

## Process of diffusing cancer survivorship care into oncology practice

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### ABSTRACT

The LIVESTRONG Centers of Excellence were funded to increase the effectiveness of survivorship care in oncology practice. This study describes the ongoing process of adopting and implementing survivorship care using the framework of the diffusion of innovation theory of change. Primary data collection included telephone interviews with 39 members from the eight centers and site visits. Organizational characteristics, overall progress, and challenges for implementation were collected from proposals and annual reports. Creating an awareness of cancer survivorship care was a major accomplishment (relative advantage). Adoption depended on the fit within the cancer center (compatibility), and changed over time based on trial and error (trialability). Implementing survivorship care within the existing culture of oncology and breaking down resistance to change was a lengthy process (complexity). Survivorship care became sustainable as it became reimbursed, and more new patients were seen (observability). Innovators and early adopters were crucial to success. Diffusion of innovation theory can provide a strategy to evaluate adoption and implementation of cancer survivorship programs into clinical practice.

### KEYWORDS

Cancer, Survivorship care, Diffusion of innovation, Implementation

### BACKGROUND

An aging population and the earlier detection of cancer through screening have increased the number of cancer patients, and more effective therapies have enabled people to live longer with cancer [1]. Added to this is the prediction that there will be insufficient numbers of oncologists available to meet the needs of cancer patients as well as survivors in the future [2]. Cancer survivors are not only at increased risk for developing a second cancer but also, as they age, for chronic illnesses that can affect survival [3]. Thus, there is an increasing need for posttreatment survivorship care to promote healthy lifestyle behaviors, such as smoking cessation, physical activity, nutrition, and a healthy weight; surveillance for new and recurring cancer and late effects of treatment; inter-

Marci K Campbell is deceased.

### Implications

**Practice:** Recognizing barriers and facilitators for change when introducing a new practice (cancer survivorship) into oncology services is essential for program success.

### Policy:

Adequate and continuing resources along with organizational commitment and support are essential for adoption and implementation of cancer survivorship care into clinical care.

### Research:

Research to identify what does and does not work in the process of adopting and implementing survivorship programs in a clinical setting should occur from the beginning to make sure programs continue.

ventions for the consequences of cancer and its treatment; and care coordination [3].

Between 2004 and 2008, a number of National Cancer Institute-designated comprehensive cancer centers were invited to respond to an invitation from the Lance Armstrong Foundation (LAF) to apply for grant funding that would provide the LIVESTRONG Survivorship Center of Excellence (COE) Network designation and infrastructure support for program development. Eight centers successfully competed for funding to join the network, and each program identified three community affiliates as partners. The goals of the LIVESTRONG Network are to (1) increase the quality of life for cancer survivors, (2) transform how survivors are treated and served, (3) contribute to the collective body of knowledge on survivorship, (4) increase the accessibility and quality of services for survivors, and (5) explore reimbursement issues and develop financial strategies to cover the cost of survivor care [2]. Network goals are accomplished by the COEs working collaboratively with one another and their community affiliates to identify best practices and develop models of care that will provide cancer survivors with comprehen-

sive medical follow-up for recurrence and late effects, screening for second cancers, developing ongoing wellness initiatives as well as building support services for survivors, education for health providers and survivors, and building community initiatives and partnerships [2]. Collaborative research is also an overarching goal of the network, and there have been and continue to be a number of research projects conducted across the network.

In 2008, the LAF funded a study to examine the clinical survivorship care and organizational characteristics of the eight COEs and provide key recommendations for future efforts. Using both quantitative and qualitative data, findings from the study offered support for several domains of the chronic care model (CCM) which emphasizes the importance of six elements essential to improve chronic illness care: health system organization, delivery design, clinical information systems, self-management care, decisional support, and community linkages [4]. A major issue that emerged from the qualitative data was the experience of the COEs in adopting and implementing the survivorship care programs into the oncology practices of their institutions. The current manuscript presents findings related to this process using the framework of diffusion of innovation theory.

#### Diffusion of innovations theory

Diffusion of innovations is a theory of social and cultural change developed over 50 years ago by Everett Rogers [5]. As defined by Rogers, diffusion of innovations is a process, not a discrete event, through which an innovation, defined as a new idea, practice, or object, unfolds over time through the communications networks of members of a system [5]. According to Rogers, there are five elements that make an innovation more likely to be adopted over time: (1) there is a *relative advantage* over what is currently being done; (2) it is *compatible* or *fits* with organizational or professional culture and values, norms, perceived needs, and ways of working with little disruption; (3) it is not difficult to understand and there are few barriers to overcome (*complexity*); (4) it can be tried on a limited basis (*trialability*); and (5) the benefits are visible to others (*observability*). If potential adopters can adapt, refine, or otherwise modify the innovation to the local context, it will also be adopted more easily [5]. New concepts usually come from outside the current system, but for change to occur, processes need to come locally from inside the system [6]. Individuals or organizations adopt innovations at varying rates. *Innovators* can imagine the possibilities and are eager to try it out; *early adopters* learn about the advantages from innovators and make a connection between the new practice and the needs; others (*early majority adopters*, *late majority adopters*) follow as they see the advantages, and *laggards* are the last to adopt, if at all [5].

A great deal of research in a variety of academic disciplines has been conducted on the diffusion of innovations since the development of the theory. The majority of diffusion studies rely on quantitative data, usually via surveys, and study the rate of adoption of a single innovation at a single point in time after widespread diffusion has already taken place [7]. The innovation is most often a simple, product-based innovation, for which the unit of adoption is the individual and diffusion occurs by means of simple imitation [5]. When the unit of adoption is a complex organization, the aforementioned “standard” characteristics of an innovation are necessary but not sufficient to explain or guarantee the adoption and implementation of complex innovations in organizations [8]. The rate of adoption depends on the interaction among a particular innovation, the intended adopter and the situational context [8].

The adoption of a new clinical practice is not a linear process; and scientific evidence, although useful, is not sufficient in itself for diffusion of a new practice or behavior [9, 10]. In practice, medical behavior is shaped as much by experience and peer comparison as by scientific evidence from randomized clinical trials or other high-quality studies [9]. Decisions about implementing best evidence practices are driven by the interplay between the interests of the patient, the clinician, and the healthcare system [11]. We need to understand more about the adoption and implementation process if we want to accelerate incorporation of evidence-based programs into practice to improve health care quality. Although much attention is currently focused on dissemination and implementation research, relatively few theories and models have been applied to studying this in the context of incorporating cancer-related interventions into health systems [12, 13].

## METHODS

### Data collection

Study data collected from the eight participating COEs is listed in Table 1. Three primary sources of qualitative data were collected: program data, telephone interviews, and site visits. *Program data* were collected from the eight proposals and 22 annual reports available for analysis at the time of the study. The reports covered the first and second years of progress in all COEs and for years 3 and 4 in the five earliest-funded centers. Program data analyzed for this manuscript included organizational issues concerning cancer survivorship, models of care, change over time, prior survivorship initiatives, and processes and lessons learned during COE development. *Telephone interviews* were completed with 39 COE members during May and June 2009 (Table 2). With permission, interviews were audio-taped and transcribed verbatim. An open-ended interview script utilized the framework of the CCM [4, 14] and added questions about the strengths and weaknesses of the COE, challenges

**Table 1** | Data collected from each of the eight cancer centers involved in the study

Cancer center	Year COE started	Annual reports <sup>a</sup> (n=22)	Telephone interviews (n=39)
Dana-Farber Cancer Institute, Harvard University	2004	4	4
Memorial Sloane-Kettering Cancer Center	2005	3	5
Fred Hutchinson Cancer Research Center / Seattle Cancer Care Alliance	2006	3	5
Jonsson Comprehensive Cancer Center, University of California Los Angeles	2006	3	5
University of Colorado Cancer Center	2006	3	3
Ohio State University Comprehensive Cancer Center	2007	2	5
Abramson Cancer Center, University of Pennsylvania	2007	2	6
Lineberger Comprehensive Cancer Center, University of North Carolina at Chapel Hill	2008	2	6

<sup>a</sup> Indicates number of years a COE at the time of the study (2009)

(lessons learned) for program development, important accomplishments of the COE, changes over time, and the value of survivorship care to oncology practice. *Site visits* were conducted in May 2009 with three of the earliest-funded COEs. Each site visit lasted 1 day and was led by a two-person staff and research assistant team. Individual and group meetings were held with COE staff and affiliates, and observation of facilities was conducted. Field notes were taken during the visit. Site visits provided observational data related to operations and facilities, as well as situational background that provided a more in-depth understanding of issues, institutional context, and challenges faced in program development. Study protocols and materials were approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

#### Analysis

Program data (annual reports), transcribed telephone interviews, and site visit field notes were imported into a qualitative data management software program (ATLAS.ti 5.0). Data were reviewed several times, and a codebook, developed. Content was coded using the initial framework of the CCM and additional questions about the COE providing a preliminary list of codes (deductive), which were supplemented with emergent codes (inductive) as analysis proceeded [15]. Data were coded and

analyzed by two independent investigators (IT, SG). The unit of analysis was the site (COE). The investigators independently coded a sample of five interview transcripts, reaching agreement on code definitions and decision rules and checking inter-coder reliability until the kappa statistic reached 0.70–0.80. Analysis revealed themes (patterns) determined by the strength, depth and frequency of concepts, and consistency between the sites (COE), derived from the coding process.

#### RESULTS

Themes related to the diffusion process are presented below with supporting quotes from the interviews and site visits. These include the following: creating awareness (relative advantage); making the cultural shift and start where they are (compatibility), trial and error (trialability); change is very hard and very slow (complexity); and the bottom line (observability). These themes are also presented in Table 3.

#### Relative advantage

##### *Creating awareness*

Creating an awareness of the scope and need for cancer survivorship care, as opposed to traditional

**Table 2** | Characteristics of interviewees from the eight COEs

Position	n	%
Center director or co-director	12	31
Clinical personnel	10	25
Administrators/coordinators	12	31
Other affiliated personnel	5	13
Time with COE		
Less than 2 years	11	28
2 years or more	19	49
Since beginning of COE	9	23

**Table 3** | Diffusion characteristics, study themes and strategies to promote adoption, and implementation of survivorship care

Diffusion characteristic	Themes	Strategies for change
Relative advantage—perceived as better than before	Creating awareness	Widespread education
Compatibility/fit – consistent with values, habits, experiences of potential adopters	Making the cultural shift; start where they are	Find the best fit for survivorship care with the institution's organizational and professional culture
Trialability—experiment before commitment	Trial and error	Flexibility and change in the models of care that work for the practice and institution
Observability/visibility—tangible results	The bottom line	Funding, institutional support, and reimbursement
Complexity/ease of use in understanding or using innovation	Change is very hard and change is very slow	Education and training for professional staff to improve performance
Innovators and early adopters	Champions	Identify leaders, invest time, and commitment

posttreatment care, was considered by many as the major accomplishment of the COEs. As one respondent said “we’re putting survivorship on the map.” Raising awareness was accomplished through various educational venues, such as integrating with the standing lecture series at the cancer center, adding survivorship-focused talks to preexisting annual disease-specific patient conferences, online and in-house continuing medical and nursing education courses, presentations for oncology and primary care practices, grand rounds presentations, survivorship conferences for health care professionals, and educational events for providers and survivors in the community.

“The most important accomplishment for the Center of Excellence, to look at it from the clinical side, is that it has brought into awareness in a new way for the treating physicians and for the cancer center, some of the concerns of patients after treatment. That’s a culture change that has definitely begun.” (*clinical coordinator*)

#### Compatibility/fit

##### *Making the cultural shift*

Creating the awareness that survivorship is something separate and different from traditional oncology care was a challenge. Oncologists typically focus on treating and curing active disease and tend to provide follow-up care and surveillance even when patients are years posttreatment. As one clinician commented on shifting this traditional paradigm, “it’s moving a freight train in a slightly different direction.”

“We probably have similar experience to other people in that it’s a change in culture. Everything is so focused on treatment and the immediacy of those problems that these patients are the well of the well, so to speak, that come here. They are not dying and they’re not in active treatment so there hasn’t been a lot of emphasis on the resources they need.” (*COE director*)

“[Survivorship care] comes from a very long history of a medical model. We are a very high-profile, research-evidence-based center, and a lot of research is geared toward eradicating cancer and that’s what the philosophy is.” (*clinical coordinator*)

Resistance to making changes in survivorship care took several forms: it was already being done; oncologists did not want to “give up” their patients; there was little evidence for the effect of survivorship initiatives on outcomes; there was little time to change the system of services; and there was limited or no reimbursement for the services. Survivors also were attached to providers and felt comfortable there.

While most COEs reported a high level of commitment from the senior leadership of their institution, this did not necessarily translate into buy-in among the practitioners and administrators throughout the system.

“The leadership of the cancer center is behind survivorship at the very top. I think that there are some challenges in the mid-section, if you will, from both some of the medical leaders being as enthusiastic as the head of the cancer center and thereby helping to facilitate things happening.” (*clinical coordinator*)

##### *Start where they are*

All COEs completed needs assessments to explore (1) what was currently being done for survivorship care and education in practices in their institution, (2) what providers and patients needed and wanted regarding survivorship care, and (3) how to adapt survivorship care to make it fit with their site’s needs and constraints. The needs assessments were administered using a variety of methods (questionnaires, online surveys, key informant interviews, focus groups).

COEs started the process of adopting survivorship care with those oncology practices and individual oncologist that saw the benefit for their patients. Some of the COEs started with separate survivor-

ship clinics, relying on individual practice areas to refer their long-term patients. However, the ultimate goal for some COEs was to integrate survivorship care into the various oncology practices. In either case, the COEs relied on the decision of the individual oncology practices to see how this was a fit for them, both in terms of referrals to a separate clinic or for integration into the practice.

“Selling a package of resources really took some time, a lot of patience and spending lots and lots of time with people, particularly the treating physicians and the nurses, about what would work in their area and what they thought was good for them. There are always champions and there are always naysayers so I started with the champions, people who wanted to do it.” (*COE director*)

#### Trialability

##### *Trial and error*

Models of survivorship care and implementation depended on fit within the cancer center and changed over time based on trial and error. Virtually all COEs started with a different model of care from their current model(s) for survivorship care. Many used more than one model, depending on the disease group and setting. All COEs tried out a number of different models of care before deciding on which model(s) worked for their institution. Some models of care worked in one clinic but not in another. A few COEs were integrating survivorship care into oncology practices, but in some cases, logistics of time and space constituted a barrier. Being a part of the LIVESTRONG network of COEs was helpful to learn about the experiences others had in the process of adoption.

“It's been an evolution. Every clinic that we start up, we've learned new things and we've taken what we've learned from the other clinics, both successes and failures. We've been able to expand on the program and have used the lessons from the previous clinics to improve upon existing clinics and future clinics.” (*Project administrator*)

#### Complexity

##### *Change is very hard and change is very slow*

Changing any system is difficult, especially a health care system. The complexity in adding survivorship care to the existing practice of oncology, particularly in these large medical institutions, was a major challenge. Changing culture and building consensus for change is a lengthy process. This process is multifaceted and a “moving target,” always evolving and requiring considerable time, effort, and commitment. Programs,

particularly the establishment of survivorship clinical programs, took longer than expected in most COEs.

“There is an honest realization from my part that integrating any new service into oncology is a long-term proposition, just as palliative care took years to reach a state of being recognized, which it is now.” (*COE director*)

Several factors made this a complex endeavor, including resistance to change from oncology practices, piloting numerous models of care, inadequate staff, and the general logistics of setting up a new program. Each COE had its own barriers that slowed down the process.

“There is constant resistance. Every single initiative that I've mentioned has met with resistance and then eventually it becomes part of the institution. I think you have to be persistent, because change doesn't happen overnight.” (*COE director*)

To help reduce the perceived difficulty or complexity of the innovation, education and training to raise awareness and to provide an overview of late effects of treatment and general guidelines for providing optimal survivorship care was provided to nurses, nurse practitioners (NPs), and physicians, as well as to social workers, psychologists, and other health professionals.

#### Observability/visibility

##### *The bottom line*

Funds from LIVESTRONG were instrumental in initiating or enhancing survivorship care. Having the initial grant funding was considered an important recognition for these research-oriented institutions, most of which probably would not have provided the resources needed for a survivorship care program. This funding enabled COEs that had already established survivorship programs to expand their efforts.

“The funds have been extremely important. Early on they were critical to be able to get things up and running and show some momentum and to demonstrate to the powers that be that this was something that could and should be done.” (*COE director*)

“The fact that this new area had national funds behind it and that there was a grant opportunity, got a lot of the academic physicians' attention because that's how they make their careers is with grants.” (*COE director*)

A major issue for the COEs was that, for the most part, survivorship care does not provide significant reimbursement. Therefore, it was important for the cancer centers to develop sustainability plans for these

survivorship programs. COEs accomplished this in various ways. For example, they demonstrated the benefit for practices of decreasing the number of long-term follow-up patients, thus allowing oncologists to see more new patients, and/or they established mechanisms of reimbursement for the NPs who staffed the clinics. The NPs at some COEs were supported by institutional funds and at others through philanthropy.

“The other big piece of it is in winning over hospital administrators because the bottom line is they are interested in budget and what brings money in or certainly what's a service that adds value in some way.” (*COE director*)

#### Innovators and early adopters

##### *Champions*

Program leaders, steering committees, leadership teams, and individual oncology groups were crucial to the success of the COEs. These champions were the *early adopters* of this process, helping to break down resistance for oncology to make that “cultural shift” to survivorship care as standard practice. The input of these groups early on was invaluable to affect these changes and reach a consensus on how to deliver this kind of care within a particular cancer center. Getting these opinion leaders involved helped obtain institutional commitment, which often included the resources to help sustain the program. These champions of survivorship care understood that the existing model for long-term follow-up care was not sufficient; those visits were very short and mainly involved evaluation for recurrence. In addition, oncology practitioners were frequently overwhelmed, and there was an institutional push to see new patients rather than the same long-term patients year after year.

“Because of the oncology work force issues nationally and locally, people are starting to realize that they can't hold on to all these patients and give them adequate follow-up care. There are just too many patients.” (*COE director*)

#### DISCUSSION

Study findings show the experience of the LIVESTRONG Centers of Excellence in the process of diffusing a new practice, survivorship care, into the existing organizational structure of oncology practice. Groups involved in setting clinical policy are part of highly complex networks of social relationships that affect their practice, and the complexity and variability of local contexts ensure that there is no one way to introduce innovations [9]. While each COE is unique and the best model for survivorship care in each is dependent on the context and history of the parent institution, there are similar processes in developing

new programs for cancer survivors in an existing system. In this study, the characteristics of the diffusion model (relative advantage, compatibility, complexity, trialability, and observability) in influencing adoption and implementation of cancer survivorship programs were evident. Table 3 summarizes these study findings and the strategies used by the COEs.

Different organizations provide widely differing contexts for innovations, and some features of organizations, both structural and cultural, influence the likelihood that an innovation will be successfully adopted into practice [6, 9]. If the innovation starts out with a budget as well as adequate and continuing resources, there is a flexible organizational structure, and top management supports and advocates for the process with continued commitment, then an innovation is more likely to be adopted [8, 11]. The COEs had a budget from LIVESTRONG to start the process and raise awareness; however, this funding was time-limited. COEs that had stronger institutional support and developed reimbursement strategies for survivorship services were further along in this process. A key determinant of successful innovation is whether the new routine associated with the innovation aligns rather than conflicts with organizational and interorganizational routines. If people are uncomfortable with the status quo and desire change, a potential innovation is more likely to be successfully adopted [16]. Alignment with routines and an understanding of the “culture of oncology,” as well as flexibility to try an approach and then change to another approach as needed, were important attributes in the diffusion process for the COEs. Oncologists often had to be persuaded of the relative advantage of a survivorship program: they tended to want to follow their own patients indefinitely, even though patients' needs and oncologists' workloads were issues that needed to be addressed. To an important extent, timing favored COE development, in that workforce limitations were being recognized and published in the same period as the onset of the survivorship programs. Center administrations were thus primed to value a change in the status quo.

The active support and involvement of opinion leaders was cited repeatedly in the interviews, and diffusion theory supports the importance of these program champions to enact change and demonstrate new ideas to later adopters. The influence of opinion leaders and champions is a powerful factor for making organizational changes in a variety of settings [8]. While impersonal channels of communication, such as brochures and publicity about a new program can create awareness of an innovation, interpersonal influence through social networks is a dominant mechanism for diffusion [8, 17], particularly as programs develop [18]. If respected and influential clinicians argue for and demonstrate the application of a new procedure or treatment approach, it is likely to have a positive impact upon adoption rates [19].

In the case of adopting survivorship care into standard practice, influence needed to occur at multiple levels, including top-down support from administrators and day-to-day buy-in and support from clinicians, nurses, and other key personnel, as well as patient feedback. In addition to promoting the relative advantage and benefits of survivorship care, these individuals were key for issues such as finding flexible strategies to promote compatibility, and providing visibility in their care and referral patterns. Opinion leaders in administration were also instrumental in providing other features to assure survivorship clinic success. This included such basic resources as space for the clinic, scheduling, intake procedures, and other basic resources required for successful patient care.

For innovations to spread, it takes time, energy, and money [6]. Facilitators for change for the COEs included the large number of patients and the need to make room for new patients, the funding that started or enhanced efforts, and the early adopters who helped promote the idea, as well as the time and energy of those innovators who wrote the grant to begin the process. Much of the success of the COEs can be attributed to the vision, persistence, and hard work of these leaders who devoted time and energy to pursuing survivorship as a priority in their institution. Additionally, LIVESTRONG funding provided the recognition and “branding” to create an interest and priority in survivorship and gave a boost to existing survivorship programs.

Barriers to change included resistance from oncology practices, lack of financial support from the parent institution, the logistics of setting up a new program in a large institution, and the slow pace of change. Changing the culture of oncology was considered a major challenge, particularly changing the awareness of survivorship care needs and overcoming the reluctance of oncologists to give up a positive aspect of their practice, i.e., the opportunity to see thriving survivors. Commitment from the senior leadership of the cancer center for the survivorship programs did not necessarily translate into buy-in among the practitioners and administrators throughout the system, nor did it translate automatically into resources to support the change. Organizational commitment from the cancer center at the highest level was necessary for success but was insufficient to ensure that survivorship priorities were actualized.

There are several limitations to this study. The process of diffusion illustrated here does not necessarily apply to all oncology practices. These COEs were in major research and teaching hospitals, all National Cancer Institute-designated comprehensive cancer centers. Research is a major initiative in these high-profile and high-volume medical centers, and this often takes priority and resources. Several of the

cancer centers already had begun initiatives to redirect care of long-term survivors, both adults and children, and large numbers of oncology patients were long-term survivors in the large-volume practices of these medical centers. This may not be true of smaller hospitals or of private practices.

## CONCLUSION

Despite any limitations the diffusion of innovations framework provides insight into the complex process of incorporating a new survivorship paradigm into clinical care. As more cancer survivorship programs become standard care, this study may offer insight into the factors important to consider when affecting change within the institutional setting.

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