

Barriers to Accessing Care for Emotional and Mental Health Concerns Among Individuals with Cancer

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Cancer Experience Registry

An online research study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify unmet needs among patients, survivors, and caregivers.

CER Study Design

Cancer Experience Registry – Longitudinal Design

Baseline

6 month

12 month

18 month

24 month

Spotlight Survey

Spotlight Survey

Disclosures



Dr. Miller:

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Dr. Zaleta:

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Dr. Rogers, Ms. Doughtie, Dr. Morris:

No disclosures

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Background

Emotional and Mental Health Concerns



Emotional and mental health concerns among cancer patients are common.



Despite screening and referring patients for mental health support and treatment, many patients **do not access it**.



Access to care depends on **awareness, availability, accessibility, accommodation, affordability, and acceptability**.



A **lack of any of these** can lead to a lack of access to care.

Aims

Barriers to Mental Health Care



To conduct a Spotlight Survey investigating the experience of care for emotional and mental health concerns among a community-based sample of adult cancer patients and survivors, living in the United States

1. Assess prevalence of unmet need as it relates to receiving health care for emotional and mental health concerns since cancer diagnosis
2. Measure barriers to accessing mental health care
3. Quantify relative magnitude of barriers among cancer patients and survivors who do and do not access mental health care

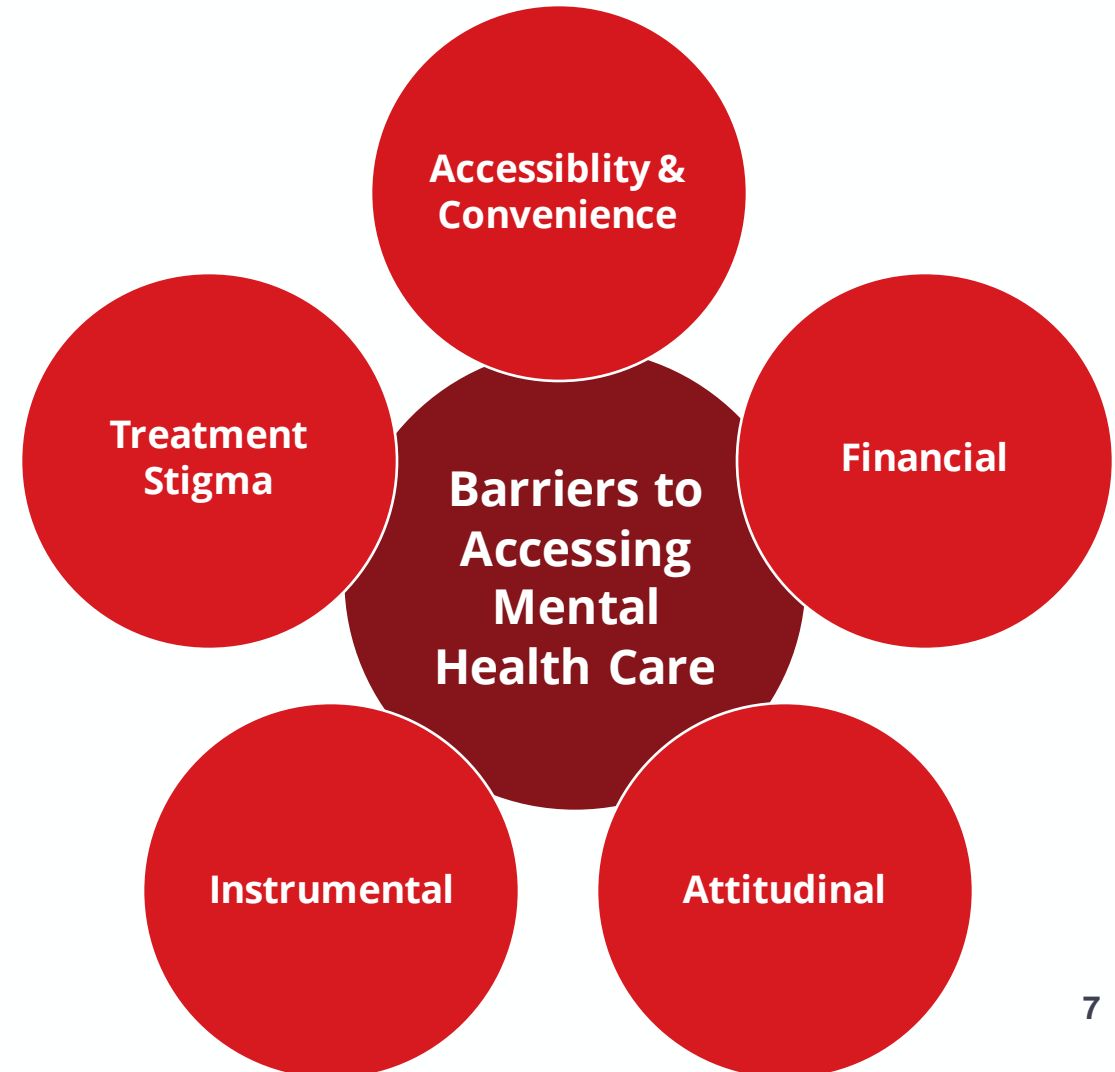
Methods

Observational, cross-sectional study

The sample included **658 individuals with cancer who self-reported an emotional or mental health concern since cancer diagnosis.**

Barriers were assessed using subscales of the Patient Satisfaction Questionnaire-Short Form and Barriers to Access to Care Evaluation scale.

Group means (Sought/Wanted + Did vs. Did Not Receive Care) were compared using ANOVA. Cohen's *d* effect sizes were reported.

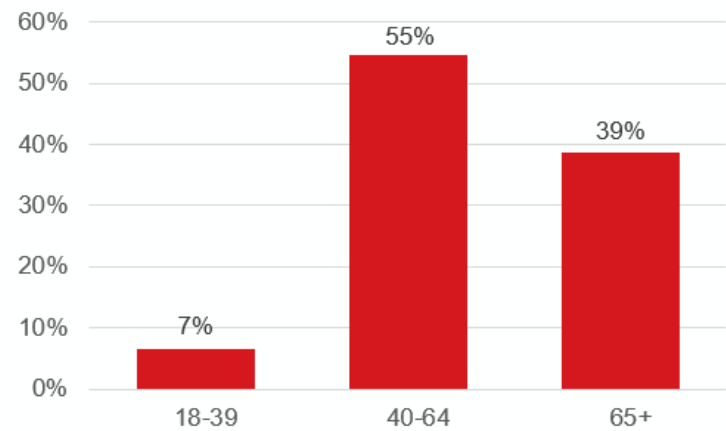


Results

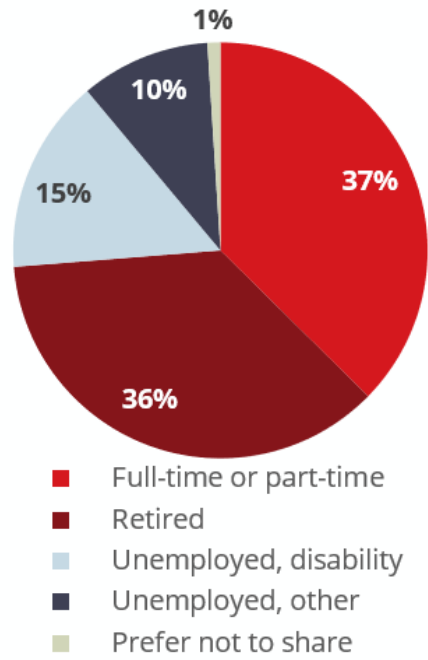
Who Took Part

- 85% Non-Hispanic White, 6% NH Black, 3% Hispanic
- 77% Women, 22% Men

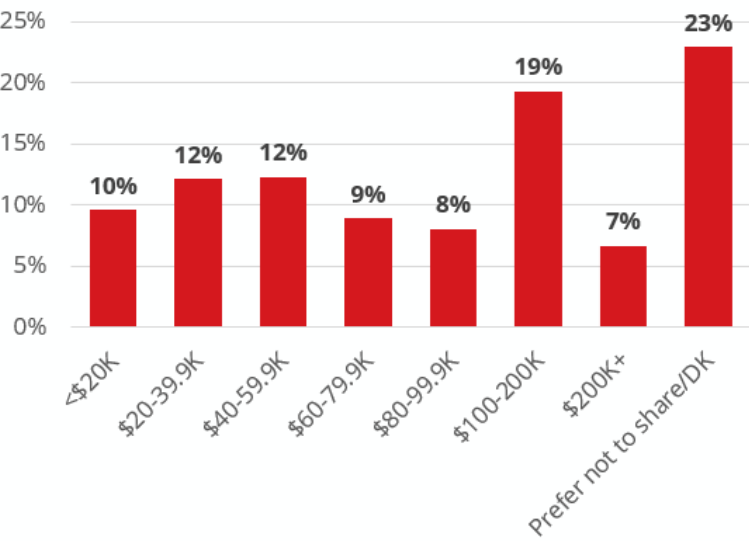
➤ Age



➤ Employment Status



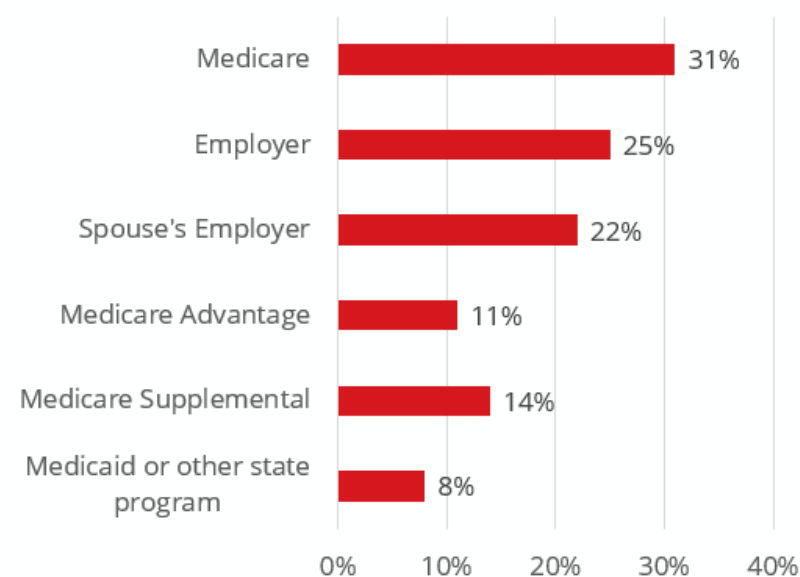
➤ Annual Household Income



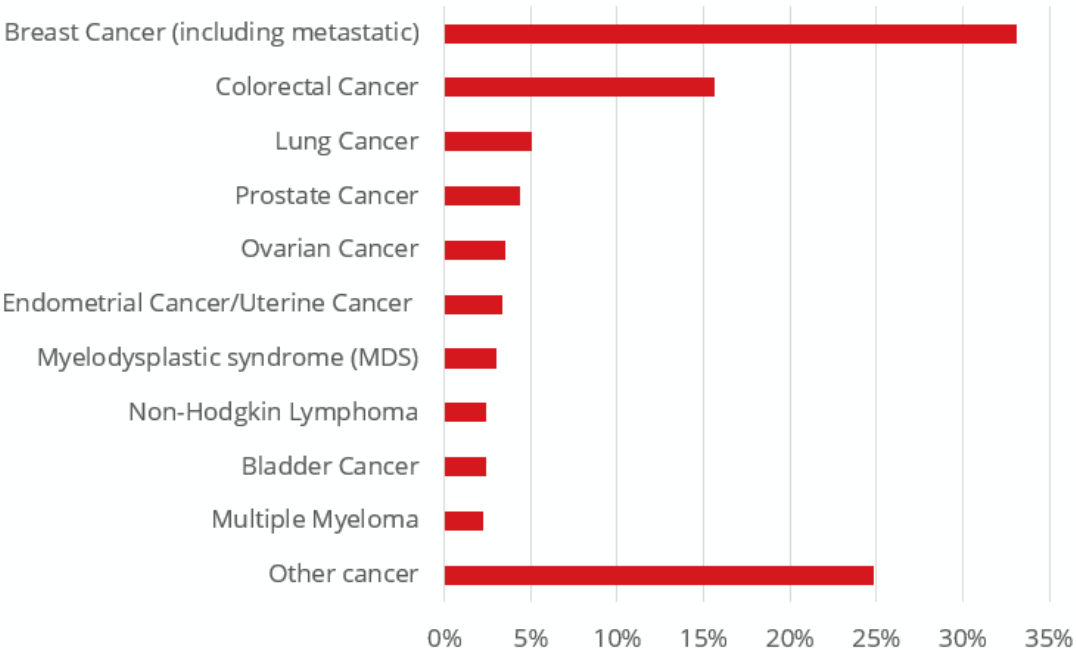
Who Took Part

- Median Years Since Diagnosis = 4 (Range: <1 to 22)
- 60% Remission, 16% Metastatic, 14% Localized

➤ Insurance Type

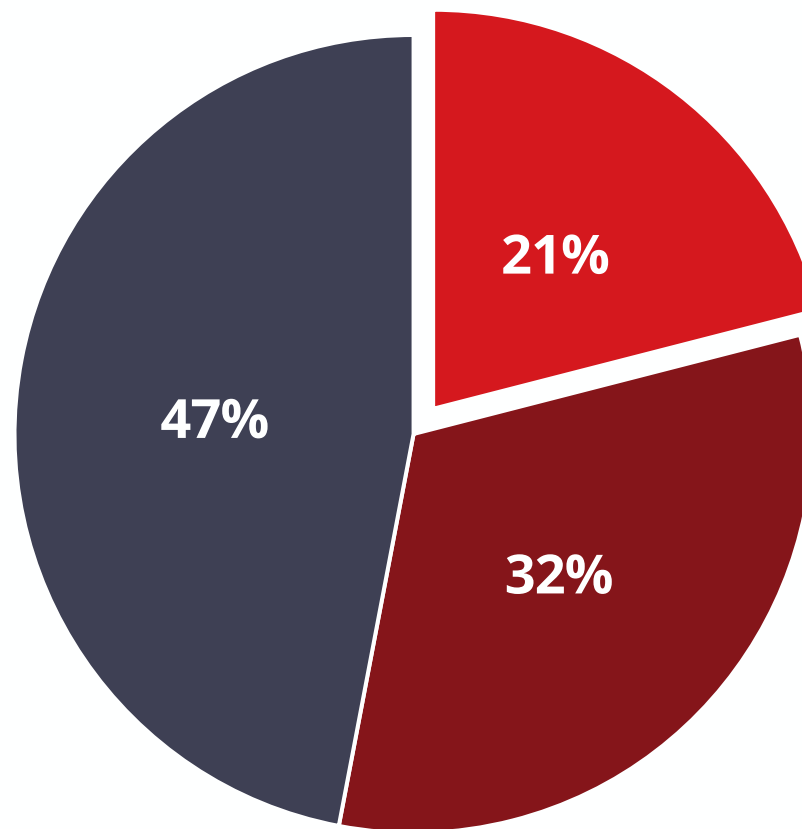


➤ Cancer Diagnosis



Many Patients Not Receiving Wanted Care

1 in 5 respondents sought or wanted but did NOT receive care for an emotional or mental health concern

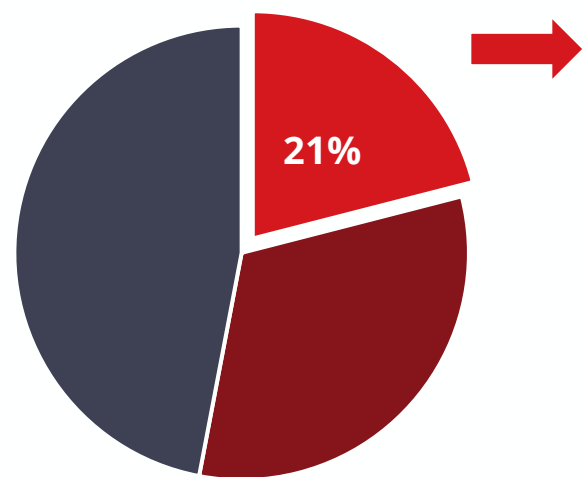


- Sought/Wanted; Did NOT receive care
- Sought/Wanted; DID receive care
- Didn't Seek/Want Care

40% who wanted mental health care did NOT receive it



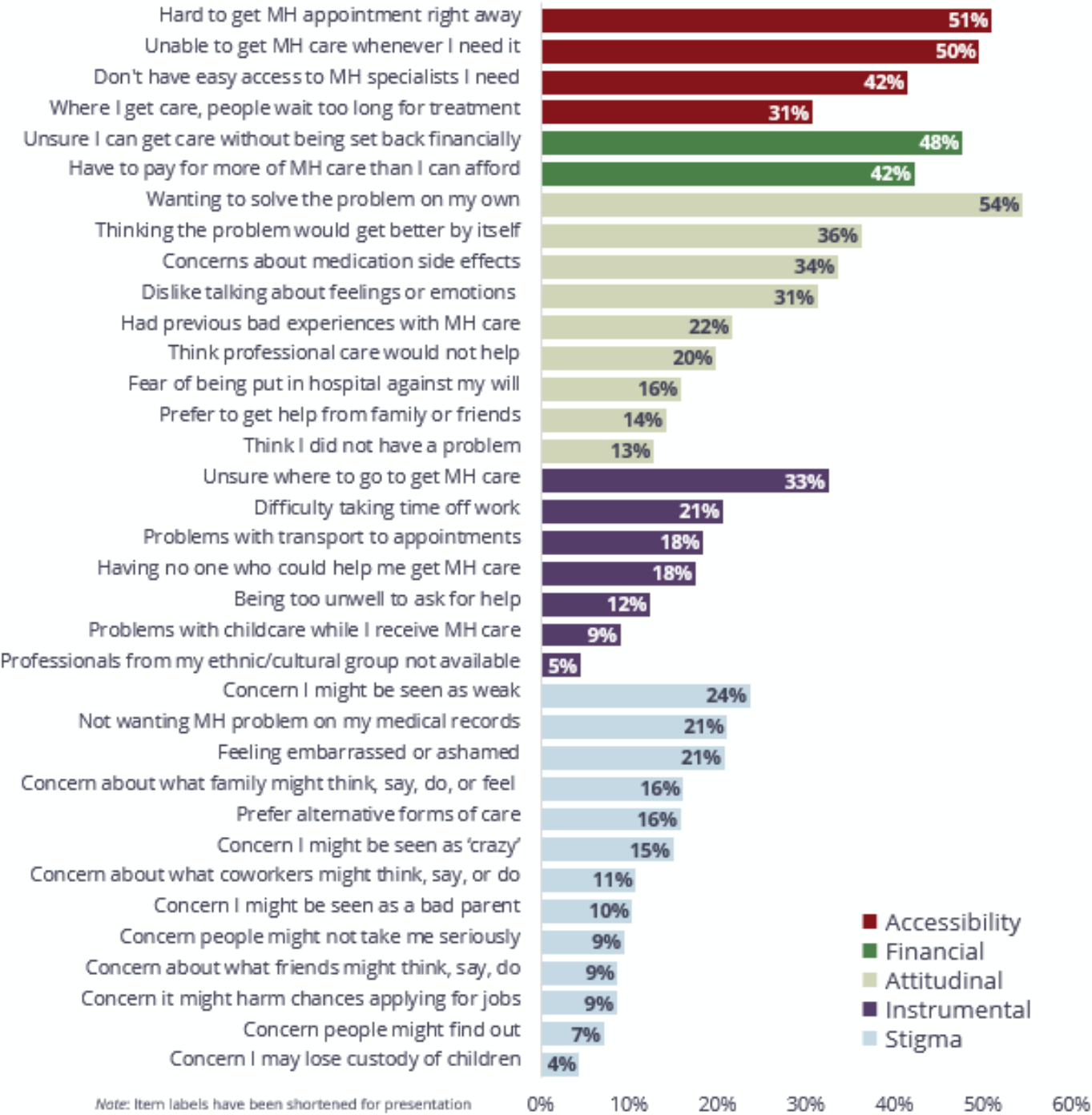
Barriers to Mental Health Care



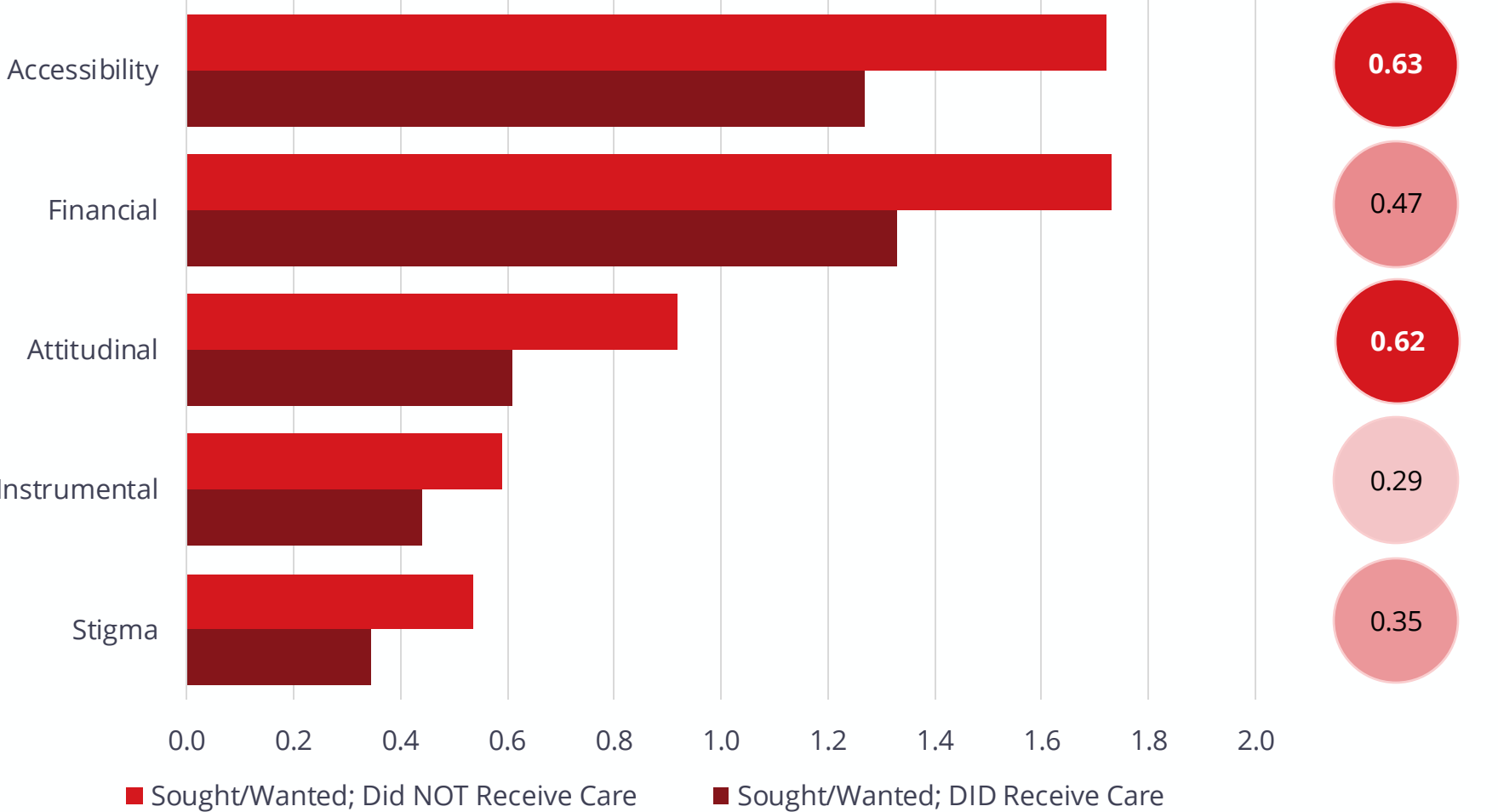
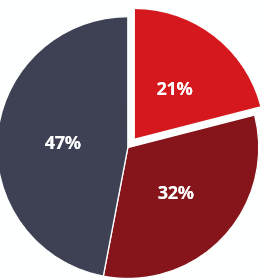
■ Sought/Wanted; did NOT receive care

Systems- and individual-factors are among common barriers reported.

n = 138



Patients Face Significant Mental Health Barriers



All p 's<.05

What Patients Say



What do you think are the main barriers?

“Lack of availability of mental health professionals who deal with cancer or chronic illness, cost because some specialists don’t take insurance, and limited availability because of so many people seeking help since the **pandemic**.”

“Probably **financial issues**. It is very expensive to have cancer and then the price of mental health care is through the roof. It is a shame that what people really need is cost prohibitive.”

“I think that cancer patients are **overwhelmed** with receiving their diagnosis, having concerns over survival, the stress of scheduling appointments (especially if working and have families), and financial concerns since a cancer diagnosis stresses families with overwhelming medical bills including fear of loss of employment and health insurance. **It’s also not one of the main questions discussed with your care team during treatment.**”

What Patients Say



What would you want other patients to know?

"Advocate for yourself! You can get help, but you have to ask and sometimes keep asking. There will be ups and downs regardless of mental health treatment, but **you don't have to do it alone.**"

"That they are not alone. Sometimes **hearing that other cancer patients experience the same thing** helps. Finding other cancer patients who have the same diagnosis helps tremendously. I also believe **seeking out a therapist** is a good thing to do...Therapy doesn't have to be a lifetime thing and medications aren't mandatory, but they help. You don't have to take them for life either."

Cancer & Mental Health

Conclusions and Implications



Our findings highlight persisting unmet needs and barriers to accessing care for emotional and mental health concerns among individuals with cancer.

Policies are needed to remove persistent access and financial barriers to mental health support.

Healthcare systems can support mental health needs through distress screenings with patients and thoughtful engagement and training of healthcare providers.

Thank you

CancerSupportCommunity.org/Registry

