



Cancer Symptoms and Side Effects: A Research Agenda to Advance Cancer Care Options

Tammeka Swinson Evans, Suzanne West, Linda Lux, Michael Halpern, and Kathleen Lohr



Background

Early detection and treatment advances have changed the cancer prevention and control landscape such that a cancer diagnosis is now often treated as one of a chronic disease. As of January 2016, there were nearly 15.5 million cancer survivors in the United States, and this number is projected to grow to 26.1 million by 2040.¹

Cancer survivors have unique physical, psychological, social, and spiritual health needs. The patient experience can include such symptoms and side effects as pain, cognitive dysfunction, insomnia, and elevated anxiety and depression. Also, patients often have coexisting conditions that cancer treatment may exacerbate, and an increased likelihood of complications that health promotion activities can help reduce or prevent.

However, the knowledge base about survivors of adult-onset cancer has numerous gaps, especially concerning the management of symptoms and side effects by both primary care and specialist physicians. This research brief summarizes a landscape review conducted for the Patient-Centered

Priority Research Areas to Advance Cancer Care Options

Monitoring and Measuring Symptoms and Side Effects.

Evolving technology requires constant updates to the literature about new communication and digital technologies. Ensuring that the literature is current is critical to identifying the most beneficial and appropriate technology to measure and monitor patient-reported symptoms and side effects.

Treatment and Prevention Options. Complementary therapies are also prevalent, but they often lack rigorous supportive evidence. Bolstering the body of evidence for complementary therapies is imperative to providing support to patients and clinicians in considering treatment options.

Patient Self-Management. Comparative effectiveness studies can focus on assessments of self-management versus clinician-managed interventions and compare outcomes associated with different types of self-management programs.

Coordinated Care Among Health Care Providers and Health Care Systems. Care coordination to address cancer symptoms and side effects needs to be investigated further.

Patient-Centered Communication and Decision Making.

As patients become more educated and informed about their condition, they are better equipped to manage it. Understanding which approach to enhancing patient-centered communication and shared decision making is most effective is critical to increasing overall patient well-being.

Outcomes Research Institute (PCORI) to develop a clear, comprehensive understanding of the state of research in this domain as of the mid-2010s.

Specifically, the review looked at studies supported by federal agencies and private-sector organizations such as the American Cancer Society.

Before conducting the landscape review, PCORI determined the criteria for the following topics, which received a designation for the review as “high”:

- Monitoring and measuring patient-reported symptoms and side effects
- Fostering patient-centered communication and decision making
- Supporting coordinated care among health care providers and health care systems
- Promoting patient self-management
- Understanding treatment options, such as prescription and over-the-counter medications, complementary alternative medicine, nutraceuticals, marijuana, group support, and cognitive behavioral therapy.

Methods

We conducted a targeted search strategy to identify projects funded by federal and commercial sources and the American Cancer Society. We also searched for funding opportunities released by the National Institutes of Health (NIH) that could be used to support activities in these research areas. We reviewed literature in the following five databases (from January 2005 through September 2015) to identify studies focused on symptom and side-effect measures and the five priority topic areas noted above:

- ClinicalTrials.gov (<https://clinicaltrials.gov>)
- International Cancer Research Partnership (ICRP; <https://www.icrpartnership.org/database.cfm>)
- NIH RePORTER (<http://projectreporter.nih.gov/reporter.cfm>)
- HSRProj (wwwcf.nlm.nih.gov/hsr_project/home_proj.cfm)
- NIH Funding (<https://grants.nih.gov/grants/guide>)

Additionally, we used the PICOTS framework, which refers to populations, interventions, comparators, outcomes, timing, and setting. PICOTS is derived from the field of evidence-based practice and establishes a classification for assessing a body of literature across these domains. Our inclusion criteria for an adapted PICOTS framework specified the following:

- Populations or patients with a personal history of cancer, such as active treatment or post-active treatment

- Interventions, medications, psychotherapy, or behavioral health interventions for treatment or prevention of cancer symptoms and side effects
- Outcomes, including cancer symptoms and side effects (both somatic and psychological), patient self-management, patient communication, patient knowledge, and care coordination.

A detailed description of our methods, the database-specific counts, and the studies can be found elsewhere.²

Current Areas of Investment and Research

We identified 692 unduplicated studies (from January 2005 to September 2015) and retained 189 studies about cancer symptom and side-effect management. Of the 189 studies, the NIH funded 41% and the American Cancer Society funded 33%. Academic institutions, health care systems, other government agencies, private foundations, or industry supported the remainder of the studies.

The number of studies by focus area—priority area, cancer type, and the cancer care continuum—is shown in Table 1 for the 141 studies funded by NIH and the American Cancer Society. Because some studies addressed more than one focus area, the sum of the studies exceeds 141.

Table 1. Number of studies supported by the National Institutes of Health or the American Cancer Society, by focus area

Focus Area	Study Topic	Number	
Priority area	Monitoring and measuring patient care for symptoms and side effects	62	
	Treatment options	45	
	Patient self-management	23	
	Other	10	
	Coordinated care among health care providers and health care systems	4	
	Patient-centered communication and decision making	1	
	Cancer type	Unspecified	74
Cancer type	Breast	25	
	Neck and head	12	
	Other (oral and gastrointestinal)	10	
	Urological	8	
	Lung	6	
	Gynecological	4	
	Brain	2	
	Cancer care continuum	Not specified	65
		Active treatment	43
		Post treatment	31
Both active and post treatment		2	

Gaps Identified Across Priority Areas of the Knowledge Base

Using the adapted PICOTS framework, we identified critical gaps in the knowledge base pertaining to populations, interventions, comparators (when relevant to comparative effectiveness reviews), and outcomes. We also identified gaps in cross-cutting topics, particularly patient decision-making studies, patient self-management of cancer symptoms and side effects, and coordinated care.

Populations

The knowledge base is limited regarding studies on middle-aged populations (as compared with pediatric or elderly populations), racial and ethnic minority populations (especially Black and Hispanic populations), and rural populations. Given the increasing recognition of disparities in research for some patient groups (let alone disparities in patient-centered outcomes), important opportunities exist for targeted research of specific and more diverse populations.

Interventions

Commonly Used Therapies

In the full landscape review, many interventions focused on modalities typically used in cancer treatment, such as medications, chemotherapy, radiation therapy, and surgery. However, most treatment studies of symptom and side-effect management focused on medications, whereas only about 25% of the treatment studies focused on psychosocial or behavioral interventions.

In addition, many of these interventions for cancer symptoms or side effects are in the developmental stage and have not yet been rigorously assessed for effectiveness among cancer patients. Consequently, studies of nonpharmacologic interventions may be warranted to help identify additional options for patient decision making and self-management.

Broader or Cross-Cutting Interventions

Funding gaps exist in programs that emphasize other or more complex aspects of care, including patient self-management, clinician-patient shared decision making, patient-centered communication, and care coordination. Other issues for patients of all ages that are only rarely investigated involve decision making for those who have not responded to cancer therapies.

Also, substantial work remains to examine care coordination across different types of health professionals, settings and health care systems, and providers of medical and social services that patients or their caregivers may need.

Comparators

Generally, the identified studies were not “classic” comparative effectiveness trials using intervention arms and an active comparator. Rather, intervention and comparison or control arms tended to be integrated with different intervention types.

Future studies involving comparators in the same general classes as the intervention—such as medications or psychological and behavioral approaches—and combinations of interventions will be needed. This is especially true when clinicians and patients engage in informed decision making and patients increase self-management activities.

Outcomes: Specific Symptoms and Side Effects

More studies focused on somatic problems (such as pain and nausea) than on mental, emotional, or psychological concerns (such as stress, anxiety, and depression). Pain was the most studied outcome.

However, additional investigations of other physical complaints and symptoms associated with cancer and cancer treatments (such as fatigue and vomiting) are warranted. Also, equally (or perhaps more) important may be studies to investigate interventions that address mental health issues often associated with or prompted by cancer and its management.

Priority Areas for Future Research

In addition to filling the gaps identified above, several other research areas warrant greater attention, as described in detail elsewhere.² Table 2 highlights five priority areas identified by PCORI for future research that reflect the topics identified in Table 1.

We ranked the priority areas for future research by assessing the number of studies within each of the priority topics identified by PCORI. For example, priority topics with the highest number of studies received a higher ranking than topics with fewer studies.

Table 2. Priority areas for future research to advance care options for cancer symptoms and side effects

1. Monitoring and measuring patient-reported symptoms and side effects
2. Treatment options
3. Patient self-management
4. Coordinated care among health care providers and health care systems
5. Patient-centered communication and decision making

Monitoring and Measuring Symptoms and Side Effects

Many technologies to measure patient-reported symptoms and side effects involve remote systems, such as computer and mobile-device applications. Given the number of studies about the effectiveness of these technologies to monitor cancer symptoms or side effects of therapies, this area is especially suited for comparative effectiveness studies in the future.

Treatment and Prevention Options

A myriad of choices confront patients and clinicians for treating cancer symptoms and side effects, including prescription and over-the-counter medications, surgery, chemotherapy, radiation therapy, alternative medicines (such as nutraceuticals), and behavioral health interventions. To help identify the most appropriate treatments for specific symptoms and patient characteristics, studies are needed to compare standard medical care with other approaches. For example, although researchers have studied common symptoms for nausea and vomiting prophylaxis, few preventive interventions for cancer symptoms and treatment-associated side effects have been developed.

Complementary therapies exist for cancer symptoms and side effects, but more rigorous studies of complementary therapies and alternative medicines (such as nutraceuticals) are needed.

Patient Self-Management

Comparative effectiveness studies focus on reviewing self-management versus clinician-managed interventions and assessing the patient-centered outcomes associated with different types of self-management programs. They should also examine how self-management affects patient engagement in shared decision making and whether it leads to improved patient-provider communication (see below).

Coordinated Care Among Health Care Providers and Health Care Systems

Currently, care coordination to address cancer symptoms or side effects is poorly investigated. Future research should include evaluating models for coordinated cancer care, expanded use of integrated health care teams, and approaches for involving primary care practitioners, patient navigators, or community-based health workers in cancer survivorship care.

Patient-Centered Communication and Decision Making

Patient-centered communication and shared decision making can be strongly linked to self-management. Evaluating the comparative effectiveness of these types of interventions is critical, particularly for patients from minority or

vulnerable populations or for whom English is not a first language. Examining the synergies of patient engagement in shared decision making and improved patient-provider communication with effective patient self-management will be an important focus for such studies.

References

1. Bluethmann SM, Mariotto AB, Rowland, JH. Anticipating the "silver tsunami": prevalence trajectories and comorbidity burden among older cancer survivors in the United States. *Cancer Epidemiol Biomarkers Prev*. 2016;25:1029-1036.
2. Swinson Evans T, West SL, Halpern M, Hamilton R, Lux, L. PCORI methods for landscape review of cancer symptom and side-effect management. Funding activities final report. Research Triangle Park (NC): RTI International; 2015 Oct. Contract No.: CVDLDSR2013. Prepared for the Patient-Centered Outcomes Research Institute.

About the Authors

Tammeka Swinson Evans, MOP, is a health services researcher at RTI International with broad experience in chronic disease research that addresses health disparities and promotes health equity.

Suzanne L. West, PhD, is an RTI Fellow whose extensive work focuses on health services research and pharmacoepidemiology.

Linda Lux, MPA, is a health research analyst at RTI with a focus on health services research, particularly systematic evidence reviews and studies focusing on chronic disease.

Michael T. Halpern, MD, PhD, is a health services and outcomes researcher at RTI who previously served as Strategic Director for Health Services Research for the American Cancer Society.

Kathleen N. Lohr, PhD, MA, is an RTI Distinguished Fellow with vast experience in health care and health policy research.

Acknowledgments

This research brief is based on a report funded by the Patient-Centered Outcomes Research Institute (PCORI) through a contract to RTI International. We thank the PCORI Project Officer and project team for advice and support throughout the original project. We also extend our thanks to former RTI colleague Royce Hamilton for his assistance with the original report. We would like to express our sincere appreciation to Loraine Monroe (RTI International) for her diligent and responsive assistance in the preparation of this research brief. RTI International provided internal funding to prepare this publication.

RTI Press Research Briefs and Policy Briefs are scholarly essays on policy, methods, or other topics relevant to RTI areas of research or technical focus.

RTI International, 3040 East Cornwallis Road, PO Box 12194
Research Triangle Park, NC 27709-2194 USA

+1.919.541.6000 rtipress@rti.org www.rti.org

©2017 RTI International. All rights reserved. Credit must be provided to the author and source of the publication when the content is quoted. No part of this publication may be reproduced in any form by any electronic or mechanical means without permission in writing from the publisher. RTI International is a registered trademark and a trade name of Research Triangle Institute.

RTI Press publication RB-0016-1707

www.rti.org/rtipress