major shift needs to occur for both providers and patients that recognizes the roles they each must play so patients are informed and empowered and providers are prepared for survivor interactions.

Attendees brought up that one significant challenge to recognizing cancer survivorship as a chronic condition is the language and perceptions about the disease. The term survivor implies that a person either has survived cancer or has not, and the post-treatment phase focuses on the disease-free period after treatment. Thus, the group discussed, referring to cancer as chronic creates cognitive dissonance given our current language use around the disease. Changing an already confusing terminology, however, might create more confusion than clarity. Moreover, because of the intense fear associated with a cancer diagnosis, patients may not even want to conceptualize cancer as a chronic condition as thinking of cancer as having an endpoint may be important for coping with the disease. Importantly, cancer survivorship currently is not widely viewed as a chronic disease by policy makers, clinicians, survivors or the general public. This is evident in the messaging around finding a cure, how cancer research and initiatives are funded separately from other diseases and how cancer is described as having an endpoint.

Several practical challenges were identified as well. Looming workforce shortages across many disciplines, including oncologists, nurses and primary care providers – the professions that have been central in new survivorship care models – threaten the ability to provide the necessary care in a changed health delivery system. This could lead, however, to an opportunity to focus outside of the healthcare system by looking to the community to take a larger role as well by incorporating self-management support into new care models that can bridge the system and the community. The need for improved infrastructure at the system and institution levels also threatens the ability to change post-treatment care delivery. Without the structural components, such as informational systems, changes will not be adequately supported, which reduces the chances for success. Ultimately, the group emphasized, the current political climate, including the shift to focus on prevention, grouping of chronic diseases into the same category, challenges in implementation of the Affordable Care Act, reduced funding and increasing need for and focus on cost-effectiveness, may inhibit improvements in post-treatment care.

In addition to the CCM, attendees recommended considering other models to inform cancer survivorship. Palliative care, for instance, followed a similar path as cancer survivorship by establishing a new field and integrating into the care delivery system. Research on models of care, cost and utilization may inform the field of cancer survivorship as it struggles to establish itself in the health care system. The rehabilitation model, which is standard of care in areas like cardiac care and brain injury, has also emerged as a model for post-treatment care, and other models outside of cancer may also be appropriate and should be explored to inform survivorship care.

Additional Information Needed

To even begin to change the dialog and perceptions around cancer, more information is needed. While CCM has been researched in other disease areas, its efficacy in cancer survivorship needs to be studied, and participants point out much of the CCM research has focused on

implementation. To be more widely applicable, research must clearly demonstrate the CCM's impact on patients, providers, the system and the community. The group indicated that self-management interventions have shown promise for cancer survivors, but also noted that more research is needed on efficacy and effectiveness of these interventions across health systems and populations. Similarly, attendees discussed that cost, especially in the current economic and political climate, must be better understood across different contexts. For instance, cost has different meaning for different audiences, so studies need to look at the cost of a changed cancer care delivery system from multiple perspectives at the individual, institutional, system and societal levels. Understanding whether and to what extent delivery changes improve outcomes, including patient-centered outcomes, and the cost associated with those changes will lead to compare the effectiveness research that will be instrumental in making decisions about how to improve care.

A particularly significant area that participants identified as needing attention is the development of measures. Performance measures have improved care in other disease areas, such as cardiovascular disease, and could be significant drivers of provider and system behavior changes. There are generic measures that may be appropriate, but cancer survivorship-specific changes are also needed. To address this need for new and better measures, the NCI has convened stakeholders to begin this measurement development, and **LIVESTRONG** spearheaded a process to define the "Essential Elements" of post-treatment care delivery. Without better understanding critical outcomes, the group cautioned, widespread changes are unlikely as the information is essential for policymakers and providers alike.

Changing the Conversation

Whether or not CCM is the appropriate framework for cancer, perceptions about survivorship must be changed to recognize that, from a medical, financial and individual perspective, cancer survivors need ongoing care beyond primary treatment and for the rest of their lives. Re-conceptualizing cancer survivorship in this way involves multiple audiences and messages. In general, the goal is to move the conversation around cancer from describing the disease as an acute illness to one that requires lifelong management and to re-define roles for survivors, providers, institutions, communities and systems.

To successfully change the conversation across stakeholders, participants stressed that understanding both the big picture conversation about health and chronic disease management as well as the conversation about cancer and its management is essential for positioning survivorship in a relevant way to audiences. For example, for Congress to understand survivorship, prevalence and impact to society are key messages. Survivors, on the other hand, must understand their role in living with the impacts of cancer. Providers need to hear about the evidence base, and the public needs to know that, while finding a cure is the ultimate goal, attention must also be given to the post-treatment phase. The group noted that it seems paradoxical to have a priority of finding a cure while seeking to shift the discussion on cancer to recognize it as a chronic disease. A cure, however, is at best years away and likely would not be a simple solution that works for all cancer types and stages. In the meantime, a growing number of Americans are facing and will continue to face the long-term impacts of the disease and its treatment. Messages must also be developed for use within the cancer community as well as between disease communities.

Conclusions

The Cancer Survivorship and Chronic Disease Roundtable was an opportunity to bring together diverse participants to explore a possible new framework to inform changes to improve cancer survivorship care. While the discussion raises many more questions than it answered, the conversation can inform the field of cancer survivorship at a critical point when there is significant momentum for improving post-treatment cancer care. Several questions emerged as themes to the discussion and should be further explored to better understand whether CCM and/or other models are appropriate for cancer survivorship.

How can cancer survivorship move forward in an environment of ambiguity? There is definitional ambiguity, such as what does the term survivorship mean, and there is policy ambiguity within the context of constantly changing health reform and the lack of clarity around how initiatives will be implemented. Much of this ambiguity will remain for the foreseeable future, so the survivorship field must develop flexible approaches that can be adapted to respond to clarity and more ambiguity. Cancer survivors cannot afford to have the field crippled in the midst of its significant momentum.

How can the cancer community collaborate with diseases that share the same risks while recognizing cancer as distinct from other chronic diseases? Although it may be essential to separate cancer because of its unique characteristics and challenges, there are clearly similarities between cancer and other diseases. These other disease communities have significantly paved the way for cancer survivorship. Coordinating efforts not only provides an opportunity to leverage the work of the chronic disease community, but it also provides an additional voice to advocate on the same issues. Policies that improve care for other chronic diseases also benefit cancer survivors and vice versa, so collaboration benefits all.

Finally, how can the cancer community work together more strategically? Much like collaboration across disease types, there must be cohesion within the cancer community. There is a great opportunity to identify common audiences, define measures of success and develop consistent language to create a larger impact. A unified effort will more effectively and efficiently lead to much-needed changes to how cancer survivors are thought about and cared for. Because these changes are significant, the challenges are great. Tackling these questions is an important next step for the field of cancer survivorship and for cancer survivors.

References

-
- ¹ Hewitt M, Greenfield S, Stovall E. (2005). *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, D.C.: The National Academies Press.
 - ² McCabe M, Baker KS, Huffman C, Miller K. Optimizing survivorship care: academic and community clinic models. In *Health Services for Cancer Survivors*. Feuerstein M and Ganz PA (Eds). 2011: 223-238.
 - ³ Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Aff (Millwood)*. 2001;20:64-78.

Appendix A: Agenda



**CANCER SURVIVORSHIP & CHRONIC CARE ROUNDTABLE
AGENDA
DECEMBER 5, 2011
THE CLOYD HECK MARVIN CENTER
ROOM 302**

The goal of the roundtable is to develop a set of principles for increasing the recognition of cancer as a chronic disease and advancing cancer survivorship as a public health priority.

- 8:00 a.m. – 8:30 a.m. Breakfast**
- 8:30 a.m. – 8:45 a.m. Welcome and Introductions**
Steven R. Patierno, PhD, Executive Director, George Washington Cancer Institute
- 8:45 a.m. – 9:00 a.m. Introduction of the Topics**
Mandi Pratt-Chapman, MA, George Washington Cancer Institute
- 9:00 a.m. – 10:00 a.m. Introduction to the Chronic Care Model**
Jessica Chubak, PhD, Group Health Research Institute
This session will orient participants to the structure and purpose of the chronic care model. Models to be discussed will include those for cancer and diabetes.
- 10:00 a.m. – 10:15 a.m. Morning Break**
- 10:15 a.m. – 11:45 a.m. Optimizing Survivorship Care – Learning from the Chronic Care Model**
Kate Lorig, RN, DrPH, Stanford University School of Medicine
M. Tish Knobf, PhD, RN, FAAN, AOCN, Yale University School of Nursing
The key focus of the first roundtable discussion session will be on identifying aspects of chronic care models that apply to cancer survivorship.
- 11:45 a.m. – 12:45 p.m. Lunch**

- 12:45 p.m. – 2:00 p.m.** **Promoting Survivorship in the Context of Health Reform**
Gwen Mayes, JD, MMSc, National Patient Advocate Foundation
Nicole Tapay, JD, National Coalition for Cancer Survivorship
The second roundtable session will focus on how policies within the Affordable Care Act can promote the development of survivorship within the Chronic Care Model.
- 2:00 p.m. – 2:15 p.m.** **Afternoon Break**
- 2:15 p.m. – 3:15 p.m.** **Advancing Cancer Survivorship as a Public Health Priority**
Allison May Rosen, Chandler Chicco Agency
The final session of the roundtable will bring in a communications expert to guide participants in moving the conversation forward, identifying core principles that will emerge from the roundtable to help integrate survivorship into public health.
- 3:15 p.m. – 3:30 p.m.** **Closing remarks and adjourn**
-

This event was made possible by support from the Pfizer Foundation and Pfizer Inc. through a grant to the George Washington University Cancer Institute’s Center for the Advancement of Cancer Survivorship, Navigation and Policy funded by the Pfizer Global Health Partnerships Program.

This event was supported by Cooperative Agreement number 1U50DP003054-01 from The Centers for Disease Control and Prevention. Its contents are solely the responsibility of the staff at the George Washington University Cancer Institute and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

Appendix B: Attendee List

Alisha Baptiste

Program Manager
DC Cancer Consortium

Becky Beauregard

Senior Research Scientist
GW Dept of Health Policy

Jennifer Bretsch, MS

Program Manager, Division of
Cancer Survivorship
GW Cancer Institute

Jessica Chubak, PhD

Assistant Investigator
Group Health Research Institute

**Rebecca Cowens-Alvarado,
MPH**

Director, Cancer Control
Mission Strategy
American Cancer Society

Annette Gardner

Public Health Advisor
Centers for Disease Control and
Prevention, Division of Cancer
Prevention and Control,
NCCDPHP

**Cherise Harrington, MPH,
PhD**

Assistant Professor
GW Dept of Prevention and
Community Health

Elizabeth Hatcher, BSN, RN

Special Projects Coordinator,
Division of Cancer Survivorship
GW Cancer Institute

Chi H. Kim, MD

Internist
GW Medical Faculty Associates

Paul Klintworth, MSPM

Project Manager
DC Citywide Patient Navigation
Network
GW Cancer Institute

**M. Tish Knobf, RN, PhD, FAAN,
AOCN**

Professor
Yale University School of Nursing

Jennifer Leonard, JD, MPH

Associate Professor
GW Dept of Health Policy

Kate Lorig, RN, DrPH

Professor/Director Patient Education
Research Center
Stanford University School of
Medicine

Gwen Mayes, JD, MMSc

Executive VP of Government Affairs
National Patient Advocate
Foundation

Holly Mead, PhD

Assistant Professor
GW Dept of Health Policy

Lorenzo Norris, MD

Director, Survivorship
Center/Consult Liaison Psychiatry
GW Medical Faculty Associates

Loyce Pace Bass, MPH

Director of Health Policy
LIVESTRONG

Lynn S. Padgett, PhD

Program Director
Office of Cancer Survivorship
National Cancer Institute,
NIH/DHHS

Steven R. Patierno, PhD

Executive Director
GW Cancer Institute

Mandi Pratt-Chapman, MA

Associate Director, Community
Programs
GW Cancer Institute

Elisabeth Reed

Program Coordinator,
Division of Cancer Survivorship
GW Cancer Institute

Allison May Rosen

Global Health Council
Chandler Chicco Agency

Nicole Tapay, JD, MPH

Senior Director of Policy
National Coalition for Cancer
Survivorship

Anne Willis, MA

Director, Division of Cancer
Survivorship
GW Cancer Institute