Cancer Survivorship Connection Website Process Evaluation

Cancer Survivorship Conference: Up Close & Personal

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Objectives

- To present the elements of the process evaluation of the Cancer Survivorship Connection (CSC) website:
 - Background
 - Purpose
 - Methodology
 - Results
 - Quantitative Surveys
 - Qualitative Focus Groups
 - Recommendations
 - Strengths and Limitations
 - Summary and Next Steps

Cancer Survivorship Connection Website



https://www.georgiacancerinfo.org/survivorship/

Background

Georgia CORE and Cancer Survivorship

- In July 2014, the Cancer Survivorship Connection (CSC) website was launched
- A team from Emory University's Rollins School of Public Health (RSPH) implemented a process evaluation that examined the use and utility of the Cancer Survivorship Connection website of the Georgia Center for Oncology Research & Education (CORE)

Purpose of Evaluation

- To validate the mission, track progress and understand the value of the website as well as information/resources obtained by individuals visiting the website and used the results of these activities to conduct continuous quality improvement.
- The process evaluation examined:
 -number and type of website user;
 -number of times the website was accessed;
 -amount of time spent on the website to acquire information and/or participate in forums, blogs, and discussions.

Purpose of Evaluation

- Focus groups were employed to meet three major goals:
- (1) explore healthcare providers, including patient navigators, staff, board members, caregivers, and survivors' perceptions of the usability and utility of the Cancer Survivorship Connection website;
- (2) reveal supports, needs and/or challenges of the website and;
- (3) identify supports and barriers in accessing and/or remaining engaged in the website

Evaluation Questions

- 1. Who were the individuals and organizations involved in designing, developing, and marketing the website?
- 2. How has the website been marketed? What individuals and organizations have been targeted to use the website?
- 3. How many hits has the website received in a 1, 3, or 6 month period?
- 4. Are survivors, caregivers, and healthcare providers using the website? If yes, in what ways?
- 5. How have the various users utilized the website?
- 6. What is the general impression of the website?

Population

- Cancer Survivors (0-3 years, 3-5 years, or 5+)
- Caregivers
- Healthcare Providers
- General Users
- Rural and Urban locations across Georgia



Methods: Participants and Sampling

- Mixed Method Evaluation Study (Quantitative and Qualitative)
- 6 in person focus group discussions with a range of 4 – 17 participants; Length: ~1 hour
- Demographic survey of all focus group participants and website users
- Convenience and Purposive Sampling Techniques

• Eligibility Criteria:

- Cancer survivor, Caregiver of cancer survivor, Healthcare Provider (Physician, Physician Assistant, Nurse, Patient Navigator), CSC website Board Member
- Interest in contributing to enhancing the CSC website and becoming familiar with the website prior to participation in focus group

Methods: Data Collection & Measures

- 6 in person Focus Groups were conducted:
 - 2 in Atlanta (survivors and general users)
 - 2 in Thomasville (healthcare providers and survivors)
 - 2 in Rome (healthcare providers and survivors/caregivers)

• 57 participants completed the demographic survey

Methods: Data Analysis

All interviews recoded for accuracy Recordings transcribed verbatim Excel: Demographic data Hand coding: Qualitative Data

Deductive and Inductive code creation for codebook 2 coders utilized for inter-coder agreement

Methods: Data Analysis

9 Key Themes were developed across focus group discussions

• Website Information • Preferences for

- Finding out about website
- Time spent on website

• Use of Website

- Visual Aspects
- Understandability
- Ease of reading
- Difficulty reading
- Topics
- Navigation

- **Preferences for Accessing Information**
 - Preferences
 - Materials
 - Literacy
 - Communication/Language
 - Race
 - Gender
 - Culture
 - Religion
 - Age
 - Sexuality
 - Search Tool

Methods: Data Analysis

9 Key Themes were developed across focus group discussions

- Survivor, Healthcare Provider, Caregiver, General User
 - Interest in website
 - Information presented
 - Success in their role
 - Informational support

Methods: Data Analysis

9 Key Themes were developed across focus group discussions

- Information on Website
 - Survivors' Voices
 - Survivorship Blog
 - Survivorship Videos
 - Survivorship Forums
 - Survivorship Apps
 - Commission on Cancer Centers

- General Questions
 - Resources Provided/Needed
 - Accessing Resources
 - Recommendations
 - Suggestions
 - Knowledgeable
 - Other









Income level of Focus Group Participants (N=57)







Survivor Information

Interest in website

"Because you got sexuality—to me, that's not—that don't fit in here, in my opinion. Mental health is good. Spirituality is good. The economic employment concerns—I'm talking about survival. I need to know different—I'm not really too worried about the economic side at this moment, especially—I tell my people, you're flying at 45,000 feet. Who's thinking about sex? You've got the same thing here. In a health issue, I don't see that. To me, it doesn't fit." (10.27.14 Survivor Focus Group)

Information presented

"Is there a page that would outline to a patient, that says, "Oh, I'm a 45-year-old male. I need to get PSA checked," or, "If I'm a 50-year-old male, I need a colonoscopy," in layman's terms that they could understand?" (11.12.14 Healthcare Provider Focus Group)

Success as a survivor

"A treatment summary and care plan....think that should be specifically underneath the survivors section and not just the healthcare providers." (11.11.14 Survivor Focus Group)

Caregiver Information

Interest in website

"(Information on) Taking care of yourself." (1.20.15 Caregiver & Survivor Focus Group)

Information presented

"I can say as a caregiver it's (website information) pretty accurate. The stages it lists. The fear of cancer coming back, the time you spend as a caregiver, needing a support system, all that stuff. Very, very accurate." (1.20.15 Caregiver & Survivor Focus Group)

Informational Support

"I think that there should be more testimonials from caregivers as well cuz I think that the caregivers are an underserved population in the whole battle against cancer." (1.20.15 Caregiver & Survivor Focus Group)

"Let people know that there's no guidebook to go by and what to expect. Just be ready. Expect the unknown 'cause you don't know. He lost his sight in 30 seconds in 1 of his eyes a couple months ago. I mean you just never know what's goin' to happen and it was because of the chemo. Permanently. You never know from day to day what's goin' to happen, so be prepared for the unknown. The uncertainty of it." (1.20.15 Caregiver Survivor Focus Group)

Healthcare Provider Information

Interest in website

"From my standpoint, resources interest me the most 'cause that's usually what I'm doing day to day, the resources for patients." (Healthcare Provider Focus Group)

"I think for me it's just helpful to know that it's coming from more of a statewide perspective. Make sure we're all on the same page and we're all looking at the same resources, and we're all driving towards the same standards and expectations. And so for me, it's just sometimes trying to figure out where everybody else is or maybe reading about something else going on, I can try to tap in and be inspired or find that knowledge about what somebody in south Georgia might be doing. Are we doing it here? Are we doing it the same way? And making sure that we are all talking about the same things, offering data that's quality." (Healthcare Provider Focus Group)

Success as a healthcare provider

"Well, I think that, you know while I've been on the website and have used it, a lot of people just probably don't. So I mean I just think more people knowing about it and knowing that those resources are there will make people more successful. I mean the information seems to be there. It's about knowing it's there. Knowing that it could be helpful...more advertising." (Healthcare Provider Focus Group)

General User Information

Interest in website

• "All of the options...with the headers up above, you could look at anything you wanted to relative to your cancer or to your friend's cancer. At different times, you're looking for different types of things, and it gave you plenty of choices, very visible, easy to find, easy to navigate." (12.3.14 General User Focus Group)

• "I like that it has survivors, caregivers, and healthcare professionals." (12.3.14 General User Focus Group)

Recommendations

- Change the gray background color to a more "vibrant color that connotes more energy"
- Reduce the amount of text on each page of the CSC
- Add more Latino/Hispanic individuals to the website
- Add younger aged individuals to the website
- Add more cancer statistics

- Add organ donation information
- Add spirituality/religious information
- Add information pertinent for military and/or veteran cancer survivors
- Add a "survivors in the news" section
- Include more "common folk" survivor stories

Recommendations

- Add Spanish language
- Add Care Plan and Treatment summary information from the HCP section to the survivors section
- Add a section for questions that patients can ask their physician
- Include national , region, and local resource information (e.g., support group meetings, financial assistance, transportation, organizations, mammography services, and activities, etc.)
- Add resources and frequently asked questions (FAQs) that will be useful for newly diagnosed patients

- Add a cancer glossary of terms
- Add general and region specific FAQs that will be useful for newly diagnosed patients
- Add a list of "model" survivorship programs and provide a name associated with each program so that others can contact this person with questions
- Highlight survivorship programs that have best practices

Strengths and Limitations

- Reached Saturation
- In-Depth Answers

Strengths

Limitations

- Variety of Background and Location
- Need for additional caregiver information
- Sample Size, recruitment & availability
- Non-cancer audience



June 2016 CSC Website Updates

- Colors updated
- Responsive Technology Function
 - Full functionality on any size device
- Added "Survivorship Help/FAQ" to assist with navigation of the site
- Cancer Survivorship Connection is more prominent on the Homepage

Acknowledgements

- Georgia CORE
 - Focus group participants (Caregivers, Healthcare Professionals, Survivors, and General Users)



