Cancer programs’ readiness to implement patient-centered standards of care: An assessment of Commission on Cancer accredited programs

Sarah. R. Arvey, PhD *corresponding author
LIVESTRONG Foundation
sarah.arvey@livestrong.org

Christopher Gayer, PhD
Patient-Centered Outcomes Research Institute

Stephanie Nutt, MA, MPA
LIVESTRONG Foundation

Haley Justice-Gardiner, MPH, CHES
March of Dimes

Nina Miller, MSSW, OSW
American College of Surgeons
Commission on Cancer

Victoria Kennedy, LCSW
Cancer Support Community

Stephanie Van Winkle
American Cancer Society, Inc.

Nina Wendling
National Coalition for Cancer Survivorship

Ruth Rechis, PhD
LIVESTRONG Foundation
Background
The Commission on Cancer (CoC) is a consortium of surgeons representing the Fellowship of the American College of Surgeons and representatives from professional organizations. The CoC is dedicated to improving survival and quality of life of cancer patients through the development and monitoring of multidisciplinary, patient-centered standards of care that focus on cancer prevention, treatment, research, education, support services, survivorship and end of life care. There are over 1400 CoC-accredited cancer programs in the United States and, annually, these accredited programs treat over 70% of cancer patients. In 2012, the CoC released updated accreditation standards to require cancer programs to include key elements of quality care.¹ The new standards challenge cancer programs to address patient-centered needs and measure the quality of the care they deliver by January 2015.

The broader CoC Standards are intended to encourage a patient-centered approach to care by addressing the full continuum of care, improving care coordination, increasing patient participation in care decisions, and increasing patient satisfaction. They include the provision of treatment and survivorship care plans; palliative care services; genetics services; navigation programs; and psychosocial distress screening. The standards were announced in 2012 with a three-year phased implementation period for specific standards including the Continuum of Care standards that address patient navigation, psychosocial distress screening, and delivery of treatment and survivorship care plans, the focus of this article.

Recognizing the importance of developing standards that enhance the patient care experience, quality of life, and treatment outcomes the CoC invited key stakeholders from patient-based organizations to become members in the CoC and serve on standard-setting workgroups, lending their expertise and helping to develop these important standards. These four, now CoC Member Organizations (LIVESTRONG Foundation, Cancer Support Community (CSC), American Cancer Society, and the National Coalition of Cancer Survivorship) worked with the CoC to support accredited programs’ compliance with these standards through education and programmatic efforts. This readiness project was a joint effort of the CoC and these four organizations and was intended to assess the: 1) current readiness across the country for implementing the CoC’s Continuum of Care Standards; 2) perceived barriers for implementing these standards; and, 3) preferred outlets for accessing resources to aid programs in implementing these standards. The goal of the project was to determine ways to use the results of the survey to develop strategies for assisting CoC-accredited programs’ in fulfilling the new patient-centered standards.

The three new Continuum of Care Standards are detailed here.¹ Standard 3.1 states, “a patient navigation process, driven by a community needs assessment, is established to address health care disparities and barriers to care for patients. Resources to address identified barriers may be provided either on-site or by referral to community-based or national organizations. The navigation process is evaluated, documented, and reported to the cancer committee annually. The patient navigation process is modified or enhanced each year to address additional barriers identified by the community needs assessment.” Standard 3.2 states, “The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care.” The purpose of Standard 3.2 is to develop a process to incorporate the screening of distress into the standard care of
oncology patients and provide patients identified with distress with resources and/or referral for psychosocial needs. The psychosocial representative on the cancer committee is required to oversee this activity and report to the cancer committee annually. Standard 3.3 states that CoC programs are required to disseminate a comprehensive care summary and follow-up plan to patients completing cancer treatment, and each year, the process is implemented, monitored, evaluated, and presented to the cancer committee. Ideally, a survivorship care plan (SCP) is a comprehensive treatment summary and follow-up care plan, created by the oncology provider and provided in a written or electronic form to the patient, the patient’s primary care provider and other members of their health care team. A survivorship care plan, developed from a patient-specific treatment summary and including medical and psychosocial components, informs the survivor and the clinicians involved in the care of the survivor.

**Methods**
Representatives from the four CoC Member Organizations and one representative from the CoC collaborated to create a survey to assess programs’ readiness to implement new Continuum of Care Standards 3.1 – 3.3. The survey was developed by the representatives through an iterative process over a period of 3 months. It contained a total of twenty-three questions focused on the three Continuum of Care Standards 3.1-3.3 and was implemented via the web-based program, Survey Monkey.

The survey (see Appendix A) was fielded August 8 through September 13, 2013 to all cancer registrars, Cancer Committee Chairs, and Psychosocial Service Coordinators listed in the Commission on Cancer’s programs database. This included 1238 registrars, 1345 Cancer Committee Chairs and 344 Psychosocial Service Representatives representing 1390 programs. Each recipient was sent an email inviting them to complete one survey per accredited program. A subsequent reminder email was sent to recipients and a notice about the survey was printed in the online newsletter “CoC Source.”

For each standard, respondents were asked to rate their confidence in implementing the standard by 2015. Additionally, respondents were asked if they were currently implementing all aspects of each of the three standards. For respondents who indicated that their program was not currently implementing all aspects of the standard, they were asked two additional questions about their progress toward implementation and additional resources needed to implement the standard. For respondents who were currently implementing all aspects of the standard, skip logic was utilized so that these respondents did not answer additional questions about that standard.

**Results**
Of the 1390 existing CoC programs that received the survey, 690 programs responded to the Survey, resulting in a 50% response rate. Responses were received from 49 states, and the District of Columbia and Puerto Rico.

Of the survey respondents, 71% represented community-based programs (i.e. Comprehensive Community Cancer Program or Community Cancer Program); 65% had more than 500 new cancer cases diagnosed per year; 73% had been accredited for 11 years or more; and 32% reported a 2015 date for their next comprehensive accreditation survey. These results are consistent with the overall makeup of CoC programs.
When asked what role the respondent played in the program, 58% reported to be certified tumor registrars and the next largest group reported to be cancer program administrators (19%). The third and fourth largest groups were cancer registry quality coordinators and cancer committee chairs at 15% and 11% respectively.

**Readiness to Implement Standard 3.1 Patient Navigation Process**
Respondents were asked to report their level of confidence in their ability to implement Standard 3.1 Patient Navigation Process. The response options included completely, somewhat, not at all, or unsure. Overall, most respondents reported confidence (51% completely, 40% somewhat) in their ability to implement Standard 3.1 and 54% indicated that their program is already implementing a process that met all aspects of this standard.

Of those 54% of programs currently implementing a process for meeting Standard 3.1, 60% identified individuals to create an implementation plan for the standard and over 48% developed a patient navigation process (see Table 1). Additionally, programs indicated progress toward implementing other components of this standard, including creating a community needs assessment and identifying internal or external resources to address implementation barriers.

Of the programs not yet addressing Standard 3.1, 75% reported needing additional information regarding requirements for successful implementation. Further, of these programs, 61% would look to CoC member organizations for recommendations on implementation.

However, most programs reported needing tools to successfully conduct community needs assessments (80%), and 84% indicated wanting more information related to evaluating the patient navigation process. In open-ended comments, respondents reported they thought they were required to hire a patient navigator although this is not required to meet the standard.

**Readiness to Implement Standard 3.2 Psychosocial Distress Screening**
Respondents were asked to report their level of confidence in their ability to implement Standard 3.2 Psychosocial Distress Screening. Overall, most respondents reported confidence (58% completely confident, 35% somewhat confident) in their ability to implement Standard 3.2 related to psychosocial distress screening and 59% indicated that their program is already implementing a process that meets all aspects of this standard.

In terms of progress toward implementing Standard 3.2, 65% had identified individuals to create an implementation plan for the standard and 64% selected a psychosocial distress screening tool to be used within their program. Additionally, programs indicated that progress toward fulfilling other components of this standard (e.g. creating a process for providing referral for psychosocial care within or outside of their program) had been made.

Of the programs not yet addressing Standard 3.2, 73% needed additional information regarding requirements for successful implementation; 55% would look to other CoC member organizations, for recommendations on implementation. Sixty-one percent reported needing validated distress screening tools and 69% seek information regarding enhancing existing distress screening programs.
Readiness to Implement Standard 3.3 Survivorship Care Plan
Respondents were asked to report their level of confidence in their ability to implement Standard 3.3 Survivorship Care Plan. Respondents reported confidence (37% complete confidence and 47% somewhat confident) in their ability to implement Standard 3.3 related to SCPs. Forty percent indicated that their program is already implementing a process that met all aspects of this standard.

Of the programs currently implementing a process for meeting Standard 3.3, 59% identified individuals to create an implementation plan and 30% selected a survivorship care planning tool to be used within their program. Nonetheless, only 18% reported actually using a standardized tool.

Of the programs that are not yet addressing Standard 3.3, 74% needed additional information regarding requirements for successful implementation of the standard and 54% reported that they would look to organizations, i.e. CoC Member Organizations, for recommendations on implementation. A majority of programs, (80%) reported needing tools that can be used to develop and deliver a comprehensive care plan and follow-up plan, and 81% seek information regarding evaluating survivorship care plan processes.

Barriers to Implementation of Patient-centered Standards
When asked about barriers to implementation of all three standards, respondents reported the highest number of barriers for implementation of survivorship care planning, followed by patient navigation. Overall, among the seven barriers listed in the survey (see Appendix A, item 19), the most commonly selected across all standards were “not enough staff,” “time,” and “financial.” Respondents indicated time was a particular barrier for the implementation of Standard 3.3. Additionally, finances and not enough staff were commonly selected barriers for both Standard 3.1 and 3.3 (Fig 1).

Figure 1: Barriers to Implementation of Standards 3.1 – 3.3

Resource Utilization among Programs: Current and Future
The survey included items to assess programs’ current and future utilization of tools and resources to support their implementation of the standards. In order to implement the new standards, programs reported a high utilization of existing resources or tools to support their activities. Resources used include
colleagues, internal resources, and resources from CoC Member Organizations or support tools provided by CoC such as the CAnswer Forum. Only 11% reported that they use a consultant or consulting firm to support their efforts to implement the new standards.

**Ease of Implementation**

Overall, programs reported that Standard 3.3, survivorship care planning, would be the most difficult to implement (Fig 2). Eighty percent reported needing tools that could be used to create a comprehensive care summary and follow-up plan. Another primary concern for all three standards was having adequate, trained staff to deliver the different services. For example, programs mentioned not having someone to deliver psychosocial care or to disseminate and provide support to patients in their utilization of SCPs. Finally, respondents were concerned by the lack of evidence supporting the impact of SCPs in improving patient outcomes.

**Figure 2: Ease of implementation**

### Discussion and Next Steps

With the increasing importance of the provision of value-based, patient-centered care in the United States, the CoC worked with stakeholder organizations to craft landmark patient-centered Standards for its accredited programs. Results demonstrated that CoC programs have made great progress towards implementation. Encouragingly, for navigation processes and distress screening, more than half of respondents were already implementing the full standard and, for SCPs, nearly 40% of respondents were implementing the full standard. For sites that were not currently implementing the full standard, many had completed the first steps of the process, especially in the case of Standards 3.1 and 3.2. Overall, Standard 3.3 on the delivery of SCPs appears to be the standard most sites are struggling to implement.

Based on respondents’ open-ended comments from the survey, some programs desired additional clarity on the standards meaning and thought that additional guidance would facilitate implementation. For example, for Standard 3.3, responses indicated that the struggle to implement the standard stems in part from a lack of comprehension about what is needed to implement it and what tools should be used to
deliver SCPs effectively. Regarding Standard 3.1, some respondents thought they were required to hire a dedicated navigator at their site, even though the CoC does not mandate the hiring of additional staff and allows for referral to external resources. Finally, additional clarification is needed regarding the community needs assessments for navigation planning.

The CoC offers valuable knowledge-sharing platforms (e.g. CAnswer Forum) to its accredited programs that enable them to share information regarding requirements and encourages sharing of lessons learned and success stories. Additional guidelines, technical assistance, and courses for training staff could be provided to ensure access to high quality, credible resources that help reduce the implementation time and costs for the sites.

Referral to external resources may be instrumental to the successful implementation of the new standards. The Member Organizations that conducted this study, as well as a plethora of other local and national organizations, can and should be used to that end. Free resources that are available to the public include the LIVESTRONG Survivorship Care Plan and the organizations’ Navigation Services (www.livestrong.org); Cancer Support Community services (www.cancersupportcommunity.org); American Cancer Society (www.acs.org); and the National Coalition of Cancer Survivorship (www.canceradvocacy.org). The American Society of Clinical Oncology hosts a Survivorship Compendium (www.asco.org/survivorship) which provides several important resources. Further, resources are being developed specifically to address this issue, such as a new guide to psychosocial support services created by members of the Alliance for Quality Psychosocial Cancer Care (www.wholecancerpatient.org). CoC Member Organizations and other stakeholders in the field are undergoing efforts to identify and disseminate useful resources and tools to help programs in meeting the standards.

The new CoC Standards represent a paradigm shift in practice of patient-centered oncologic care. In addition to the increasing attention on the part of the National Cancer Institute, the Institute of Medicine, and the National Comprehensive Cancer Network, the CoC accreditation has helped galvanize professionals to study and disseminate knowledge related to the clinical and research issues of patient navigation, psychosocial distress, and survivorship care planning more than ever before. For example, investigators of the CDC Cancer Prevention and Control Research Network Survivorship Workgroup focused much of their in 2012-2013 on regional implementation of the care services described in the new standards. Additionally, an informal review of the 2014 American Psychosocial Oncology Society annual conference program reveals that approximately 65% of presentations were related to the importance of distress screening, referral to care and follow-up in cancer care.

While advocates and providers alike support the emphasis on patient-centered care, more research is needed to demonstrate the impact of patient-centered standards on healthcare utilization and health outcomes. Nonetheless, the strong leadership of the CoC in implementing the new standards has greatly advanced this effort. This study highlights a unique partnership between an accrediting organization and its member organizations that work together to assess, identify, and ultimately offer solutions to enable programs to implement these important standards of care. Findings show that, despite challenges, it is possible to implement meaningful patient-centered care standards. Community cancer care providers face many challenges in managing limited staff and resources. It behooves patients, providers, payers and
advocates to develop innovative and cost-effective solutions for implementing patient-centered care. Efforts to secure reimbursement for navigation, distress screening and survivor care planning are critical in truly transforming cancer care. Other steps involve offering solutions to facilitate implementation and encouraging funders and the research community to build an evidence base that demonstrates the effectiveness of these components in improving health and quality of life outcomes, a factor necessary to impact regulatory changes for the future.

Limitations
While multiple steps were taken to ensure that each respondents represented only one program, the survey was anonymous and it is possible that multiple surveys were submitted for one site. Further, as a little over half of the existing CoC programs responded to the survey, it could be that the sites least likely to respond are the ones struggling the most implementation. Finally, in some cases, survey respondents may not have had access to all the information needed to answer some survey questions accurately.
References


APPENDIX

See Table 1 and Readiness Assessment Survey attached separately.