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Identifying key questions to advance research and practice in cancer survivorship follow-up care: A Report from the ASPO Survivorship Interest Group

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Introduction

Cancer survivorship encompasses the physical, psychosocial, and economic consequences of cancer, including issues related to health care and follow-up treatment, late effects of treatment, surveillance for recurrence of the primary, screening for second primary cancers, and quality of life. Almost two-thirds of individuals diagnosed with cancer are expected to survive for at least 5 years. For some cancers, such as breast and prostate, 5-year survival rates exceed 88%.¹ There is concern that the increasing numbers of cancer survivors combined with greater cancer incidence² will result in an oncologic service challenge that the US health care system is ill-equipped to handle. The American Society of Clinical Oncology (ASCO) projects a medical oncologist shortage by 2020 that will necessitate a multifaceted strategy in order to meet future oncology and cancer follow-up care demands.³

Survivor follow-up care is more than surveillance for recurrence of cancer.^{4,5} The Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*,⁵ and a growing number of researchers, describe continuity of care⁶⁻⁹ and care coordination¹⁰ as paramount for achieving better survivor care. According to the IOM report, comprehensive follow-up care incorporates: (1) prevention and detection of new and recurrent cancers; (2) surveillance for cancer spread, recurrence or second cancer; (3) intervention for late and

long-term effects of treatment; and, (4) coordination between specialists and primary care physicians to meet survivors' ongoing health care needs.⁵

At the 2009 annual meeting of the American Society of Preventive Oncology (ASPO),¹¹ the Survivorship Interest Group (SIG) raised questions important to advancing cancer survivorship research and practice related to follow-up care. This is a developing area of inquiry for researchers and clinicians. Similar to previous meetings of the ASPO SIG, the group asserted that cancer-related follow-up care requires transdisciplinary collaborations across research and practice-based organizations.¹² Such collaborations are required to build a strong evidence base to inform design of interventions that can help providers and survivors more effectively manage cancer related follow-up care. In addition, the ASPO SIG focused on the tension between narrowly defining survivorship follow-up care as addressing the cancer prevention and surveillance needs of survivors versus examining those issues within the broader context of health promotion and competing demands of managing both late and long-term effects of treatment and other co-morbid conditions. Issues addressed in the forum included: (1) care redesign, (2) the importance of evaluating the effectiveness of new models of care, and (3) the role of patients in their follow-up care. The purpose of this report is to summarize the group's key discussion points for dissemination to cancer prevention and control researchers, primary care and oncology professionals, and to engage survivor advocates and other professional organizations in dialogue around this topic.

Care Redesign

The ASPO SIG strongly advocated that cancer survivorship follow-up care models and plans should be based on evidence of efficacy and effectiveness. Redesigning cancer follow-up care was a topic that resonated throughout discussions. One discussion focus was how to design cancer survivorship care that better interfaces with primary care and ensures better knowledge transfer between oncologists and primary care physicians (PCPs). A second focus was a perceived disconnect between follow-up practice patterns across multiple settings, such as cancer centers, academic-based oncology practices, community-based oncology practices and primary care practices. Finally, participants acknowledged the need to ensure that research and interventions developed in academic and cancer center settings are designed with an eye toward translation, dissemination and sustainability into practice in other settings.

With these issues in mind, the ASPO SIG identified the following questions as priority topics that need to be answered as we build and expand the evidence base to develop and evaluate models of care for cancer survivorship follow-up:

- *Content:* What follow-up care should cancer survivors receive?
- *Setting:* Where should cancer survivors receive their follow-up care (e.g., community settings, academic cancer centers)?
- *Providers:* Which healthcare providers should deliver follow-up care to cancer survivors (e.g., PCPs, oncologists, advanced practice clinicians)? What kind of training do these providers need? How can appropriate communication be maintained among different providers?

- *Sustainability*: What cost-effective strategies will work for providing follow-up care to a large and growing population of cancer survivors?
- *Acceptability*: What are cancer survivors' preferences regarding the receipt of cancer survivorship follow-up care?
- *Reimbursement*: What are the optimal approaches for reimbursement of cancer survivorship follow-up care?

Models of Care

The current practice of cancer follow-up care has been described in the IOM report as “haphazard, unplanned and inadequate.”⁵ The IOM documented several models for providing survivor follow-up care; however, the research base and empirical evidence are insufficient to draw broad conclusions on best practices or best models. Oeffinger and McCabe,⁸ building on the IOM report, describe models of cancer survivorship follow-up care for which it will be important to gather data on effectiveness and cost:

1. The community-based shared care model, in which both the oncologist and the PCP provide care for the patient. The PCP refers the patient to the oncologist for cancer therapy and periodic follow-up consultation, and the PCP provides ongoing maintenance of comorbid diseases and health-maintenance care. A cancer survivorship care plan is provided to the PCP by the oncologist.
2. Disease-specific cancer survivorship programs at academic institutions
3. Comprehensive survivorship programs at academic institutions, including the following three models: consultative option, advanced practitioner clinician-led survivor clinic, and specialized multidisciplinary survivorship program.

Survivorship clinics have been instituted in some academic/cancer center settings and a number of institutions are currently conducting their own internal evaluations. Shared care has also been proposed as a viable alternative in non-academic/non-cancer center settings as it encourages oncologists and primary care providers to work together to manage patient care. In some ways, shared care might be a better alternative to current practice, as it provides links to necessary expertise of medical oncology, while also ensuring that primary care providers are involved in co-managing other acute and/or chronic illnesses. While the survivor clinic and shared care models of follow-up care make intuitive sense, the relative effectiveness of each model has not been evaluated. We believe this is a high priority research area.

The ASPO SIG also discussed the importance of collecting data on health-related outcomes and cost associated with the delivery of cancer survivorship follow-up care by various healthcare providers, including:

1. Advanced practice clinicians (e.g., nurse practitioners, physician assistants)
2. PCPs with additional training in oncology (e.g., see care models in parts of Canada and the United Kingdom^{13, 14})
3. Oncologists who specialize in primary care

Participants expressed that future research to test the health outcomes and costs of varying models of cancer survivorship follow-up care should be informed by existing models of evidence-based practice and dissemination. These include the Chronic Care Model¹⁵, Diffusion of Innovations,¹⁶ and the RE-AIM framework,¹⁷ which have been successfully applied to care delivery across multiple disease sites. Such future research should also be designed in view of its potential for integration into practice, as guided, for example, by the Practical, Robust Implementation and Sustainability Model (PRISM).¹⁸

Activated Patients

There are a number of research articles that detail the importance of providing survivorship care plans to patients, with the aim of assisting the patient in creating links between care providers for cancer related follow-up care.^{9, 19, 20} ASPO SIG members agreed that patient empowerment is important not only during active treatment but also during the extended period of follow-up care and that research examining how to engage and activate patients around their follow-up care is necessary and needed. Topics integral to moving forward that research agenda center around tailoring care plans for patients (e.g., should patient care plans be simplified versions of care plans that are given to providers?). Other questions included: How much detail is enough versus too much or too little? and What is the best way to provide care plans (e.g., via web portals, paper)?

Conclusions

Cancer follow-up care is increasing in visibility and importance as the number of survivors continues to grow. New survivorship research focused on follow-up care is needed and has been identified as a priority issue by multiple organizations (e.g., American Society of Preventive Oncology, American Association for Cancer Research, American Society of Clinical Oncology, American College of Preventive Medicine and International Primary Care and Cancer Research Group). Further research in this area and collaborations across research organizations will be required to build a strong, evidence-based foundation for developing and testing interventions to help providers and survivors manage cancer-related follow-up care.

REFERENCES

1. American Cancer Society. Cancer Facts & Figures 2009. American Cancer Society; Atlanta, GA: 2009.
2. Smith BD, Smith GL, Hurria A, Hortobagyi GN, Buchholz TA. Future of cancer incidence in the United States: burdens upon an aging, changing nation. *J Clin Oncol*. Jun 10; 2009 27(17):2758–2765. [PubMed: 19403886]
3. Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future Supply and Demand for Oncologists. *Journal of Oncology Practice*. 2007; 3(2):79–86. [PubMed: 20859376]
4. Hewitt, ME.; Ganz, PA.; Institute of Medicine (U.S.), American Society of Clinical Oncology (U.S.). From cancer patient to cancer survivor : lost in transition : an American Society of Clinical Oncology and Institute of Medicine Symposium. National Academies Press; Washington, D.C.: 2006.
5. Hewitt, ME.; Greenfield, S.; Stovall, E.; National Cancer Policy Board (U.S.). Committee on Cancer Survivorship: Improving Care and Quality of Life. From cancer patient to cancer survivor: lost in transition. National Academies Press; Washington, D.C.: 2006.

6. Edwards BK, Howe HL, Ries LA, et al. Annual report to the nation on the status of cancer, 1973-1999, featuring implications of age and aging on U.S. cancer burden. *Cancer*. May 15; 2002 94(10):2766–2792. [PubMed: 12173348]
7. Grunfeld E. Looking beyond survival: how are we looking at survivorship? *J Clin Oncol*. Nov 10; 2006 24(32):5166–5169. [PubMed: 17093281]
8. Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol*. Nov 10; 2006 24(32):5117–5124. [PubMed: 17093273]
9. Oeffinger KC, Wallace WH. Barriers to follow-up care of survivors in the United States and the United Kingdom. *Pediatric blood & cancer*. Feb; 2006 46(2):135–142. [PubMed: 16369921]
10. Ganz PA. Monitoring the physical health of cancer survivors: a survivorship-focused medical history. *J Clin Oncol*. Nov 10; 2006 24(32):5105–5111. [PubMed: 17093271]
11. American Society of Preventive Oncology. [June 10, 2009] Annual Meeting of the American Society of Preventive Oncology. 2009. <http://www.aspo.org/>.
12. Trentham-Dietz A, Buist DS, Kelly KM, Jacobson JS, Paskett E. Charting a strategic direction for the American Society of Preventive Oncology's Survivorship Interest Group. *Cancer Epidemiol Biomarkers Prev*. Sep; 2007 16(9):1912–1913. [PubMed: 17855715]
13. Campbell NC, MacLeod U, Weller D. Primary care oncology: essential if high quality cancer care is to be achieved for all. *Fam Pract*. Dec; 2002 19(6):577–578. [PubMed: 12429657]
14. Sisler J, McCormack-Speak P. Bridging the gap between primary care and the cancer system: the UPCON Network of CancerCare Manitoba. *Can Fam Physician*. Mar; 2009 55(3):273–278. [PubMed: 19282538]
15. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Aff (Millwood)*. Nov-Dec; 2001 20(6):64–78. [PubMed: 11816692]
16. Rogers, EM. *Diffusion of innovations*. 5th ed.. Free Press; New York: 2003.
17. Glasgow RE, McKay HG, Piette JD, Reynolds KD. The RE-AIM framework for evaluating interventions: what can it tell us about approaches to chronic illness management? *Patient Educ Couns*. Aug; 2001 44(2):119–127. [PubMed: 11479052]
18. Feldstein AC, Glasgow RE. A practical, robust implementation and sustainability model (PRISM) for integrating research findings into practice. *Jt Comm J Qual Patient Saf*. Apr; 2008 34(4):228–243. [PubMed: 18468362]
19. Cheung WY, Neville BA, Cameron DB, Cook EF, Earle CC. Comparisons of patient and physician expectations for cancer survivorship care. *J Clin Oncol*. Mar 30; 2009 27(15):2489–2495. [PubMed: 19332716]
20. Hewitt ME, Bamundo A, Day R, Harvey C. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *J Clin Oncol*. Jun 1; 2007 25(16):2270–2273. [PubMed: 17538172]