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Evaluating the Needs of Cancer Survivors through Focus Groups and Surveillance Data

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Institutional Review Board (IRB) Status

The focus group program was classified as exempt human subjects research by the Michigan Department of Health and Human Services Institutional Review Board.

Introduction

Cancer is the second leading cause of death in the United States, therefore, much of the research focuses on its prevention and treatment. As these prevention methods and treatments improve, the survival rates for most cancers continue to rise. The American Cancer Society estimated that there were 526,100 cancer survivors in the state of Michigan in 2016 (American Cancer Society [ACS], 2016). A person is considered a cancer survivor from the time of diagnosis through the duration of his or her life (ACS, 2016).

Unfortunately, many post-treatment cancer survivors have an array of ongoing mental and physical health needs due to their cancer or its treatment. Many of these needs can be addressed through public health interventions that concentrate on tobacco use (National Cancer Institute [NCI], 2014), physical activity, nutrition (Rock et al., 2012), and emotional well-being (Salvatore, Ahn, Jiang, Lorig, & Ory, 2015), which can increase cancer survivors' duration and quality of life. When assessing and planning for the needs of the cancer survivor population, it is important to note that this population tends to be older; in 2014, 88.2% of all cancer diagnosed in Michigan were in people 50 years of age or older.

Public health has typically emphasized prevention and early detection, while the medical community has focused on treatment. Therefore, the ongoing needs of post-treatment cancer survivors are often overlooked. It has become essential for states to examine the public health needs of this growing population. Data from the Michigan Cancer Surveillance Program and the 2015 Michigan Behavioral Risk Factor Survey (MiBRFS), and talking with survivors through focus groups, can assist public health

professionals in understanding how to resolve the mental and physical health issues within this population.

Methods

The Michigan Cancer Surveillance Program is a central Cancer Registry that was established by state law (Act 82 of 1984) to collect reports on cases for in situ and invasive malignancies diagnosed throughout the state. The Cancer Registry provides a basis for cancer surveillance. Data on cancer incidence and mortality are available for the years 1985 to 2014. (Michigan Cancer Surveillance Program [MCSP], 2018)

The MiBRFS is an annual statewide phone survey of Michigan adults aged 18 years and older, which is coordinated with the Centers for Disease Control and Prevention (CDC). It includes a standard questionnaire, which states can customize to target and collect data from specific populations. In 2015, the Michigan Department of Health and Human Services Cancer Prevention and Control Section's Cancer Survivorship Program added a cancer survivorship module to the MiBRFS that consisted of 13 questions. Prevalence of cancer survivorship was defined as ever being told by a doctor, nurse, or other health professional that you had skin cancer or any other type of cancer. For those who were identified as a cancer survivor, the survivorship module was administered and included questions about treatment, post-cancer care, participation in clinical trials, and pain. The results of these questions were used to determine the prevalence of cancer survivors and analyze relevant characteristics of this population. Additional analyses were performed using questions from the core questionnaire to better understand the behaviors and physical and mental health amongst cancer survivors. Prevalence estimates and 95% confidence intervals were calculated using SAS-Callable SUDAAN (version 11.0.1). (Michigan Behavioral Factor Surveillance System [MiBRFSS], 2018)

The MiBRFS and the Cancer Registry provide essential resources when reviewing cancer survivorship, however they have limitations in terms of the data that they provide. To increase the scope of our understanding about challenges survivors face, we implemented cancer survivor focus groups throughout the state. There was a total of seven focus groups conducted with four urban groups from Ann

Arbor, MI, one rural group from Traverse City, MI, and two rural groups from Cadillac, MI. Survivors were recruited through health systems operating in each region. Health systems were instructed to recruit survivors who were post-treatment, although length of time since treatment was not a consideration. Two of the urban focus groups recruited only Black or African American cancer survivors; one group of men and one group of women. The other rural and urban groups were open to anyone who had been diagnosed with cancer in their lifetime and had completed initial treatment or were receiving long term treatment for cancer. Focus groups had between two and ten participants. Focus groups were not recorded but were conducted with two note-takers. The focus groups included four activities. The first activity was a general introduction designed to 'break the ice'. The second activity requested that the survivors write down three things that were different now that they were cancer survivors. The third activity asked survivors to write down their needs related to being cancer survivors and to categorize them by common themes that had been previously identified by cancer experts. The cancer experts were recruited from the Michigan Cancer Consortium Cancer Survivorship Workgroup membership roster. Themes identified by cancer experts included: fatigue, mental and cognitive health, education, physical health, medical care, social and emotional needs, and financial and insurance needs. The fourth activity requested survivors to develop a list of the things that surprised them the most about cancer or being survivors. These activities were then transcribed and coded for themes.

Conclusions were drawn by comparing the three data resources to find similarities and differences in cancer survivorship groups in Michigan. This project was not considered human research.

Results

Cancer is the second leading cause of death in Michigan with 20,347 Michigan residents dying from cancer in 2015. In 2014, there were 438.2 new diagnoses of cancer per 100,000 Michigan residents, totaling 52,704 new cases of invasive cancer. From 1985 to 2014, 86.4% of cancer patients in the registry had only one cancer diagnosis. The Cancer Registry reports 68.6% of cases who were diagnosed in 2014 were diagnosed at age 60 or older. For all cases diagnosed in 2005, the Cancer Registry reports a 64.1% survival rate.

In the 2015 MiBRFS, 10.0% of Michigan residents age 18 and older reported ever being told they have cancer. *Table 1* describes the age-adjusted cancer survivor population. Among respondents, 38% reported being first diagnosed with cancer at age 60 or older (data not shown). The discrepancy between the Cancer Registry and MiBRFS sources are likely due, in part, to survivor bias. The MiBRFS only surveys people who are alive and healthy enough to complete the phone interview and does not accept proxy responses. Because of this, the needs of severely ill or disabled survivors may not be captured in these data. Additionally, the MiBRFS asks for the age of the first cancer diagnosis and some respondents may have had a second diagnosis at a later age.

Statistical differences were seen in cancer survivorship among subgroups including: gender, race, education, and employment. Among MiBRFS respondents, 10.9% of females and 9.3% of males reported being cancer survivors. Non-Hispanic Blacks had the lowest percentage of cancer survivors (5.4%) compared to non-Hispanic Whites (11.0%), and Other and multi-racial respondents (6.9%). Results for Hispanics or Latinos were suppressed due to having too few respondents. Significant differences existed in employment status, with 12.6% of non-working individuals reported being a cancer survivor compared to 10.5% of employed individuals.

Three major themes were identified from the focus groups based off responses to specific questions: health care, health-related behaviors, and social/emotional support; three sub-themes related to health care needs were then identified and are shown in *Figure 1*. The first theme relates to the survivors' experiences in seeking a physician post-cancer; cancer survivors are often seen by more than one physician for their medical care. According to the MiBRFS, 51.9% of survivors reported receiving any type of instructions on where to go for post-cancer care, and 40.5% of survivors had those instructions given to them as a written summary. However, in our focus groups survivors reported being unsure of what questions to ask which doctors. Survivors reported that, at times when they would ask a doctor a question, they would be told to ask a different doctor their question. Supportive and understanding medical care staff were viewed as important by the focus groups for improving the medical experience for all survivors.

The second health care theme centered on the primary care provider's ability to properly care for cancer survivors. In the MiBRFS, 84.0% of cancer survivors reported seeing a physician for routine care within the last year. This is important as 29.9% of survivors reported their general health as poor. Among cancer survivors who were at least three months post cancer treatment, 58.8% reported they receive their primary care from a Primary Care Physician (PCP). Those who did not see a PCP reported seeing an oncologist, surgeon, or another type of physician for their primary care. In the focus groups, survivors noted their PCP was not always aware of current screening practices and long-term effects of cancer treatments.

The third health care sub-theme centered on finances. In the MiBRFS, 10.3% of cancer survivors reported that they needed to see a doctor but could not because of cost. In the 2014 MiBRFS, 19.8% of cancer survivors reported that they were paying medical bills related to their cancer treatment over time. This question was not asked in the 2015 MiBRFS. Focus group participants reported that insurance did not always cover treatment for side-effects and that medical bills and copays were a challenge to pay. Some survivors simply reported that they needed money, with no qualifications about the underlying need for the money. Medical bills and disputes with insurance companies over cancer treatment coverage were also cited as a source of stress that survivors believed interrupted the healing process.

Nutrition has long been a prime focus for public health interventions. Experts recommend that everyone eat at least 5 servings of fruits and vegetables a day. In the MiBRFS, 15.9% of cancer survivors reported eating at least five servings of fruits and vegetables a day. Adopting healthy behaviors post-cancer was also a theme in the focus groups. Education on proper nutrition and what to eat to stay healthy was one need identified by survivors. Suggested nutritional-related resources mentioned by the focus groups included meal delivery and nutritional resources tailored to cancer survivors.

The promotion of physical activity is another area common to public health. However, in the MiBRFS, 42.0% of cancer survivors reported being limited in activities due to a physical, mental, or emotional problem and 34.3% had a Body Mass Index classified as obese. The loss of common activities

(e.g. golf) was a concern for some focus group participants. Cancer survivors in the focus groups were interested in resources for things like rehabilitation, adapted exercise classes, and complementary therapies (e.g. yoga and massage) to assist them with staying engaged with favorite leisure activities or to improve their health. *Figure 3* provides the prevalence of these health-related behaviors among cancer survivors.

From the MiBRFS, 11.3% of cancer survivors report having poor mental health (*Figure 3*). All the focus groups discussed the need for additional social and emotional help. Survivors discussed not only body image issues, but the need for help with depression from loss of work, issues around identity, and self-image. Additionally, all focus groups discussed fear of cancer reoccurrence as a major source of anxiety. Support groups with other cancer survivors who are post-treatment, were identified as a resource that could be helpful in addressing mental health issues. Individual counseling was another suggested resource. Family support was also discussed with many survivors stating that cancer is a family disease that can change a family dynamic and cause caregiver fatigue. As seen in our focus group, mental health support is a large need amongst the cancer survivor population and their families; however, quantitative data on this topic is limited because these needs are too specific for a general population surveillance system.

There were issues discussed in focus groups that are currently not measured by a surveillance system. For example, sexual function was a very common theme. Some of this related to changes in body image and some of it related to changes in body function. This demonstrates the importance of combining surveillance activities with activities like focus groups to understand cancer survivor needs.

The focus groups also demonstrated a difference between urban and rural participants. While rural survivors only mentioned transportation as a concern when they had to travel several hours for second opinions, urban survivors mentioned transportation was an ongoing concern due to high traffic in urban areas. Rural groups also reported concerns around PCP training in regards to post-cancer care while the topic did not come up in the four urban groups.

Although smoking was not discussed amongst survivors in the focus group, smoking prevalence is a common behavior examined within the cancer survivor community. From the MiBRFS, the prevalence of smoking among cancer survivors has decreased from 19.0% in 2011 to 12.3% in 2016 (data not shown). In 2015, 71.3% of cancer survivors who were current smokers reported they had been advised or referred to resources to stop smoking.

Conclusions

The availability and usefulness of surveillance data in cancer survivorship has often been overlooked. Surveillance data on cancer survivorship can assist us in understanding the population and measuring the impact of public health interventions. However, surveillance has some limitations. First, there are questions that are not appropriate for a telephone survey (i.e., sexual functioning). Second, due to the number of people interviewed who report a history of cancer (N=1,433), some results from questions specific to survivorship cannot be analyzed because there are too few respondents. The small sample size of cancer survivors is also an issue when trying to examine disparities amongst certain sub-populations. Given these limitations, it is important to seek the direct input of cancer survivors through activities like focus groups.

By including cancer survivors in the discussion surrounding their own needs, public health organizations can ensure that their programs are more successful by encompassing important survivorship concerns that may not have emerged in typical surveillance sources. This will become increasingly important as the number of survivors grows. Questions that cannot be asked in a typical survey, such as sexual functioning, can often be overlooked in public health initiatives as there is limited data. Therefore, it is imperative that providers and public health professionals use not only the data available to them, but also the experiences of survivors to have a more complete outline of the public health need.

In 2012, the Michigan Cancer Consortium, the Michigan Department of Health and Human Services and the Michigan Oncology Quality Consortium started a public health intervention to decrease the prevalence of smoking in cancer survivors. Through a policy and system change model, oncologists

now refer their patients who smoke to cessation services. Data obtained from the Michigan Behavioral Risk Factor Surveillance System demonstrates that there has been a statistically significant reduction in the number of current smokers in our survivor population (2011 to 2015) (data not shown). The success of this intervention suggests that other coordinated initiatives should be identified to frame other public health topics

Tracking the physical and mental health of cancer survivors is important. There are many ways that surveillance data can assist public health agencies in understanding cancer survivor needs. This is especially important because, as expressed from the focus groups, this growing group of cancer survivors often feel that their needs are still unmet. One of the most consistent messages that came out of the focus groups was appreciation for the focus group itself. As a whole, the focus group participants reported that “no one ever asks us what we need”. Therefore, it is crucial that public health professionals should not merely analyze data, but also seek the input of the communities which they serve, especially in areas that are not adequately assessed through surveillance measures.

Using a wide-range of data, providers and public health workers can continue to address cancer survivor needs throughout the cancer-care continuum. The need for public health programming and provider interventions surrounding cancer survivorship will continue to grow as the population of survivors increases. By using surveillance data, along with focus groups, public health organizations can more accurately target the needs of their survivorship program participants and measure programmatic outcomes. It should be noted that survivorship is experienced differently by all survivors. Conclusions that can be made with data from the Michigan Behavioral Risk Factor Surveillance System are limited at this time. As the survivorship module questions are asked over the following years, results will be combined with the data reported in this paper to give a better understanding of how survivorship is experienced by various populations.

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Table 1: Characteristics of Participants from the 2015 Michigan Behavioral Risk Factor Survey who reported being a cancer survivor (Age-Adjusted)

Cancer Survivors ^a	Percent	95% Confidence Interval
Overall Michigan	10.0	(9.4, 10.6)
Female	10.9	(10.0, 11.8)
Male	9.3	(8.5, 10.2)
Non-Hispanic White	11.0	(10.3, 11.8)
Non-Hispanic Black	5.4	(4.2, 6.9)
Hispanic or Latino ^b	Suppressed	Suppressed
Other and multi-racial, non-Hispanic	6.9	(4.7, 10.0)
Less than \$20,000	9.9	(8.2, 11.9)
\$20,000 to \$34,999	10.1	(8.6, 11.8)
\$35,000 to \$49,999	10.8	(9.1, 12.9)
\$50,000 to \$74,9999	9.8	(8.4, 11.3)
\$75,000 or more	10.9	(9.7, 12.2)
Less than high school diploma	7.5	(5.7, 9.9)
High school diploma or GED	9.4	(8.4, 10.4)
Some college or Trade School	10.8	(9.7, 12.0)
College graduate or higher	11.4	(10.4, 12.5)
Employed	9.5	(8.2, 11.1)
Unemployed	10.2	(7.2, 14.2)
Non-working	11.9	(10.6, 13.2)
Married	10.7	(9.8, 11.7)
Formerly married	9.3	(7.4, 11.6)
Never married	8.3	(6.3, 10.9)
Widowed	15.8	(11.0, 22.3)
Veteran	11.3	(9.1, 14.0)
Homosexual or Bisexual	11.1	(6.9, 17.3)
18 to 39 ^{c,d}	2.0	(1.4, 2.7)
40 to 54 ^{c,d}	7.2	(6.1, 8.5)
55 to 69 ^{c,d}	18.0	(16.5, 19.7)
70 and Older ^{c,d}	19.4	(14.8, 25.0)

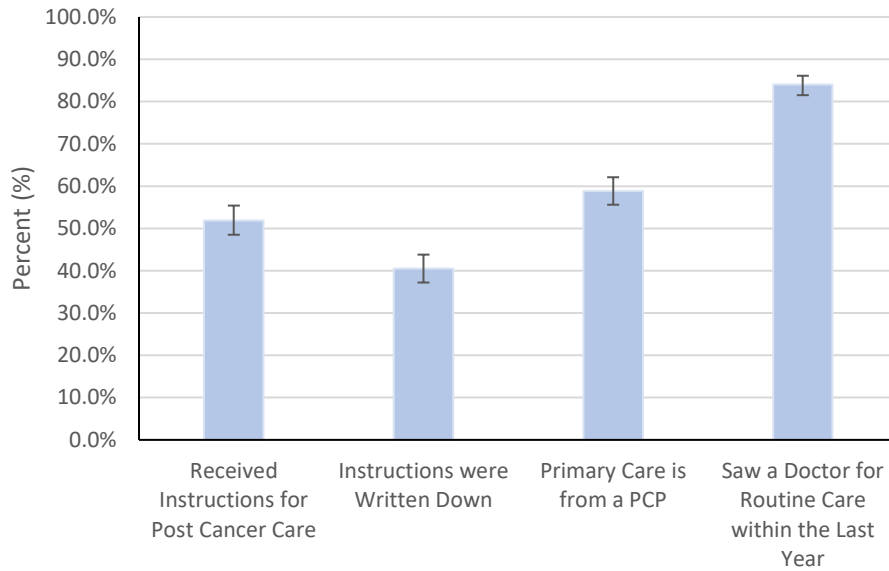
NOTE: ^a Cancer survivor is defined as responding 'Yes' to either "Have you ever been told you have skin cancer" or "Have you ever been told you have any other type of cancer"

^b Prevalence estimate suppressed due to having a standard error of greater than 30%

^c Estimates are not age adjusted

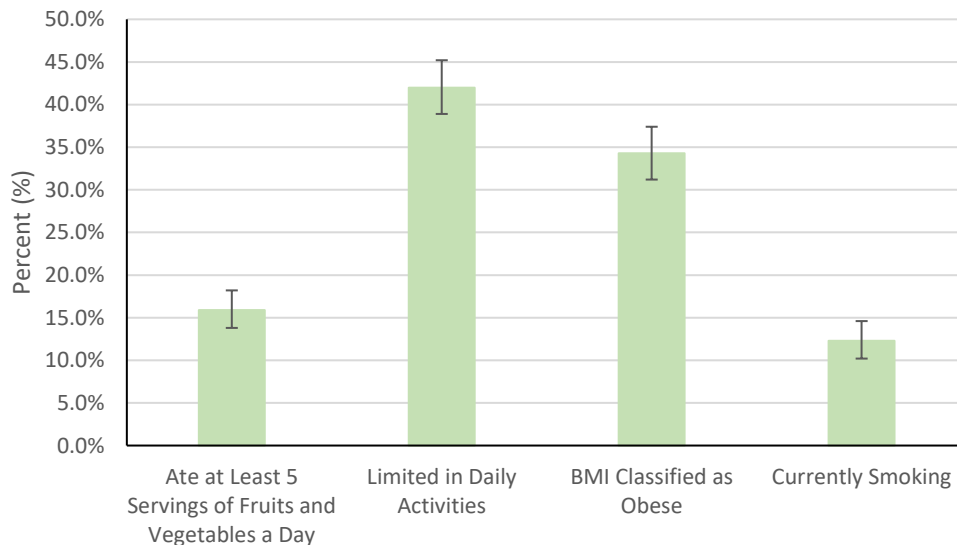
^d Represents the age of the respondent at the time of the survey

Figure 1: Prevalence of Health Care Utilization among Cancer Survivors, 2015 Michigan Behavioral Risk Factor Survey ^a



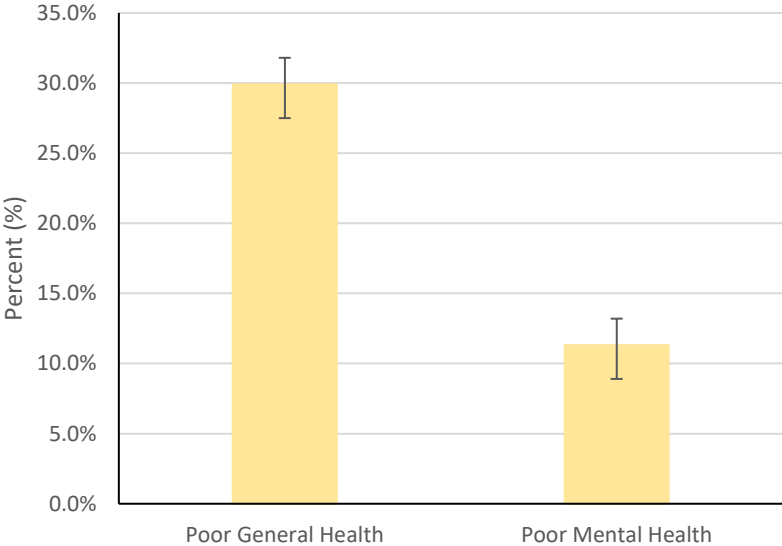
NOTE: ^a Cancer survivor is defined as responding ‘Yes’ to either “Have you ever been told you have skin cancer” or “Have you ever been told you have any other type of cancer”

Figure 2: Prevalence of Health-Related Behaviors among Cancer Survivors, 2015 Michigan Behavioral Risk Factor Survey ^a



NOTE: ^a Cancer survivor is defined as responding ‘Yes’ to either “Have you ever been told you have skin cancer” or “Have you ever been told you have any other type of cancer”

Figure 3: Prevalence of Poor Health among Cancer Survivors, 2015 Michigan Behavioral Risk Factor Survey ^a



NOTE: ^a Cancer survivor is defined as responding 'Yes' to either "Have you ever been told you have skin cancer" or "Have you ever been told you have any other type of cancer"