Adult cancer survivorship care: experiences from the LIVESTRONG centers of excellence network

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Abstract

Background—The objectives of this study were to characterize survivorship models of care across eight LIVESTRONG Survivorship Center of Excellence (COE) Network sites and to identify barriers and facilitators influencing survivorship care.

Methods—Using the framework of the Chronic Care Model (CCM), quantitative and qualitative methods of inquiry were conducted with the COEs. Methods included document reviews, key informant telephone interviews with 39 participants, online Assessment of Chronic Illness Care (ACIC) surveys with 40 participants, and three site visits.

Results—Several overarching themes emerged in qualitative interviews and were substantiated by quantitative methods. Health system factors supporting survivorship care include organization and leadership commitment and program champions at various levels of the health care team. System barriers include reimbursement issues, lack of space, and the need for leadership commitment to support changes in clinical practices as well as having program "champions" among clinical staff. Multiple models of care include separate survivorship clinics and integrated models as well as consultative models. COEs' scores on the ACIC survey showed overall "reasonable support" for survivorship care; however, the clinical information system domain was least developed. Although the ACIC findings indicated "reasonable support" for self-management, the qualitative analysis revealed that self-management support was largely limited to health promotion provided in clinic-based education and counseling sessions, with few COEs providing patients with self-management tools and interventions.

Conclusions—The CCM framework captured experiences and challenges of these COEs and provided insight into the current state of survivorship care in the context of National Cancer Institute-designated comprehensive cancer centers. Findings showed that cancer patients and providers could benefit from clinical information systems that would better identify candidates for survivorship care and provide timely information. In addition, a crucial area for development is self-management support outside of clinical care.

Implications for cancer survivors—Cancer survivors may benefit from learning about the experience and challenges faced by the eight LIVESTRONG Centers of Excellence in developing programs and models for cancer survivorship care, and these findings may inform patient and caregiver efforts to seek, evaluate, and advocate for quality survivorship programs designed to meet their needs.

Keywords

Background

Improvements in early detection and treatment have resulted in a substantial increase in the number of cancer survivors. In 1971, there were approximately three million cancer survivors surviving at least 5 years after initial diagnosis in the USA. In 2009, 12 million people in the USA and an estimated 28 million worldwide were survivors of cancer [1]. To enhance medical and psychosocial outcomes for these individuals, management of treatment-associated long-term issues and late effects is needed, in addition to ongoing surveillance and health promotion strategies [2]. The growing number of survivors, coupled with limits to the projected oncology workforce, requires a different paradigm for providing care; this presents both an opportunity and a challenge to the development and delivery of

cancer care services [3, 4]. Understanding existing models of care and identifying gaps and barriers to optimal care can help to inform future efforts to enhance the field of survivorship programs and research for the benefit of patients, families, caregivers, and professionals.

The LIVESTRONG Survivorship Center of Excellence (COE) Network is a collaborative effort of eight National Cancer Institute-designated Comprehensive Cancer Centers (Centers) competitively chosen and funded by LIVESTRONG between 2004 and 2008 and created to accelerate progress in addressing the needs of the survivor community [5]. A summary of the sites appears in Table 1.

The current study was informed by the Chronic Care Model (CCM), a widely embraced approach to improving primary care that has guided clinical quality initiatives in the USA and abroad [6, 7]. The CCM is designed to help transform practice and patient outcomes by addressing comprehensive system issues and changes that promote patient-centered, evidenced-based routine care [8] and has been recently proposed as a framework for facilitating change in cancer survivorship health care [9]. The CCM identifies the six essential elements of a health care system that encourages high-quality chronic disease care: organization of the health care delivery system, delivery system design, decision support, clinical information systems (CIS), self-management support, and community linkages. The ultimate goal of improving these components of the care system is to redesign health care to produce more prepared providers and more educated and empowered patients, leading to better outcomes of care.

Increasing evidence supports the CCM as an integrated framework to guide practice redesign and quality improvement initiatives. The model has been applied to a variety of chronic illnesses, health care settings, and populations, and use of the CCM framework enables comparisons among various disease management programs and outcomes in evaluation research [8, 10–13]. For example, a review of 51 organizations that participated in quality improvement collaboratives based on the CCM indicated that practice processes and patient outcomes were improved for patients with congestive heart failure and those with diabetes; however, null results were found in a pediatric asthma management study that may have had study design flaws [13]. Thus, evidence is encouraging, but variations in illness characteristics and studies make it difficult to attribute positive outcomes solely to use of the CCM to guide change efforts.

Long-term cancer survivorship is a new chronic disease paradigm, sometimes in conflict with existing paradigms of cancer care as an acute and time-limited course of treatment, managed by oncology specialists in specialized centers [9]. This is very different from many other chronic conditions, e.g., diabetes care, which have long been recognized as ongoing illnesses usually manageable in primary care and largely dependent on patient self-management. Cancer care has unique characteristics including variety of diseases, life-threatening nature of the illness, many treatment options and changes in treatment depending on cancer type and stage, long-term late effects, and individualized patient profiles. Cancer survivorship care requires oncology practice to redefine the illness beyond acute treatment in a medical model and to find resources for long-term provision and support of follow-up needs for the growing population of patients in the USA and around the world who may be living with cancer for many years [2, 4]. In the UK, for example, recent World Health Organization statistics estimate that overall cancer deaths are falling, whereas the number of people living with cancer is increasing by 3% per year [14], leading one expert to state: "Cancer is changing. For many cancer is now a long-term condition and it is important to realise that it is no longer just about people dying quickly of cancer or being cured."

Because the CCM has generally been shown to be a useful framework and tool for assessing progress in health delivery improvement, we hypothesized that the CCM could be used to assess the LIVESTRONG Centers' progress and quality improvement in the care of cancer survivors over time [8, 9]. Thus, in 2009, we applied the CCM as a framework to examine models of clinical survivorship care and community outreach, organizational factors, and Center evolution in the eight COEs, as well as to provide a set of recommendations on best practices and the development of successful comprehensive survivorship programs.

The objectives of this study were to describe the organizational and environmental characteristics of the Network Centers as they relate to the CCM, to identify barriers and facilitators that influence survivorship care, and to examine the CCM as a framework for developing, implementing, and evaluating cancer survivorship care models, programs, and services.

Methods

Study overview and participants

This study used a mixed-methods approach to allow for triangulation of qualitative and quantitative data. The research team reviewed archival documents from each of the eight COEs and asked each Center's Director to recruit a purposive sample of Center personnel for participation in key informant interviews ("Appendix") (Table 2) and surveys. Key informants included the Director and at least one representative of the clinical, administrative, and community outreach roles in each COE. For site visits, we selected three COEs at different stages of development, which represented varied models of survivorship care and institutional structures. COE Directors, clinicians, educators, program leaders, and affiliated researchers participated in the site visits. The Institutional Review Board of the University of North Carolina approved study protocols and materials. All participants provided written or oral consent to being interviewed, audiotaped, and/or observed.

Data collection and measures

Document review—During the initial assessment, baseline information regarding provider characteristics and organizational context was collected from documents such as grant proposals and interim reports to the LIVESTRONG Foundation. We also collected information on services offered and populations served from a review of COE websites and shared Network extranet files, such as meeting minutes and PowerPoint presentations.

Key informant interviews—Following the document review, we interviewed 39 key informants by telephone during May–June 2009, using a series of open-ended questions. Key informants from each site were nominated by the COE Principal Investigator (PI) and represented different position categories (administrator, principal investigator, community outreach personnel, or clinician). A total of 40 key informants were nominated for interviews. Of those, one interview could not be completed due to inability to schedule a call during the study period. Qualitative approaches facilitated in-depth inquiry into participants' experiences and the organizational context for developing and implementing survivorship models of care. We based questions around the CCM essential elements/domains and added questions relevant to survivorship care, such as the role of the funding agency, important accomplishments, care coordination, and strengths, weaknesses, and challenges for program development. Informed consent was obtained and key informants were assured of the confidentiality of their responses. Interviews were audio-recorded and transcribed verbatim for coding and analysis. Two investigators conducted a pilot test by independently coding a sample of five interview transcripts. Differences in coding were discussed and agreement was reached, sharpening the coding manual's code definitions, decision rules, and examples.

The investigators then independently coded the same five transcripts, checked inter-coder reliability using a kappa statistic, and repeated the process until the kappa statistics reached 0.70–0.80.

Modified assessment of chronic illness care survey—All nominated key informants were emailed a web-based link to complete a confidential, anonymous online Assessment of Chronic Illness Care (ACIC) survey about their Centers, with each Center having a different link in order to track completion. The ACIC is designed to assess quality improvement indicators over time in organizations and health systems [10–13]. A total of 40 ACIC surveys were completed within 1 to 2 months of the qualitative interviews. We modified the survey items to focus on the needs of cancer survivors. The modified ACIC included 28 items, grouped into six CCM-based subscores.

All items were measured on a 12-point scale from 0=does not exist/not done/discouraged to 11=completely done/full implementation/integration. Means for each element/domain were then calculated, and categories of support ranged from 0–2 (limited support) through 3–5 (basic support) and 6–8 (reasonable support) to 9–11 (full support) for survivorship care [6, 7].

Site visits—Following a preliminary review of documents and informant interview transcripts, one-day site visits were conducted by study staff at three Centers during May 2009. Centers were selected to represent geographic diversity and different institutional structures and models of care, as well as different lengths of time since LIVESTRONG COE funding began (range 2–4 years). Data collection involved qualitative open-ended interviews of COE personnel, individually and in groups, and in some cases, the research team was able to observe team meetings and conference calls with community-based centers (CBCs). Site visit questions were tailored to each site and designed to supplement and probe more deeply into information obtained from the qualitative key informant interviews. The site visits provided a more in-depth look at the processes of COE and survivorship program development and maintenance, interactions with the CBCs and LIVESTRONG, strengths and challenges they were facing, and organizational context. A trained research assistant logged detailed notes of each visit throughout the day, and these notes were added to the qualitative analysis.

Data analysis

Documents, notes, and interview transcripts were imported into ATLAS.ti (Version 5.0, Humboldt, Germany). Two authors coded text, using a coding manual to ensure consistency in analysis and to increase internal validity. The CCM domains provided a starting list of topical codes, which were supplemented with emergent codes as analysis proceeded. We generated reports of all text segments for each code and assessed the degree to which constructs emerged from the data (strength) and positively or negatively affected the COE (valence). We identified recurring themes among COEs and examined whether cross-Center variation was explained by the emergent themes and their levels of strength and valence.

Quantitative data from the online surveys were tabulated and interpreted in accordance with analysis instructions for the ACIC [10]. Mean values for item-specific responses and for each of the domains were computed across all respondents. We derived domain-specific scores by summing all items within each domain and calculating the mean across items.

Results

Table 1 outlines the characteristics of the participating Centers and key informants who completed both the interviews and the ACIC surveys. Of the key informants, nine were

physicians, 11 were nurses (registered nurses or nurse practitioners), four were Ph.D.s, five were community representatives, and ten were administrative and project coordinators, usually with a master's degree. CCM domains and qualitative interview questions are listed in Table 2, and ACIC questions are listed in Table 3. Quantitative ACIC survey results are displayed by mean domain subscore in Table 4. Findings were aggregated across COEs rather than comparing responses of individual COEs, in order to preserve confidentiality. The following results present the emergent themes of the qualitative research, followed by findings from the quantitative ACIC surveys.

Qualitative findings by CCM domain

Organization of the health care delivery system

Role of the parent institution: Parent institutions, both cancer centers and hospital systems, played crucial roles in COE development. Success depended not only on institutional commitment but also on establishing survivorship as an organizational priority. For some Centers, obtaining the LIVESTRONG COE grant funding was a key factor in strengthened institutional commitment. Even though dedication to survivorship existed at the highest levels in most COEs, one interviewee stated: "I think that the difficulty sometimes is in having that commitment from the leadership actually transfer down, trickle down through the system in terms of getting to the folks that are actually doing kind of the day-to-day work."

Institutional size was often mentioned as a barrier to COE development, due to large numbers of patients and inefficient care coordination. Many Centers are housed within large medical centers, and lack of dedicated clinic space was a barrier. One interviewee shared: "We've been able to eke out space to conduct the clinical work that we think is important. But we don't have a visible special space somewhere."

Financial support and reimbursement challenges: Lack of financial support from the parent institution was a major challenge for a number of the Centers, especially given the financial climate at the time. Some Centers have secured private funds to support research, services, and salaries; others have obtained institutional support through state funds, grants, or by demonstrating the Centers' value to patient care and hospital revenue. However, reimbursement for clinical services remains a key issue for Centers. A few have overcome this challenge by obtaining reimbursements for nurse practitioner (NP) services. One interviewee reflected, "Challenges have to do with insurance and funding. And we're not able to get insurers to pay for survivorship visits." This comment refers primarily to lack of reimbursement for time spent preparing treatment summaries and care plans.

Delivery system design

One-size model of care does not fit all: Several models of care are consistently utilized in varying degrees by the Centers. Components of the models of care include: who provides service, how the population of survivors is distinguished, separate vs. integrated models, and consultative vs. transition models. Most Centers have multiple models of survivorship care (e.g., pediatric, adult survivor of pediatric cancer, and adult). Some have NP-led clinics [5, 15]. Change and experimentation in models used was a theme that emerged for all but one Center. Programs benefitted from recommendations and advice from LIVESTRONG expert consultants and site visits, Center-specific external and internal advisory committees, institutional review of barriers and successes, and staff experiences. Many changes involved trial and error based on experience with the different oncology practices.

All but one Center started with disease-specific clinics but then evolved toward piloting a general consultative visit model. Within this model of care, usually called a survivorship or

transition clinic, a survivor is referred for a single visit with the survivorship program [15]. Some Centers differentiate between transition and long-term consultative models. The transition model includes immediate post-treatment follow-up, while the long-term model serves patients further out from treatment. The majority of Centers are moving toward adding integrative models, in which survivorship care is embedded within the primary oncology team, generally with a NP. This shift often involves identifying a council of champions within each disease-specific oncology service. Centers may choose their own staff and clinicians to provide survivorship care within the various services' clinics, or may hire outside personnel.

All Centers have chosen to work with each disease clinic to develop survivorship care while moving toward a model of integrated care. One interviewee described the process of model development this way: "As we've tried different approaches and tried to do different things somewhat naively, not really knowing, we called them pilots. And we would pilot one approach. For example, doing a clinic for breast cancer survivors eight years ago would not fly. Now, eight years later, with all the other initiatives in place, people are interested in doing that. So the models have changed and evolved based on what we've tried to pilot and whether or not it's worked."

Survivorship visits: Participants reported that care of adult survivors usually entails both medical and psychosocial components. Medical evaluation included a review of medical and family history, lab results, and a physical exam performed by a physician, NP, or both. Adult survivors of pediatric cancers received more comprehensive medical evaluations on a more frequent basis. Some Centers have had patients fill out surveys prior to appointments in order to assess needs, and most Centers offer patients psychosocial counseling visits as part of standard care.

Timing of referrals and identification of survivors for care is dependent on the model of care used. Although self-referrals accounted for most of the patients seen in survivorship clinics, all Centers reported several avenues. For example, one Center with disease-specific clinics reported that all patients in each disease group are seen for survivorship care up to 2 years post-treatment. Other common referral patterns include internal referrals (from physicians, nurses, social workers), as well as external referrals (from primary care providers, other Centers, and non-profit cancer organizations) and self-referrals. While most Centers reported seeing patients close to the cessation of active treatment, survivorship care referrals were made from completion of active treatment to any length of time after treatment.

Treatment summaries and survivorship care plans: All Centers reported that they were committed to the goal of providing treatment summaries and survivorship care plans for patients at the end of active treatment; however, implementing these initiatives presented challenges. Several Centers created their own treatment summaries, but most were using an adaptation of one of the preexisting forms and templates, such as the Journey Forward (http://journeyforward.org) and LIVESTRONG Care Plans powered by Penn Medicine's *OncoLink* (http://www.livestrongcareplan.org). Beyond choosing a tool, the biggest difficulties were the time, personnel, and resources needed to complete the treatment summary. Medical record abstractions were done by different personnel, including RNs or NPs involved in the survivorship programs and specially trained administrative staff. At most Centers, respondents felt medical abstraction for treatment summaries was a poor use of clinicians' time. A common theme was the hope that future medical record abstraction would be facilitated by the use of electronic medical records; however, this system was not in place at any Center at the time of this analysis.

Decision support—All Centers reported using the Children's Oncology Group (COG) guidelines for childhood cancers, but a similar evidence-based set of guidelines does not exist for most adult cancers. At the majority of Centers, adult survivorship guidelines are obtained from the American Society of Clinical Oncology, the National Comprehensive Cancer Network, other networks, recommendations from internal medical groups, and advisory boards. However, guidelines and standards for comprehensive adult survivorship care and follow-up were considered by most clinicians to be continually evolving.

Centers offered survivorship education to clinical staff, ranging from grand rounds presentations, workshops, and conference events to CME education for health providers in the community. Much of this education focused on providers' ability to address psychosocial needs and health and wellness counseling as components of the survivorship clinic visit.

One interviewee commented: "Well, we began by adopting the COG guidelines at the beginning, because we didn't have adult guidelines. And then, as the program grew and matured, we've used specialists in the different arenas to help us to better adapt those for adults. And that's an ongoing conversation between sometimes directors, co-director, and the oncologists or specialists in the specific fields, as well as going to conferences and trying to read as much as we can."

Clinical information systems—All Centers have set up systems to capture survivor data from program participants, including needs assessments, appointment tracking, patient satisfaction, evaluation of programs and services, and in some cases outcome evaluation. Many informants expressed frustration regarding the limitations of current information systems and technology at their institutions to provide sufficient and timely data to support survivorship care. While new electronic information systems are in place at a few institutions, some raised concerns about the adequacy of these systems for identifying patients who could benefit from survivorship initiatives and accessing information for informing survivorship care. Many Centers cited limitations of hospital IT systems designed to support clinical care and billing but not designed to extract information for treatment summaries and care plans. One interviewee shared, "I think that we've become very technology-driven, and the technology for survivorship care planning is not quite there yet."

Self-management support

<u>Health promotion guidelines and strategies:</u> Centers used health and wellness education guidelines that were generally Center-specific and followed less-structured patterns compared to clinical guidelines. Existing health promotion materials for cancer survivors were often obtained from non-profit and governmental organizations such as the American Cancer Society, the National Cancer Institute, and LIVESTRONG. All Centers recognized that survivorship programs need more emphasis on health promotion and wellness, in addition to follow-up and surveillance for late effects of treatment and possible other disease-related risks. One participant shared, "Health promotion is incorporated into every visit. I mean the focus of the visit is surveillance for disease of course, but at least 50% of the visit is devoted to health promotion, disease prevention." Several Centers offer educational workshops for patients, and other Centers had developed evidence-based psychoeducational individual or group programs. Health promotion strategies commonly included counseling about diet, physical activity, and smoking cessation, with follow-up referral as needed to health professionals such as dietitians, physical therapists, and psychologists.

<u>Patient-centered self-management:</u> Most Centers did not mention or describe using self-management tools or interventions outside of the clinic-based education and counseling

model. We probed further on this topic at site visits. One Center had developed and evaluated a group exercise program in partnership with the YMCA. Another was in the process of developing and testing a telephone-based peer-to-peer education and support program.

Community linkages

Working with community-based centers: Community linkages focused mainly on the Centers' work with CBCs. As part of the COE grant process, LIVESTRONG stipulated the creation and support of up to three CBCs for each COE. Centers recruited and worked with a variety of CBCs, including non-profit organizations and community, public, and private hospitals. Most Centers had no prior experience with community partners, and without LIVESTRONG's mandate and funding to establish the CBCs, these new associations may not have been possible. CBCs were at different stages in their readiness to develop survivorship initiatives. Two Centers saw community-based participatory research (CBPR) as a way to bridge cultural gaps and build on preexisting relationships [16]. One interviewee stated, "We've built on our long-standing relationships in CBPR, so communities that are represented by our CBCs are very engaged with us and we have good relationships. We've used the strategy of hiring community coordinators who are kind of like community navigators and opinion leaders."

Many COEs were committed to reaching out to minority and underserved populations and selected their CBCs on that basis. As one interviewee said: "One of the things that I wanted to do was to have our community partners (provide services) to the underserved, you know, services in underserved communities. We're a big fancy cancer center sitting in (city) and one of the things that's been important to me is to make sure that some of what we do, or as much as possible what we do, is transportable to other groups around the country that may not have the opportunity to try all these things out."

Other community/regional outreach: Beyond the CBCs, several Centers had existing relationships with clinical practice and hospital networks in their regions, as well as with non-profit organizations. Community outreach and education was often a component of their involvement with these networks. In addition, many COE Directors and staff were involved in policy-related survivorship activities, such as maintaining memberships on state and national cancer-related task forces and committees.

Quantitative ACIC survey findings

The ACIC survey responses were used to extend and triangulate information gained from the qualitative study. As shown in Table 4, ACIC responses indicated that Health Care System Organization and Delivery System Design subscales were both scored as "reasonable support" for survivorship care. Looking at individual items, respondents cited strong support from senior leadership and the dedication of specific resources (monetary and personnel). Survey findings also highlighted delivery system aspects supporting survivorship, namely regular team meetings, the appointment of a Center team leader, monitoring of patient follow-up, and continuity of care. However, respondents felt that improvements in flexibility and innovation, e.g., in appointment systems, could improve the delivery system.

Participants' scores on decision support also corroborated interview findings. Evidence-based guidelines and specialist involvement in improving cancer care were rated as providing "reasonable support." However, participants reported that clinician education for cancer survivorship care provided only "basic support." In addition, the establishment of

patient treatment plans was rated as non-collaborative between provider and patient, with minimal clinical and self-management goals included.

In terms of CIS support, respondents generally scored in the range of "basic support." They noted that cancer patient registry systems in general and identification of patients with special needs required improvement. It was clear that CIS was an area of relative weakness across the COEs, a concern that also was highlighted in the qualitative study.

Respondents reported "reasonable support" for patient self-management support. ACIC survey responses indicated that self-management support is provided by trained clinicians, and patients and families are encouraged to voice concerns. In addition, support groups and mentoring programs are available. However, effective behavior change interventions and peer support were not typically offered but some sites reported that such services were available by referral.

In terms of community linkages, survey ratings indicated that designated staffers or resource centers connected patients with outside cancer survivorship resources. Furthermore, respondents felt that partnerships with communities have developed supportive programs and policies. However, community programs were weaker in feedback and communication between the community providers and the COE-based health care system about patient progress, resulting in overall domain scores between "basic" and "reasonable" support.

Discussion

The CCM as a conceptual framework was applicable to understanding and evaluating cancer survivorship models and programs. Certain factors, such as disease variation and complexity, resource needs, and changing paradigms, may differentiate cancer survivorship care from most other chronic diseases to which the model has been applied thus far. Despite this difference, we found that the model helped to organize the factors that promote or inhibit adoption of survivorship programs.

Regarding the Health system organization domain, we found that each Center is unique and dependent on the context and history of the parent institution. Some Centers were able to build on existing infrastructure and programs that prioritized survivorship care, whereas others "started from scratch." Developing a Center is a process of organizational change and adoption of new innovations into practice. Successful Centers are able to be flexible and adapt to the needs of different groups within their organization. These findings are consistent with previous work indicating that flexibility and focus are critical for success of comprehensive survivor programs [3]. Resource issues such as reimbursement, however, remain problematic in some COEs, and this will be critical moving forward to institutionalization of survivorship care programs.

In terms of delivery system design, there is no one best model for survivorship care that could be replicated across cancer centers and health systems. A model of survivorship care will grow from the context, history, capacity, and resources of the given institution. Models of care also are likely to change over time based on trial and error as well as evolution of new knowledge. Commitment from senior leadership of the cancer center is necessary but insufficient to ensure that survivorship priorities are actualized and may not translate into resources to support change or buy-in among practitioners and administrators throughout the system. Culture change within oncology practice remains necessary for implementation and, ultimately, for sustainability.

Overwhelmingly, the most important requirement for the development and delivery of survivorship care was considered to be the staff of the Center, especially its leadership, but

also key clinic staff and others on the team involved in patient care and outreach. Support from the top down and "bottom-up" support from trained, dedicated staff are both essential, and this is true for improving health care delivery in other disease domains [17]. Identifying and maintaining the commitment of such dedicated individuals over time is a major task for successful Centers. However, the competing demands on everyone's time and the emphasis on research, particularly in academic institutions, make it difficult to advance the agenda of survivorship clinical care.

Clinical information systems support was least well developed. Both qualitative and quantitative findings demonstrated that COEs were generally struggling with inadequate IT systems and personnel to support survivorship-related activities or follow-up. Most hospital IT systems were designed for tracking medical care and patient billing and were inadequate for identifying patients in need of survivorship care or for pulling electronic medical record data to generate comprehensive treatment summaries and patient care plans. Thus, in many cases, these activities were done using separate databases or by manual chart abstraction. Development of more integrated and accessible IT systems will be critical in order to meet the goal of providing treatment summaries and care plans to all cancer patients. Many COEs collected needs assessment and program evaluation data among their patient population and using their own databases. However, currently there is a lack of common metrics to evaluate longer-term and clinically relevant outcomes for survivors [3]. Ideally, such metrics could be incorporated into routine data collection for hospital/clinic IT systems.

Patient self-management support and use of evidence-based health promotion interventions were areas of relative weakness. This finding is similar to other studies of the CCM for understanding chronic care improvement [18–20]. Most COEs were relying on a clinic-based personal or group counseling model, often supplemented by written or internet-based information or outside referrals, to educate patients about health and wellness issues such as diet and weight management. Some Centers, however, were developing promising programs that have potential for dissemination across COEs and to other cancer centers and community partners. There is a pressing need for more research to develop and test self-management programs among cancer survivors and caregivers and to assess their effects on health behaviors and health outcomes.

In terms of community linkages, each Center approached collaboration with CBCs and the community from a different perspective, based on its experience, philosophy, and connections. Most Centers recognized the value and potential of partnering with the CBCs and have seen evolution over time, although success has been uneven thus far. For sustainability, it is essential that communities are empowered to design programs that fit with their agendas, resources, and environments and that they "buy-in" to the importance of survivorship care. In addition, broadening reach into communities via local and regional primary practice networks was a strategy that some COEs were pursuing.

This study had a number of limitations. The eight LIVESTRONG COEs probably represent a group of motivated "early adopters" of survivorship care and thus may not be typical of other cancer centers. They were at different stages of adoption and implementation, based on the age of their COE. The interview and ACIC protocols attempted to obtain a diverse perspective by interviewing Directors, physician and nurse clinicians, and administrative staff; however, it is possible that other important viewpoints were missed. The quantitative study was limited by the single administration of the ACIC, whereas repeated ACIC administration over time would be more informative for observing the evolution of survivorship care, as well as for comparing psychometrics from our sample to other research [9, 15, 18–20]. Also, there were preexisting differences between Centers, especially between those that have existed longer or already had survivorship programs in place, such that well-

established Centers reported more fully developed programs compared to newer Centers. In addition, participants' positions in the survivorship program, length of service, and understanding of CCM questions and concepts may have influenced or biased individual responses.

Despite these limitations, the study findings provide empirical validity, especially with triangulation of both qualitative and quantitative data. The study results allowed us to assemble a set of overarching themes that provide insight into the current state of survivorship care at the Centers and offer guidance for future efforts. Based on this study of the Network Centers, some key recommendations for future efforts to develop high-quality cancer survivorship programs are as follows:

Key recommendations

An understanding of preexisting organizational and environmental structure, key interests, stakeholders, norms, and institutional culture is critical for moving forward.

Support of the institution's senior leadership is the sine qua non.

Not all Centers have the resources to accomplish a "gold standard" survivorship care model. Developing one or more priorities and starting with a single disease or two may be more feasible than trying to launch a full-scale program, especially where resources are limited.

Flexibility and options must be built into planning and implementation of survivorship care models and delivery systems.

Expect that whatever model is initially chosen will change and evolve over time.

Capitalize on catalysts for health system change as opportunities to move forward with survivorship priorities.

Integrating survivorship into practice is a long process of culture change; thus, leadership needs to be committed for the long term and not be discouraged by early failures and obstacles, such as groups that are resistant to change.

Finding and working with program champions is critical to promoting practice changes and adopting survivorship care models. Role models can then be ambassadors to promote the benefits of the new model among later adopter groups.

Community partners are a key component of advancing the field of survivorship beyond the walls of the academic centers and have great potential for public health impact.

Each community is different; survivorship programs and priorities need to be tailored to the needs of diverse communities and individual organizational structures and missions.

Conclusions

The Centers of Excellence provided a unique opportunity to evaluate the development of survivorship models using the CCM across a variety of settings and institutional structures. The CCM framework was useful to categorize and compare qualitative and quantitative findings in order to present a snapshot of the current state of survivorship care in these Centers [9]. As the number of cancer survivors continues to grow, the need to understand optimal models and ways to meet patient and caregiver needs is ever more pressing. Developing effective models to implement, deliver, evaluate, and sustain high-quality comprehensive survivorship programs remains an ongoing challenge requiring further health systems change and research.

Acknowledgments

Appendix: Qualitative phone interview questionnaire (version shown was used for COE Directors; slight adaptations were made for clinical staff, administrator, and community versions)

I. Background and introduction

1 How long have you been with the LAF-COE?

Probe: So how many years is that?

2 What is your role with the LAF-COE?

3 Is your role full-time with LAF-COE?

Probe: If no, what percentage of your time is devoted to LAF-COE?

Probe: What other responsibilities do you have at your (cancer center)?

II. About the LAF-COE

1 What has been the most important accomplishment of the LAF-COE at (cancer center) and why?

2 In what ways has the LAF-COE enhanced cancer survivorship at (cancer center)?

3 What new programs have been developed and added because of the LAF-COE?

4 From your perspective, what do you think would not have been done at (cancer center) around survivorship without the LAF-COE funding?

5 How has the LAF-COE as a whole changed over time?

Probe: Have there been personnel changes? If so, what was their impact on the LAFCOE?

Probe: Have there been program changes? If so, describe their impact on the LAF-COE.

6 What do you think are your COE's core strengths?

7 What do you think are your COE's core weaknesses?

8 How could the LAF-COE function better?

III. About the LAF COE Network (not reported on in this paper)

1 Describe how your COE has used the LAF Network of COEs?

2 What have been the advantages of working with the network?

3 What have been the disadvantages of working with the network?

4 What has the network added to the success of your center?

IV. Specifics about your cancer center

1 How committed do you think the leadership of (cancer center) is to cancer survivorship?

2 What are the plans for the future of the LAF-COE at (cancer center)?

V. General questions about your organization

1   What models of care are being used at your LAF-COE?

2   In what ways, if any, have these models changed over time?

       Probe: If there is a different direction from the original outset, describe it.

3   What challenges have you witnessed at (cancer center) in adding survivorship care to the treatment model?

4   What barriers exist that inhibit the organizational changes necessary at (cancer center) to focus more on the care of cancer survivors?

5   What have been the most successful health promotion strategies you've used in your survivorship program?

6   What guides your recommendations for health and wellness education?

7   How have you evaluated or plan on evaluating your survivorship programs?

VI. Community

Instructions: Let me ask you a few questions about your community:

8   Describe the experience of the LAF-COE working with the community?

9   What has been the most helpful strategy for community involvement? Why?

10   What have been barriers to working with the community? How are they being addressed?

If PI is also a Clinician, ask these questions

Instructions: Now let me ask you a few questions about patient care:

1   How are patients referred to the survivorship program?

       Probe: Who refers? When?

2   How are survivors evaluated medically?

3   How are survivors evaluated psychosocially?

       Probe: Where is this done and who does it?

       If not mentioned, use this probe: You haven't mentioned any screening. Do you use any screening tools before the clinic visit?

4   What cancer patients at (cancer center) do you think have benefited most from LAF-COE and why?

5   What guides your recommendations for clinical surveillance?

6   Who does the medical record abstraction?

7   What treatment summary is used to compile data for survivorship care plans?

VII. Wrap-up

What have we not covered that you would like to share about LAF-COE?

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Table 1

Characteristics of eight Centers in LIVESTRONG Survivorship Center of Excellence Network and telephone interview participants

Center	Regional location	Year center began	Prior history of survivorship program	Public or private cancer center	Number of community affiliates
Dana Farber	Northeast	2004	Yes	Private	3
Memorial Sloan-Kettering	Northeast	2005	Yes	Private	3
Fred Hutchinson	Northwest	2006	Yes	Private	3
UCLA Jonsson	West	2006	Yes	Public	3
University of Colorado	West	2006	No	Public	3
Ohio State University	Midwest	2007	No	Public	2
Penn Abramson	Northeast	2007	Yes	Public	3
UNC Lineberger	South	2008	No	Public	3

Characteristics of respondents	Number	%
Length of time with Center		
Less than 6 months	3	8
Between 6 months and 1 year	2	5
More than 1 year	6	15
More than 2 years	19	49
Since COE began	9	23
Full-time equivalent		
Full-time	19	49
Part-time	20	51
Position		
Director or Co-director	12	31
Clinician	10	25
Administrator or project coordinator	7	18
Outreach coordinator	5	13
CBC personnel	3	8
Program leader	2	5
Other responsibilities at cancer center?		
Yes	16	41
No	23	59

Centers were selected based on diversity of geographic location, patient demographics, type of cancer center (matrix or freestanding), models of clinical care, community-based center model, length of time as Center, and history of survivorship programming prior to LAF support

Table 2

Chronic Care Model qualitative evaluation questions

Health system organization—create a culture, organization, and mechanisms that promote safe, high-quality care; use strategies aimed at organizational change; obtain support from leadership

  1. How committed do you think the leadership of (cancer center) is to cancer survivorship?

  2. What barriers exist that inhibit the organizational changes necessary at (cancer center) to focus more on the care of cancer survivors?

  3. What challenges have you witnessed at (cancer center) in adding survivorship care to the treatment model?

Delivery system design—assure the delivery of effective, efficient clinical care and self-management support, case management, treatment summary, care plans, regular follow-up, culturally appropriate care, referral systems

  1. What models of care are being used at your COE?

  2. In what ways, if any, have these models changed over time?

  3. How are survivors evaluated medically and psychologically?

  4. Who does medical record abstraction?

  5. How are patients referred to the survivorship program?

  6. What treatment summary is used to compile data for survivorship care plan?

Decision support—promote clinical care consistent with scientific evidence and patient preferences; use evidence-based guidelines in daily clinical practice, integrate primary and cancer care, provide education on survivorship

  1. What guides recommendations for clinical surveillance?

  2. How have you engaged other health professionals at your cancer center/hospital in survivorship issues?

  3. What new programs have been developed and added because of the COE, e.g., education for providers?

Clinical information systems—organize patient and population data to facilitate efficient and effective care; provide reminders for providers and patients re: survivorship care, identify populations in need of survivorship care, use data to track and provide survivorship care

  1. What methods and data systems have you used successfully to track the needs of cancer survivors in the populations your cancer center serves?

  2. How have you evaluated or do you plan on evaluating your survivorship programs?

Self-management support—empower and prepare patients to manage health and health care; use effective self-management strategies and internal and external community resources to provide self-management support

  1. What guides recommendations for health and wellness education?

  2. What are the most successful health promotion strategies used in your survivorship program?

  3. What new programs have been developed and added because of the COE, e.g., patient education, health promotion?

Community linkages—mobilize community resources to meet needs of patients; participate in community programs, partnerships with community organizations

  1. What barriers have you found to working with the community?

  2. What experiences has the COE had in working with the community?

  3. What new community programs have been developed and added because of the COE, e.g., clinic, education?

  4. What has been the most helpful strategy for community involvement?

Table 3

Quantitative question topics for Assessment of Chronic Illness Care (ACIC)

Organization of the health care delivery system (6 items)

    Overall organizational leadership in cancer survivorship

    Organizational goals for cancer survivorship

    Improvement strategies for cancer survivorship

    Incentives and regulations for cancer survivorship

    Senior leaders

    Benefits

Delivery system design (6 items)

    Survivorship team functioning

    Survivorship team leadership

    Appointment system

    Follow-up system for cancer patients

    Planned visits for cancer patients regarding survivorship issues

    Continuity of care for cancer patients

Decision support (4 items)

    Evidence-based guidelines

    Involvement of specialists in improving cancer care

    Clinician education for issues of cancer survivor care

    Informing patients about cancer survivorship guidelines

Clinical information systems (5 items)

    Registry (list of patients with cancer)

    Reminders to providers

    Feedback with respect to cancer survivorship

    Information about relevant subgroups of patients needing services

    Patient treatment plans regarding cancer survivorship

Self-management support (4 items)

    Assessment and documentation of self-management needs and activities for cancer patients

    Self-management support for cancer patients

    Addressing concerns of cancer patients and families

    Effective behavior change interventions and peer support for cancer patients

Community linkages (3 items)

    Linking patients to outside resources for cancer survivorship

    Partnerships with community organizations with respect to cancer survivorship

    Regional health plans

Table 4

ACIC data analysis (*N*=40)

ACIC domain	Mean	SD	Support for chronic illness care
Section I: Organization of the health care delivery system	7.01	1.3	Reasonably good
Section II: Delivery system design	6.83	1.1	Reasonably good
Section III: Decision support	6.14	0.7	Reasonably good
Section IV: Clinical information systems	5.03	0.8	Basic
Section V: Self-management support	6.84	0.5	Reasonably good
Section VI: Community linkages	6.28	2.1	Reasonably good
Overall score	6.13	1.9	Reasonably good