



**Wisconsin
Cancer
Collaborative**

Wisconsin Cancer Survivorship

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How do we define "cancer survivorship"?

- According to the National Cancer Institute (NCI), “an individual is considered a cancer survivor from the time of diagnosis, through the balance of their life.” Survivors include people with a current diagnosis and people now free from cancer. Caregivers (often called “co-survivors”), family members, and friends are an important part of the survivor experience.
- Cancer survivorship refers to “the health and life of a person with a cancer, post-treatment until the end of life.”



2020 Wisconsin Survivorship Care Survey

Objectives of the Wisconsin Survivorship Care Survey

- Assess current survivorship care practices in Wisconsin
- Share key survey findings and opportunities for improvement in survivorship care for Wisconsinites.
- Connect those who work on survivorship with other survivorship programs in Wisconsin.
- Compile and share resources.
- Establish a community of practice to improve survivorship programs in the state.

Survey Results

Publication in the Journal of Cancer Survivorship

Key findings were published in the *Journal of Cancer Survivorship*: [The current status of survivorship care provision at the state level: a Wisconsin-based assessment.](#)

This work supports the Wisconsin Cancer Plan 2020-2030, [Chapter 5: Survivorship.](#)



Survey Sites

Ascension Columbia
St Mary's Milwaukee

Ascension Columbia
St Mary's Ozaukee
Cancer Center

Ascension Wisconsin
Cancer Care - Mayfair
Road Cancer Center -
Wauwatosa

Ascension Wisconsin
Cancer Care - Reiman
Cancer Center

Ascension Wisconsin
Cancer Care -
Sherman Cancer
Center Elmbrook

Aspirus Medford
Hospital

Aspirus Wausau
Hospital

Aurora Cancer Care -
Grafton

Aurora Cancer Care -
Green Bay

Aurora Cancer Care -
Marinette

Aurora Cancer Care -
Metro Milwaukee

Aurora Cancer Care -
Oshkosh

Aurora Cancer Care -
Racine

Aurora Cancer Care -
Sheboygan

Aurora Cancer Care -
Summit

Aurora Cancer Care -
Two Rivers

Aurora Cancer Care
(Kenosha)

Aurora Cancer Care
(Southern Lakes)

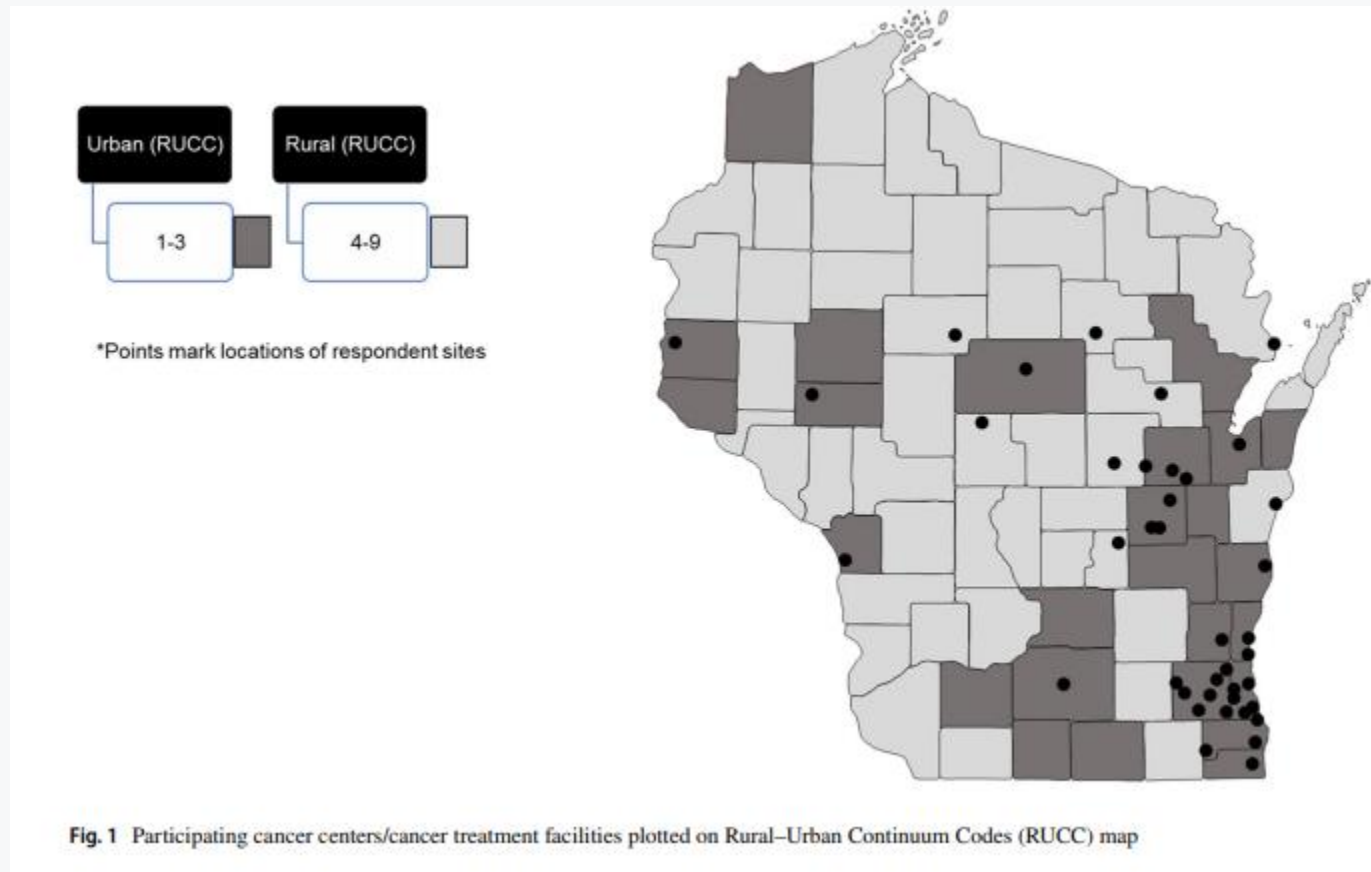
Cancer Care Center
at Froedtert
Menomonee Falls
Hospital

Cancer Center at
Drexel Town Square
Health Center
(Froedtert)

Sites continued...

| | | | | |
|---|--|---|---|--|
| Cancer Center at Moorland Reserve Health Center (Froedtert) | Cancer Center of Western WI-- Westfields Hospital & Clinics Site | Froedtert & MCW Cancer Center | Gundersen Health System - La Crosse | Kraemer Cancer Center - Froedtert West Bend Hospital |
| Marshfield Clinic Health System - Marshfield Center | Marshfield Medical Center- Eau Claire Cancer Center | Mayo Clinic Health System Franciscan Healthcare - La Crosse | ProHealth - Mukwonago | ProHealth – Oconomowoc |
| ProHealth – Pewaukee | ThedaCare Cancer Care - Appleton | Thedacare Cancer care (outreach) - Berlin | Thedacare Cancer care (outreach) - New London | Thedacare Cancer care (outreach) - Oshkosh |
| Thedacare Cancer care (outreach) - Shawano | Thedacare Cancer care (outreach) - Waupaca | Thedacare Cancer care (outreach) Neenah | UW Carbone Cancer Center | Volm Cancer Center- Aspirus Langlade Hospital |

Survey Sites



Strengths: Over 80% of sites have these services available to survivors:



Strengths

Standards of Care:

- Discussion of need for regular follow-up and screening post treatment
- Provide survivor written treatment summary
- PCP also are given survivorship care plans

Many survey sites indicated discussing the following late/long term effects with all or almost all patients

- Emotional distress 90%
- Fatigue 85%
- Health practice changes 80%
- Mood changes 70%

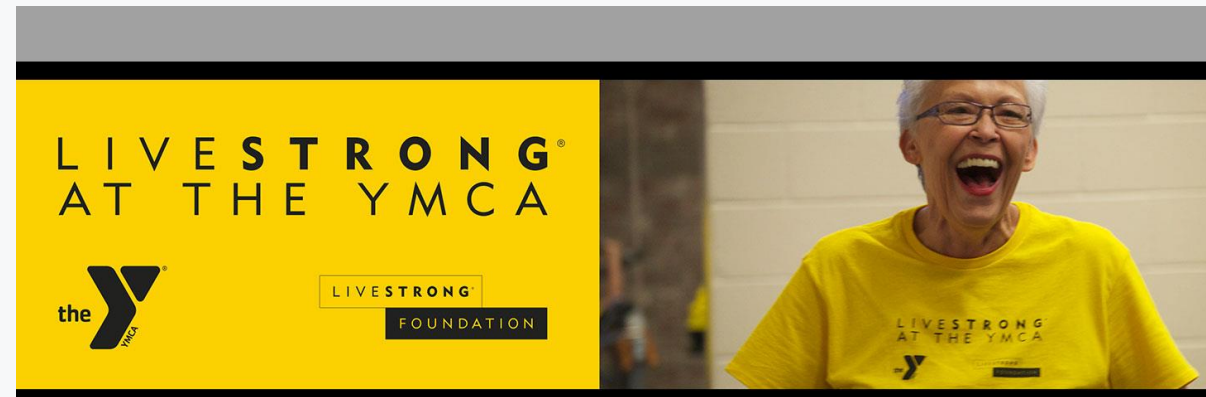
Gap: Mental Health Services

- Discussing need for emotional and social support was most often a standard of care, however, referral to a specialist for mental/behavioral health concerns was not.
 - This service received the largest spread of responses



Gap: Risk Reduction Services

- Risk reduction services, dietary services, and access to physical activity were described as standards of care in less than half of sites.
 - Dietary Services (42.5% 17/40)
 - Physical activity (25% 10/40)
 - Risk reduction services (20%; 8/40)



Gap: Sexual Health and/or Fertility Services

- Reproductive endocrinology was included at about a third of follow-up care teams (35.0%; 14/40), as were fertility specialist services (32.5%; 13/40).
- Sexual health services were offered at 55.0% (22/40) of sites
- Sexual functioning was the only late-term effect with any responses for “rarely or never discussed” (7.5%; 3/40), indicating a possible gap area.

Common Themes

- These services may be offered less often due to variable insurance coverage.
- Reimbursement for many important survivorship services, such as behavioral interventions in survivors, is not currently available.
- Policy solutions should be explored to increase insurance coverage and provision rates of necessary survivorship services to keep up with the projected increase in demand.

Limitations

- COVID-19
- Not every site was surveyed
- Not every site responded, or we didn't have correct contact information
- Self-report
- This is not from the survivor perspective

Next Steps

- Continue to share relevant cancer survivorship resources and opportunities to members.
- Amplify work that our members are doing to improve survivorship care.
- Expand the community of practice to improve survivorship programs in the state.
- Explore policy and systems changes relevant to cancer survivors.
- Identify key priorities and strategies to implement change.

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Cancer Survivor Surveys

2019 and 2020

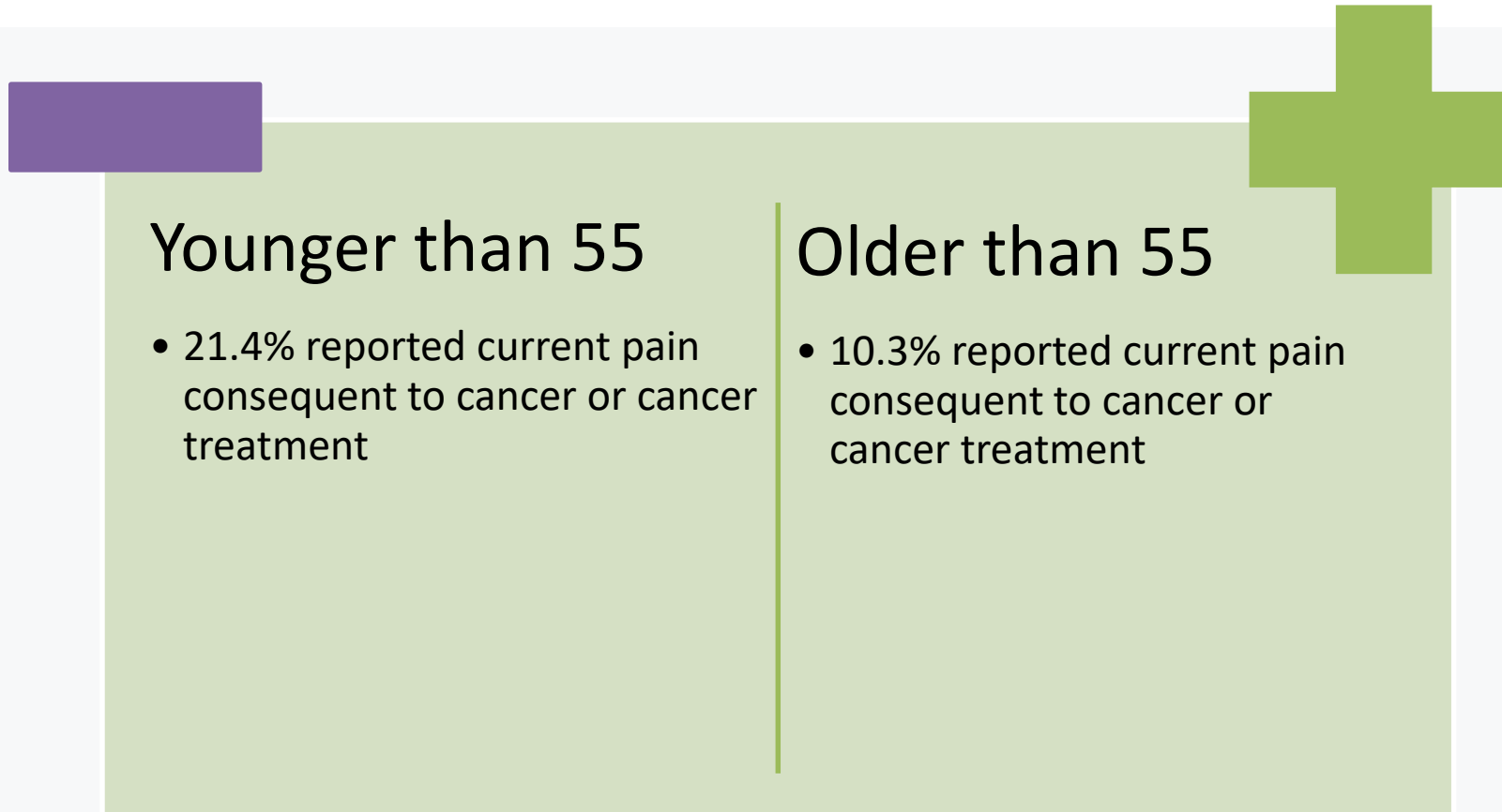


Behavioral Risk Factor Surveillance System (BRFSS) - Survivorship Results

2020



What did respondents have to say based on their age?



Survey of Health of Wisconsin- Survivorship Results

2019



Survivorship Care



78% of respondents felt their worries were addressed by their treatment staff



66% of respondents reported satisfaction with the degree to which their cancer care was explained to them (4% reported dissatisfaction)



74% of respondents felt they could discuss any concerns with their provider without discomfort or feeling as if the provider was not receptive to these issues



Sexual health (9%) and emotional distress were two examples of topics some survivors did not feel they could discuss with their provider



27% of respondents reported never having discussions with their provider about late/long term effects

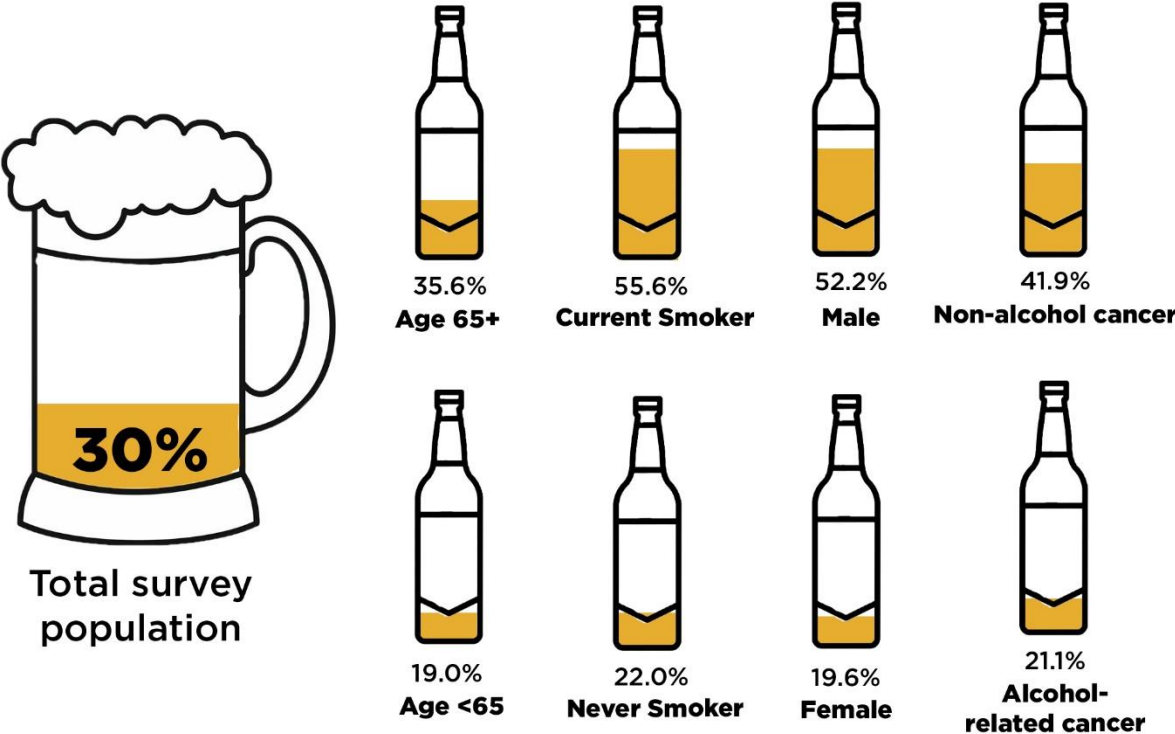
Financial Toxicity of Cancer

Greater financial burden is more common among:

- Younger and female survivors
- African American survivors
- Survivors with less than a high school diploma
- Survivors with cancers such as lung and ovarian

Alcohol Use during Chemotherapy

Higher Self Reported Alcohol Use During Chemo



Implications

- Inclusion of groups whose identities are underrepresented in prior data should be prioritized.
- Mental health and sexual health services are often underutilized in cancer survivorship, and many survivors feel discomfort. Work is needed to reduce stigma regarding these issues and increase access to these services.

Contact information

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