Delivering patient-centered cancer care: creation of a blueprint for a model of patient-centered cancer care in Austin

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Background
Patient-centered care, or care that is “respectful of and responsive to individual patient preferences, needs and values, and ensures that patient values guide all clinical decisions”1 is on the forefront of the national dialogue about healthcare. The initiation of the Affordable Care Act and an explosion of interest in new models of payment reform to control costs and improve outcomes are indicators that the healthcare landscape is rapidly shifting in the US. Patient-centered care is the next paradigm of healthcare delivery, and it has the power and potential to shift systems and change lives.

In the United States, nearly 14 million people have had cancer and more than 1.6 million new cases are currently diagnosed each year.2 By 2022, there will likely be 18 million cancer survivors and by 2030, cancer incidence is projected to rise to 2.3 million cases annually.3 In the cancer space, no single institution to date has been able to successfully implement a comprehensive model of patient-centered cancer care (PCCC). While the cancer community knows what patient-centered cancer care means, we have an unprecedented opportunity to determine how to deliver it in a way that results in the patient feeling informed, respected and cared for.

The LIVESTRONG Foundation conducted research in 2013-2014 to craft a list of essential elements of PCCC with the goal of constructing a useful tool to help advance delivery of truly patient-centered cancer care. The resulting tool- the Elements of Patient-Centered Cancer Care, is a collection of key building blocks which we are using to initiate dialogue and ideation about how to deliver cancer care across a variety of settings.

Our latest research, for which we share the findings and implications below, intended to determine how to deliver the Elements of Patient-Centered Cancer Care as initial steps of creating a new model of patient-centered cancer care4 to be deployed in Austin over the next few years in partnership with the Dell Medical School at the University of Texas at Austin.

Methods
In June of 2014, LIVESTRONG Foundation convened a one-and-a-half day Symposium in Austin, Texas with 83 stakeholders including patients, survivors, caregivers, health care providers, academics, researchers, community organizations, business leaders, policymakers and innovators from around the country. The goals of the Symposium were to:

1.) Discuss how the Elements of Patient-Centered Cancer Care should be prioritized and implemented in various care settings.

2 Ibid
3 Ibid
4 Through the LIVESTRONG Cancer Institutes
2.) Unearth best practices in delivering patient-centered cancer care and inspire healthcare stakeholders to consider how they might enhance models of PCCC within their own institutional context;

3.) Collectively create a roadmap for implementation of a community-based patient-centered cancer care model in Austin that could serve as the pilot for creation of models that are relevant nationally and globally.

The Symposium agenda\(^5\) included presentations and panel discussions with experts, cancer survivors, and caregivers and human-centered design activities focused on conceptualizing models of patient-centered cancer care, including a model canvassing activity and a round robin exercise.

Two paper surveys were utilized to assess participant perspectives on the *Elements of Patient-Centered Cancer Care*. Participants first rated each element on how challenging they thought it would be to implement as part of delivery of patient-centered cancer care. Each element was rated on a scale from one to five, with five being “most challenging.” Symposium participants later completed a survey in which they rated each element on how essential\(^6\) they thought it was to delivery of patient-centered cancer care. Each element was rated on a scale from one to five, with five being “most essential.” We examined which elements received the highest percentage of all the votes. Each Symposium participant could only endorse any specific item once on either survey.

**Results**

Figure 1 below lists the 23 lists the *Elements of Patient-Centered Cancer Care*. Figure 2 shows the survey results. Not all Symposium participants participated in the surveys (there were 50 responses to the survey on the most challenging elements and 38 responses to the survey on the most essential elements).

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\(^5\) The full Symposium agenda is available at [http://www.livestrong.org/junesymposium/](http://www.livestrong.org/junesymposium/).

\(^6\) An element is “essential” if it: directly facilitates or results in the patient (and, if valued by the patient, their family, friends, and caregivers) feeling informed, respected, and cared for; is able to be implemented across a variety of care settings; and is supported by an *evidence base*\(^*\) which exists in cancer survivorship or other related health domains. *When an evidence base does not exist, the element must*: address expressed needs of cancer survivors; have been agreed upon through consensus among the provider community; and/or be able to be tested through further research.
Five elements were rated as “most challenging” over 20 percent of the time. These were:

1. Coordinated, integrated care across multiple disciplines within and outside of oncology (including primary care and allied health professionals)
2. Access to comparative information about the costs of care before care is provided
3. A technology-enabled learning health-care system that uses data capturing patient reported outcomes (PROs) to support the provision of care, both during and between clinical encounters.

4. Architecture or a built environment that is designed to promote a patient-centered experience.

5. Accessible, timely, clear, and effective communication between all parties engaged in the care of the patient and, with the patient's permission, their family and caregivers.

Four elements were rated as “most essential” over 70 percent of the time:

1. Accessible, timely, clear, and effective communication between all parties engaged in the care of the patient and, with the patient’s permission, their family and caregivers.

2. Providers who identify and communicate realistic goals to the patient and their family and caregivers.

3. Cancer care which incorporates best practices and new evidence as they are generated.

4. Emotional and psychosocial support for the patient and their family and caregivers.

In addition, many specific innovative ideas emerged from discussions and activities about how to deliver the Elements of Patient-Centered Cancer Care. Some of these included:

- Create an online, mobile-based social network that connects all members of the care team to the patient and, with the patient’s permission, their family and caregivers. Have an Internet-based platform option available for patients who do not have smartphones.

- Implement one to three questions asked at the beginning of each medical visit to assess the patient’s current values. Use a “primary facilitator” to gather this information ahead of the clinical encounter and to provide a summary of the clinical encounter via a secure patient portal.

- Provide all patients with wearable devices like a SmartWatch to monitor biometrics and allow patients to respond to push notifications at intervals between clinical encounters.

- Provide access to skilled psychosocial providers as part of a “village-style” medical home wherein the providers are available for scheduled and on-demand appointments, and their services are billable encounters.

Discussion and Implications

Meeting the challenge of delivering high-quality, patient-centered cancer care to every patient every time is ambitious, and it will take time to achieve this goal. The ideas generated at this Symposium point to five high-priority elements among the 23 Elements of Patient-Centered Cancer Care and also offer innovative strategies to implement these elements:

1. Enhance communication processes – both between providers and patients and between providers on a care team – so that the processes are more efficient and reliable.

2. Enhance the information systems and informatics infrastructure in the cancer care setting, including useable electronic medical records and patient-facing personal health records.

3. Incentivize, at the institutional level, the provision of patient-centered cancer care.

4. Create opportunities for patients, families, and caregivers to express and document their needs, preferences, and values.

5. Incorporate elements of patient-centered cancer care into all institution-based trainings for staff and healthcare providers.
The Foundation intends to utilize these five strategies, as well as the collection of 23 *Elements of PCCC* and resulting ideas about how to deliver them to frame a new model of patient-centered cancer care through implementation of the LIVESTRONG Cancer Institutes with the Dell Medical School at the University of Texas at Austin. The Institutes are an innovative enterprise that places people affected by cancer in the center of designing and delivering cancer care, education, and research. Over the next 1-2 years, the Institutes will be designed in collaboration with local community partners, healthcare providers, institutions, cancer patients and caregivers. Through the Institutes, we intend to put the patient at the center of the cancer care experience, and to work collectively to make Austin a first of its kind innovative hub for cancer care, as well as a model for the country and perhaps even the world in how to truly deliver patient-centered cancer care.