University of Nebraska Medical Center

Health Disparities in Cancer Survivorship

Kendra L. Ratnapradipa, PhD, MSW
UNMC Department of Epidemiology

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Disclosures

No financial disclosures.

As a young adult, I was caregiver to my mother during the 1st year of her recovery from a bone marrow transplant (leukemia). She was a cancer survivor for 17 years.

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Presentation Learning Objectives

Describe	how cancer survivorship varies by sociodemographic factors (race/ethnicity, sex, age)
Identify	potential disparities in shared-decision making
Discuss	how shared decision-making can impact survivors' quality of life

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Epidemiology of Survivorship Disparities

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Epidemiology

US, 2022 data

- Estimated 18.1 million cancer survivors (5.4% of population)
- Expected to increase nearly 24% in the next 10 years

18.1 MILLION

+7.9 Million Cancer Survivors

26.0 MILLION CANCER SURVIVORS

2022 — 2040

National Cancer Institute. *Statistics and Graphs.* https://cancercontrol.cancer.gov/ocs/statistics#stats
American Cancer Society. (2022). *Cancer Treatment & Survivorship Facts & Figures 2022-2024.*
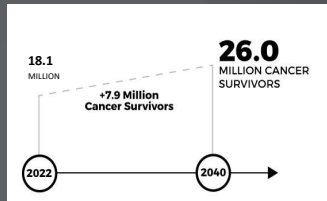
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Epidemiology
US, 2022 data

- Estimated 18.1 million cancer survivors (5.4% of population)
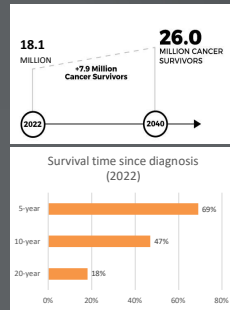- Expected to increase nearly 24% in the next 10 years

- The number of cancer survivors who live 5+ years since diagnosis is expected to increase by nearly 30% in the next 10 years

18.1 MILLION → +7.9 Million Cancer Survivors → 26.0 MILLION CANCER SURVIVORS
2022 → 2040

Survival time since diagnosis (2022)
- 5-year: 69%
- 10-year: 47%
- 20-year: 18%

National Cancer Institute. *Statistics and Graphs.* https://cancercontrol.cancer.gov/ocs/statistics#stats
American Cancer Society. (2022). *Cancer Treatment & Survivorship Facts & Figures 2022-2024.*

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Epidemiology
Survivorship Prevalence
of people still living who have ever been diagnosed with cancer

- Driven by 2 main factors
  - Incidence (new cases)
  - Mortality (deaths)

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Incidence Disparities
All cancers combined

Age-Adjusted Incidence Rates by Race/Ethnicity, All Stages (2015-2019)	Nebraska Rate	USA Rate
All Races (includes Hispanic)	469.7	449.4
White Non-Hispanic	473.7	466.6
Black Non-Hispanic	496.2	453.8
American Indian/Alaska Native Non-Hispanic	494.4	396.3
Asian/Pacific Islander Non-Hispanic	292.4	295.5
Hispanic (any race)	354.2	352.6

Age-Adjusted Incidence Rates by Sex, All Stages (2015-2019)	Nebraska Rate	USA Rate
Both Sexes	469.7	449.4
Male	510.1	488.3
Female	442.6	423.3

Age-Adjusted Incidence Rates by Age, All Stages (2015-2019)	Nebraska Rate	USA Rate
All Ages	469.7	449.4
Ages <65	238.8	228.3
Ages <50	114.9	106.5
Ages 50+	1402.8	1351.4
Ages 65+	2065.5	1977.8

https://statecancerprofiles.cancer.gov

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Epidemiology: Female breast cancer
Incidence (2014-2018)

	Non-Hispanic White	African American	American Indian/Alaska Native	Hispanic (Any Race)
United States	132.6	124.3	72.9	95.4
Nebraska	134.2	108.5	99.8	101.2

Mortality (2015-2019)

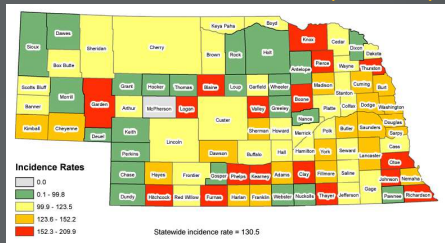|	Non-Hispanic White	African American	American Indian/Alaska Native	Hispanic (Any Race)
United States	19.9	27.1	11.8	13.7
Nebraska	20.1	30.3		5.6
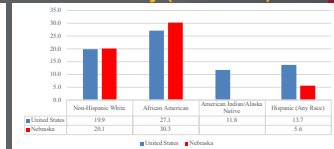
Age-adjusted to 2000 US population
Rates per 100,000 population by race/ethnicity, with African American and American Indian/Alaska Native populations including Hispanics.
Data source: NCI, State Cancer Profile.

https://go.unmc.edu/coereports
Watanabe-Galloway S, Ratnapradipa KL, Li L, Robinson T, Rohde J, Luma LL, Carritt N, Zhang X, Liu Y, Wang X, Napit K, Ranta, J. Cancer Burden in Nebraska (2022). University of Nebraska Medical Center.

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Female Breast Cancer Incidence (2014-2018)

Incidence Rates
- 0.0
- 0.1 - 99.8
- 99.9 - 123.5
- 123.6 - 152.2
- 152.3 - 209.9

Statewide incidence rate = 130.5

Age-adjusted to 2000 US standard population
Rates per 100,000 population by county.
Data source: Nebraska Dept. of Health & Human Services.

https://go.unmc.edu/coereports
Watanabe-Galloway S, Ratnapradipa KL, Li L, Robinson T, Rohde J, Luma LL, Carritt N, Zhang X, Liu Y, Wang X, Napit K, Ranta, J. Cancer Burden in Nebraska (2022). University of Nebraska Medical Center.

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Understanding Task Force Draft Recommendations

Are the differences due to screening?

USPSTF. https://www.uspreventiveservicestaskforce.org
American Cancer Society. https://www.cancer.org

Differences are not (all) due to screening
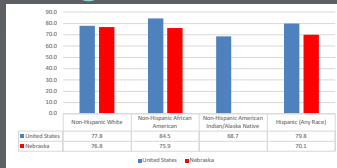
Proportion of women ages 50–74 who reported having a mammogram in the last two years, by race/ethnicity: Nebraska and the United States, 2020
Nebraska data for the American Indian/Alaska Native population are suppressed.
Data source: CDC BRFSS
https://go.unmc.edu/coereports
Watanabe-Galloway S, Ratnapradipa KL, Li L, Robinson T, Rohde J, Luma LL, Carritt N, Zhang X, Liu Y, Wang X, Napit K, Ranta, J. Cancer Burden in Nebraska (2022). University of Nebraska Medical Center.

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What factors impact disparities in survival?

Cancer
- Site (& sub-type)
- Stage at diagnosis (how far it has spread)

Person
- Age
- Sex
- Race/ethnicity
- Genetics
- Health behaviors
- Healthcare utilization patterns

Resources
- Urbanicity (where you live)
- Insurance status

Treatment options

Hospital/Provider

Screening

Comorbidities

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Shared Decision Making

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Shared Decision Making

"Shared decision making occurs when a health care provider and a patient work together to make a health care decision that is best for the patient. The optimal decision takes into account evidence-based information about available options, the provider's knowledge and experience, and the patient's values and preferences."

Agency for Healthcare Research and Quality. *The SHARE Approach: A Model for Shared Decision Making.* (2014). Fact sheet. https://www.ahrq.gov/health-literacy/professional-training/shared-decision/index.html

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https://www.ahrq.gov/health-literacy/professional-training/shared-decision/index.html
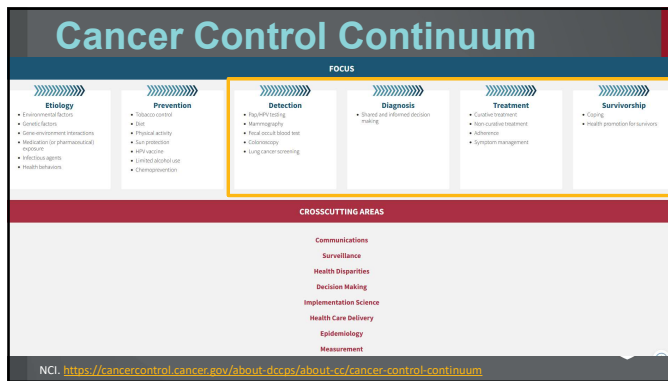
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Listening Session Results

https://go.unmc.edu/coereports
Ratnapradipa KL, Napit K, Watanabe-Galloway S. (2022). *Nebraska Cancer Community Health Needs Assessment: Listening Sessions Summary Report.* Omaha, NE: University of Nebraska Medical Center.

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Cancer Control Continuum

FOCUS

Etiology	Prevention	Detection	Diagnosis	Treatment	Survivorship
• Environmental factors • Genetic factors • Gene-environment interactions • Medication (or pharmaceutical) exposure • Infectious agents • Health behaviors	• Tobacco control • Diet • Physical activity • Sun protection • HPV vaccine • Limited alcohol use • Chemoprevention	• Pap/HPV testing • Mammography • Fecal occult blood test • Colonoscopy • Lung cancer screening	• Shared and informed decision making	• Curative treatment • Non-curative treatment • Adherence • Symptom management	• Coping • Health promotion for survivors

CROSSCUTTING AREAS

Communications
Surveillance
Health Disparities
Decision Making
Implementation Science
Health Care Delivery
Epidemiology
Measurement

NCI. https://cancercontrol.cancer.gov/about-dccps/about-cc/cancer-control-continuum

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Were concerns taken seriously?

- Some participants related experiences where they noticed a lump or ball, pain, or other concerning symptoms. When they told their doctor about the symptoms, they were not immediately referred for follow-up. This led to delayed diagnosis and a more advanced stage of the disease. (mentioned in multiple groups)

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Patient-Provider Communication

How to contact provider	"The problem was just communication. I just could not get nobody to communicate with me." (Native American)
How information is presented	"Words have power and you can't just tell me I've only got three years to live." (African American)

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Patient-Provider Communication

Treated rudely
- Surgeon's explanation to patient was overwhelming & surgeon "had no desire to listen to what I was telling him, and I did not have a good experience with my surgeon" who "thought he knew it all…was just really rude" and downplayed mastectomy saying "It is just a breast…it's no big deal." (Rural)
- Oncologist "called me a crybaby. He yelled at my husband in the office." (Rural)

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Patient-Provider Communication

- Not allowed to ask questions
  - Doctor made assumptions about what patient already knew; patient not given enough information (Rural)
- Not listened to
  - Wished there was a way to "talk to doctors and just tell them what it feels like, especially that first diagnosis. I don't think they always realize how traumatic it is." (Rural)
  - "I didn't feel like [local providers] listened and I didn't feel like they heard us as a family." (African American)

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Patient-Provider Communication

In contrast
- participants had positive experiences when their providers used easy-to-understand language, allowed questions, and shared decision-making with the patients and caregivers.
  - "They were really good at answering [questions]." (Native American, with similar sentiments shared across groups)
  - "Kept us all involved and never rushed those kinds of things" (Rural)
  - Choice of local vs radical surgery with discussion of side effects (African American)

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Patient-Provider Communication

Language barriers

- Medical terminology can be very confusing, even for native English speakers.
- Even some Hispanic participants who considered themselves to be bilingual had difficulty with the medical terminology.
  - The patient recorded everything because although she is bilingual, "cancer" was confusing and sometimes she misunderstood what the doctor said so she wanted to be able to relisten to the conversation. (Hispanic)

"You don't know how many times patients don't really understand what they're communicating and you have to interrupt and say, 'That's not what the doctor said.' You're not telling the patient what the doctor is really communicating-- he's communicating. You have to intervene on behalf of those people." (Hispanic)

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Patient-Provider Communication

Language barriers

- Wide variety of languages and dialects spoken within Hispanic communities
- Formal interpreter services are not always offered to those who need them
  - Relying on children to translate in medical settings
  - Community members informally translate for each other

They didn't tell us in front of my husband. The doctor told me and, and my son was translating for me. And my, my boy was little…And then he says, "Mom, uh, the doctor says my dad has cancer." I swear to you, I looked at it like any disease, I was so closed that, what cancer? I mean, what is cancer? And, and then I say, "My God, how could I--?" I mean, I looked at it like anything. I said to my son, "Oh, does he have cancer?" And my son, "Yes." When the doctor left, my son told me - my son so young, he says to me, "Do you know what cancer is, mom? And I say:" Hmm, no." And he says, "That my dad can die." (Hispanic)

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Shared Decision Making Impacts Quality of Life

- Some participants lacked understanding about the long-term nature of treatment side-effects. They thought that they could "bounce back to normal" (African American) but instead had a very gradual recovery.
  - This suggests that additional patient education and survivorship counseling may be needed.
  - "She would have a reaction to a medicine, and we didn't… know what it was because so much happened that day" during different treatments. (African American)
- "Had no side effects" (Rural)
- Surgery scar "virtually disappeared" & no need for medication (African American)

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