

Data Brief

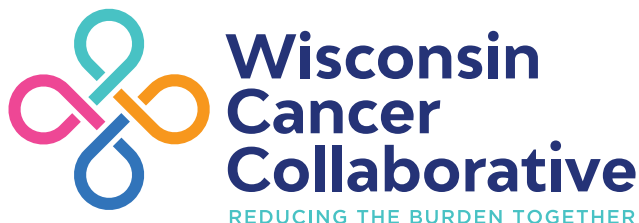
2020 Behavioral Risk Factor Surveillance System Wisconsin Cancer Survivorship Report

John Krebsbach, BS¹; Alexandria Cull Weatherer, MPH¹; Thomas Patrick Lawler, PhD^{2,3}; Amy Trentham-Dietz, PhD^{2,3,4}; Noelle K. LoConte, MD^{2,3}

¹Wisconsin Cancer Collaborative; ²University of Wisconsin Carbone Cancer Center; ³University of Wisconsin School of Medicine and Public Health; ⁴Department of Population Health Sciences, University of Wisconsin-Madison

A REPORT FROM THE WISCONSIN CANCER COLLABORATIVE

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KEY POINTS

- In 2020, BRFSS surveyed cancer survivors in Wisconsin about their experiences.
- The survey found some differences in cancer survivorship experiences. For example, survivors younger than 55 reported higher levels of current pain related to their cancer or cancer treatment, compared to survivors who were older than 55.
- Future surveys need improved representation from different racial groups and LGBTQ+ populations, so that the data can better reflect the survivorship experiences of all Wisconsinites.

Introduction

As defined by the National Cancer Institute, a cancer survivor is a person who continues to live and function from the time of diagnosis until the end of life¹. Thus, survivorship care encompasses all care, including the physical, psychological, social, and financial effects of a cancer diagnosis and treatment, as well as prevention and screening for future cancers. Survivorship care spans multiple disciplines and requires the work of many different specialists within medicine, psychology, and more.

The Behavioral Risk Factor Surveillance System (BRFSS) is an annual telephone survey run by the Centers for Disease Control and Prevention (CDC) to collect state-level data on chronic conditions, health-related behavioral risk factors, and the use of preventive services². In 2020, BRFSS modules on the topic of cancer survivorship were conducted, and this data was obtained by the Wisconsin Cancer Collaborative to monitor the unique needs of Wisconsin cancer survivors. The following report is part of a larger effort by the Wisconsin Cancer Collaborative to improve the collection and dissemination of cancer survivorship data in Wisconsin to ensure we are meeting cancer survivors' needs.

Methods

Wisconsin residents were interviewed by telephone (N=5,099). BRFSS modules specific to cancer survivorship in Wisconsin included responses to cancer survivorship-related questions from participants with a self-reported history of cancer. Respondents were asked questions regarding type of cancer, course of treatment (including topics such as receipt of written treatment plans, health insurance status, and clinical trial participation), and pain management.

Participants with no cancer history (N=4,327) or with history limited to "other" types of skin cancer (i.e., non-melanoma skin cancers, N=204) were excluded from the analysis, as were those who were eligible but did not respond to

any questions (N=67). In total, 501 cancer survivors were included in the analysis. Data are shown with weighted percentages per BRFSS recommendations³. BRFSS provides survey weight so that results are representative of the demographic characteristics of the entire state of Wisconsin, not just the group of respondents. After accounting for many factors that may influence a given person's decision to complete the survey, raw percentages were converted into weighted percentages to yield more representative results and to reflect the survey sampling.

Results

Of the full sample of 501 respondents who completed at least part of the survey, the majority were white (91%), older than 55 years old (86%), lived in an urban setting (78%), heterosexual (94%), and had completed treatment (73%).

The percentage of respondents who received written treatment summaries of their cancer treatments varied across racial/ethnic categories, with more Hispanic respondents (65%) saying "yes" compared to non-Hispanic White (49%) and non-Hispanic Black (30%) respondents. Additionally, a greater percentage of respondents younger than 55 years old reported receipt of a written treatment summary (63%) than that of respondents 55 years and older (45%). Breast cancer respondents reported the lowest percentage of written summary receipt (45%) of all cancer types. Additionally, fewer rural survivors (65%) reported receiving follow-up instructions after completing cancer treatment compared to urban respondents (83%). Receipt of written summaries and follow-up instructions were comparable across different sexual orientations.

Over 89% of respondents across all racial, age, residential, sex, and sexual orientation categories reported that health insurance paid for at least part of their cancer treatment, except for Hispanic (40%) and other race (54%) respondents. Hispanic respondents also reported the largest percentage

of denied insurance coverage due to a cancer diagnosis (22%). Additionally, a larger percentage of respondents younger than 55 years old (21%) reported current pain consequent to cancer or cancer treatment than respondents older than 55 years old (10%). Clinical trial participation was highest among breast cancer survivors (16%) and lowest among prostate and lung cancer survivors (0%). Overall clinical trial participation was 7%.

Limitations

Sample sizes were limited for racial/ethnic groups other than white, LGBTQ+ respondents, and lung cancer respondents. Thus, the margin of error for the results for these groups is large, and these results should be interpreted with caution.

Additionally, since the BRFSS is a general population survey, the participants in the study tend to represent cancer types with excellent survival rates. The results of this survey may not reflect the experience of cancer survivors with poor-prognosis tumors, for example, pancreatic and brain, in Wisconsin.

Implications for Cancer Survivors

These results suggest several paths for improving the care and experiences of Wisconsin cancer survivors, in line with priorities outlined in the Wisconsin Cancer Plan 2020-2030. Increasing the use of treatment summaries and written instructions may help some patients better understand and follow treatment plans. Increasing access to high-quality health insurance should be a priority to decrease cancer's financial burden. Additional efforts can be made to address pain among cancer survivors, and clinical trial participation can be improved among some groups of survivors to help identify new developments in treatment, screening, and survivorship care.

Additionally, these results highlight the need to improve the inclusion of diverse populations who are currently underrepresented in the available data. Future survey efforts should better reflect the experiences of groups disparately impacted by cancer, so that we can increase representation and engagement of those groups in the development of culturally and linguistically appropriate cancer control activities.

Patient Characteristics	Respondents (N)	Count (Percentage)
Sex	501	
Male		230 (46%)
Female		271 (54%)
Residence	501	
Urban		391 (78%)
Rural		110 (22%)
Race (* = Non-Hispanic)	493	
White*		447 (90%)
Black*		13 (3%)
American Indian, Alaska Native*		11 (2%)
Hispanic		7 (1%)
Other*		5 (1%)
Age	501	
<55		68 (14%)
55+		433 (86%)
Sexual Orientation	477	
Heterosexual		447 (94%)
Gay/Lesbian		4 (1%)
Bisexual		11 (2%)
Other or don't know		15 (3%)
Treatment Status	466	
Active		66 (14%)
Completed		350 (73%)
Declined		9 (3%)
Not Yet Started		41 (10%)

Survivorship Experience	Respondents (N)	Answered "Yes"
Care Plan		
Received Written Treatment Summary	338	173 (49%)
Received Follow-Up Care Plan	339	268 (80%)
Insurance		
Paid for all or part of treatment costs	343	330 (95%)
Denied health or life insurance due to cancer	345	28 (8%)
Clinical trial participation	343	30 (7%)
Pain		
Experiencing current pain secondary to cancer or treatment	489	50 (12%)

Survivorship Experience	Breast (N=92)	Prostate (N=70)	Colon and Rectal (N=29)	Lung (N=12)	Other Cancers (N=249)
Care Plan					
Received Written Treatment Summary	32 (45%)	26 (62%)	12 (62%)	3 (64%)	93 (48%)
Received Follow-Up Care Plan	59 (84%)	32 (79%)	20 (72%)	7 (100%)	140 (81%)
Insurance					
Paid for all or part of treatment costs	63 (97%)	42 (84%)	25 (100%)	8 (100%)	173 (96%)
Denied health or life insurance due to cancer	7 (10%)	0 (0%)	2 (6%)	0 (0%)	19 (12%)
Clinical trial participation	16 (16%)	0 (0%)	3 (9%)	0 (0%)	11 (6%)
Pain					
Experiencing current pain secondary to cancer or treatment	14 (13%)	2 (2%)	6 (19%)	1 (21%)	22 (12%)

References

1. National Cancer Institute. NCI Definition of Cancer Terms 20.09d: survivor. October 9, 2020. Available at: <https://www.cancer.gov/publications/dictionaries/cancer-terms>
2. National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health. About BRFSS. May 16, 2014. Available at: <https://www.cdc.gov/brfss/about/index.htm>
3. Complex Sample Weights and Preparing 2020 BRFSS Module Data for Analysis. Centers for Disease Control and Prevention. Updated July 2021. Accessed February 24, 2022. https://www.cdc.gov/brfss/annual_data/2020/pdf/Complex-Smple-Weights-Prep-Module-Data-Analysis-2020-508.pdf

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