



Memorial Sloan Kettering
Cancer Center



Implementation and Effects of a Cancer Caregiver Distress Screening and Targeted Referral and Consultation Program

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Disclosures

Dr. Miller:

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Dr. Zaleta:

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Dr. Applebaum:

Bluenote Therapeutics
Beigene

Cancer Caregivers

Distress Screening and Referral



Cancer Support Community developed **CancerSupportSource™-Caregiver** (CSS-Caregiver) distress screening, referral, and support program

The goal of CSS-Caregiver is to **rapidly identify and respond to unmet caregiver need**, thereby better enabling the caregiver to navigate care and treatment, practice self-care, and provide support for the unique needs of the patient.

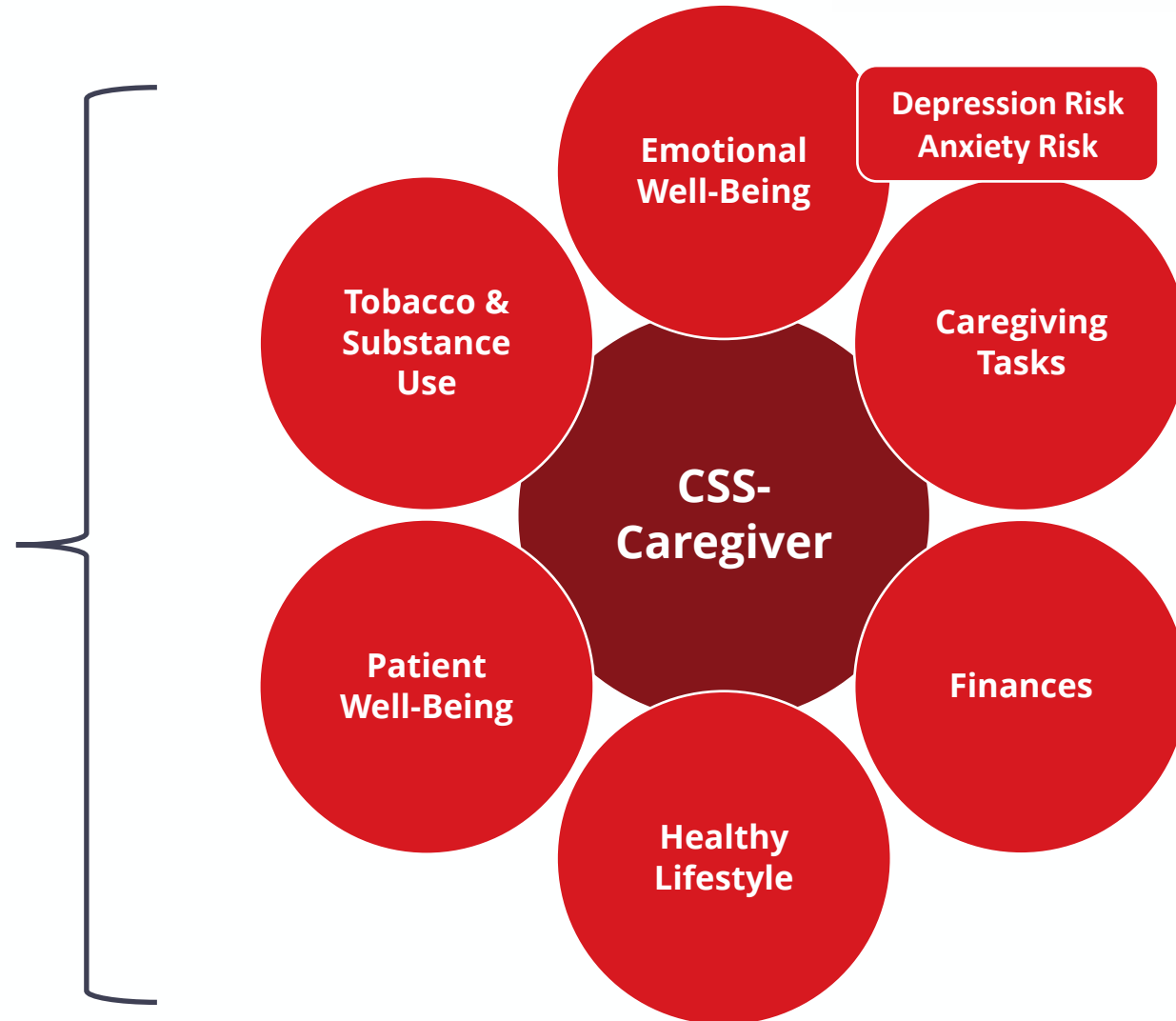


CancerSupportSource-Caregiver **screens for:**

Caregiver concerns
across key areas
of life

Desired support and
resource needs

Risk for
clinically significant
depression and anxiety



CancerSupportSource-Caregiver

Factors and Items



ITEM	FACTOR
"First, we want to understand your concerns about the PATIENT"	
The patient's eating and nutrition	Patient Well-Being
Changes in the patient's mood or behavior	
Changes in the patient's memory or thinking	
The patient's pain or physical discomfort	
"Next, we want to understand your concerns about YOURSELF"	
Eating and nutrition	Healthy Lifestyle
Exercising and being physically active	
Keeping up with your health care needs	
Providing transportation to treatment and appointments	Caregiving Tasks
Making treatment decisions	
Coordinating medical care for the patient	
Providing physical or medical care to the patient	
Managing household finances	Finances
Managing health insurance and medical bills	
Changes or disruptions in work, school, or home life	Emotional Well-Being
Feeling sad or depressed*	
Feeling nervous or afraid**	
Worrying about the future and what lies ahead**	
Feeling lonely or isolated*	
Tobacco, alcohol, or other substance use [†]	Tobacco or Substance Use

(Zaleta, Miller, et al, 2023)

Note: * = 2-item depression risk; ** = 2-item anxiety risk; [†] Optional item (recommended)

How It Works

Caregiver Distress Screening and Referral



Caregiver
Completes
Screener



Caregiver
Customized
Resource Report



Automated
Staff
Report



Automated
At-Risk
Flags



Referral and
Follow-Up



How It Works

Caregiver Completes Screener & Chooses Desired Support



The tablet screen shows a web browser with the URL <https://samplehospital.mycarereport.com/patient/patient-survey-qa-site/113654>. The page header includes the 'Sample Hospital' logo and a progress bar at 3/31. The main content area asks, 'Today, how CONCERNED are you about... Feeling sad or depressed'. Below this question are five radio button options: 'Not at all', 'Slightly', 'Moderately' (which is selected and highlighted in green), 'Seriously', and 'Very Seriously'. A second section asks, 'Feeling sad or depressed: please let us know how we can help you.', followed by three unchecked checkboxes: 'Have a staff person talk with you', 'Provide you additional information', and 'No action needed'. A 'Next →' button is located at the bottom right of the form. A footer at the bottom of the screen reads '© 2022 Patient Planning Services, Inc., a Cancer Support Community company.'

How It Works

Caregiver Receives Customized Resource Report



Caregiver Screener

Thank you for completing your CancerSupportSource® Questionnaire. This report was created for you based on how you answered the questions. It is a guide to finding the information and services that could be most useful to you right now. Please review the helpful tips, print and online materials provided in this report. A staff person will be happy to go over this report with you and help you find more resources.

Name: peyton SAMPLE

Date of Birth: 01/01/1990

Date of Survey: 01/10/2022



CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

Patient Well-Being

As a caregiver, you may be the first to notice changes in your loved one's eating habits, mood, behavior, or memory. Their medical team may ask you to look out for these changes, or other symptoms like physical discomfort and pain. You noted that you would like more information on the following topics.



Here are some related online resources that you may want to check:

Changes in the patient's mood or behavior

https://files.mycarereport2.com/22Caregiver_Changes_in_your_loved_ones_mood_or_behavior.pdf



Here are some related online resources that you may want to check:

Changes in the patient's memory or thinking

https://files.mycarereport2.com/22Caregiver_Changes_in_Your_Loved_Ones_Memory.pdf



Here are some related online resources that you may want to check:

The patient's pain or physical discomfort


https://files.mycarereport2.com/22Caregiver_Concerns_about_a_loved_ones_pain_or_discomfort.pdf

Healthy Lifestyle

Caring for someone with cancer can change your daily life. The demands of caregiving can make it hard for you to have a healthy lifestyle. You may not have the time, resources, or ability to do things like exercising regularly or making home cooked meals. You may even find that you are missing your own doctor's appointments. You have requested the following resources to support your own health and well-being.

How It Works

Staff Receive Automated Report with At-Risk Flags



Caregiver Screener

Name: peyton SAMPLE
Date of Birth: 01/01/1990
Date of Screening: 01/07/2022

Risk for Depression: YES
Risk of Anxiety: YES

Survey Results

Key	Concern	Screening 01/07/22	Action Required
	The patient's eating and nutrition	1. Slightly	Information
	Changes in the patient's mood or behavior	2. Moderately	Information
	Changes in the patient's memory or thinking	1. Slightly	Information
	The patient's pain or physical discomfort	2. Moderately	Information
	Eating and nutrition	1. Slightly	Information
	Exercising and being physically active	3. Seriously	Information
	Keeping up with your health care needs	2. Moderately	Information
	Providing transportation to treatment and appointments	2. Moderately	Information
	Making treatment decisions	2. Moderately	Information
	Coordinating medical care for the patient	1. Slightly	Information
	Providing physical or medical care to the patient	3. Seriously	Information
	Managing household finances	3. Seriously	Information
	Managing health insurance and medical bills	1. Slightly	Information
	Changes or disruptions in work, school, or home life	2. Moderately	Information
	Feeling sad or depressed	3. Seriously	Information
	Feeling nervous or afraid	3. Seriously	Information
	Worrying about the future and what lies ahead	2. Moderately	Information
	Feeling lonely or isolated	3. Seriously	Information
	Tobacco, alcohol, or other substance use	3. Seriously	Information

Patient Well-Being

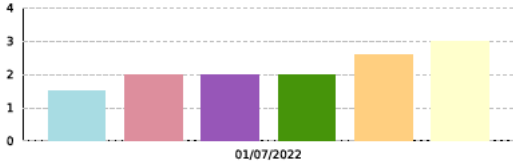
Healthy Lifestyle

Caregiving Tasks

Finances

Emotional Well-Being

Tobacco, Alcohol, or other Substance use





How It Works

Staff Facilitate Referrals and Follow-Up



Review Referrals

Making a treatment decision

Status: In progress

Patient:	peyton SAMPLE	Referral date:	12/13/2022
Form name:			
Doctor:		Email:	peytonyopmail@yopmail.com
MRN:	-	Mobile phone:	
Birthdate:	01/01/1990		
Support assigned:	Test MYCARE		

Status History Update

Date	Reminder Date	Notes	User
12/13/2022 14:13 PM	-	Add detailed case notes here.	Peyton LENGACHER
12/13/2022 14:12 PM	-	Assigned by Peyton LENGACHER	Test MYCARE

How It Works

Automated Report Tracks Referrals History and Status



My Support Care Plan

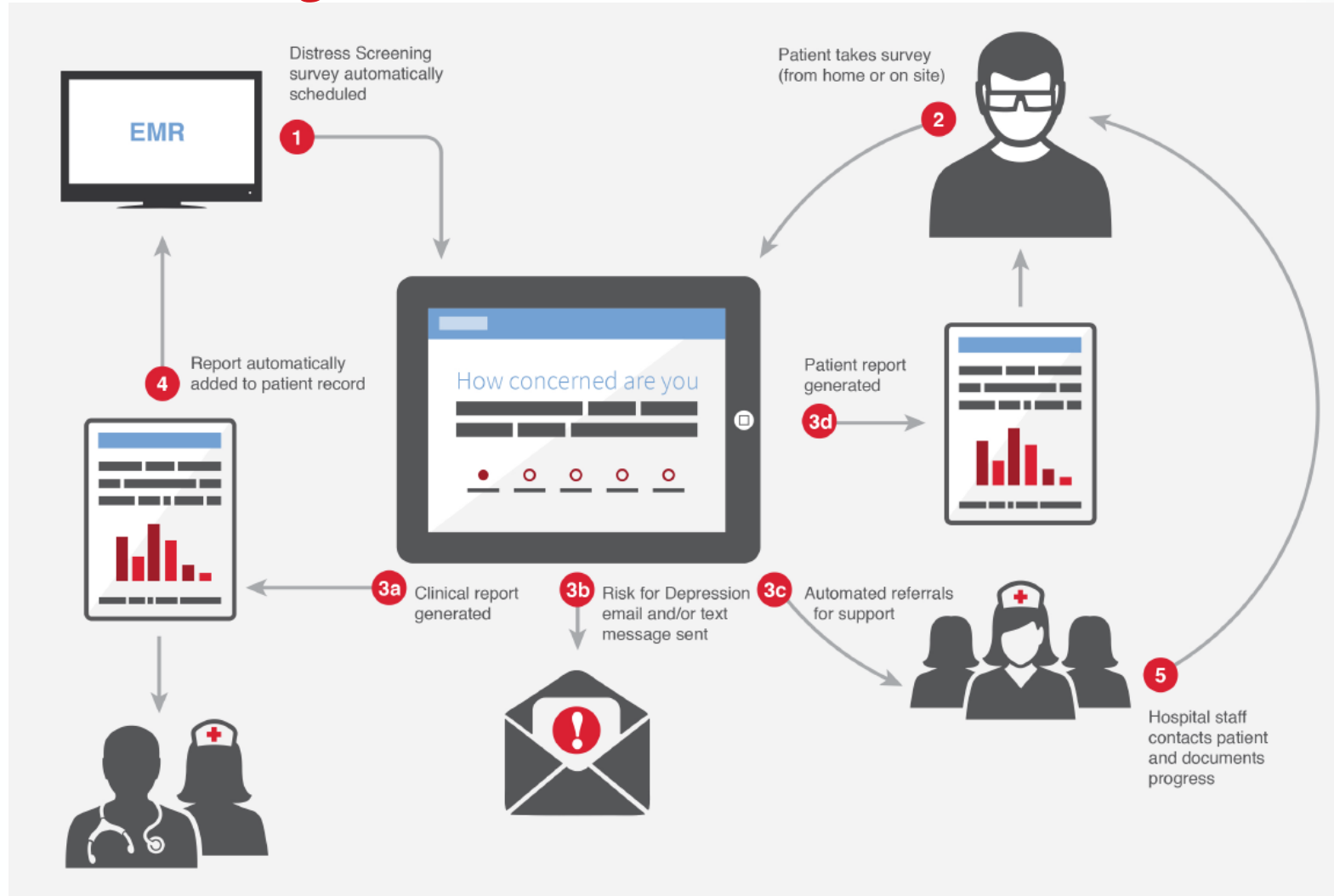
Name peyton SAMPLE (Male)
Date of Birth: 01/01/1990
Date of Screening: 12/13/2022
Distress score: 31/76

Referrals History

Date	Referral	Assigned To	Status	History
12/13/22	Sleep problems	Test MYCARE	Resolved	<ul style="list-style-type: none">- Assigned by Peyton LENGACHER- Add detailed case notes here.- Referral closed by Peyton LENGACHER:
12/13/22	Making a treatment decision	Test MYCARE	In progress	<ul style="list-style-type: none">- Assigned by Peyton LENGACHER- Add detailed case notes here.
12/13/22	Worrying about family, children and/or friends	Test MYCARE	In progress	<ul style="list-style-type: none">- Assigned by Peyton LENGACHER- Add detailed case notes here.
12/13/22	Risk for depression	Test MYCARE	In progress	<ul style="list-style-type: none">- Assigned by Peyton LENGACHER- Add detailed case notes here.

How It Works

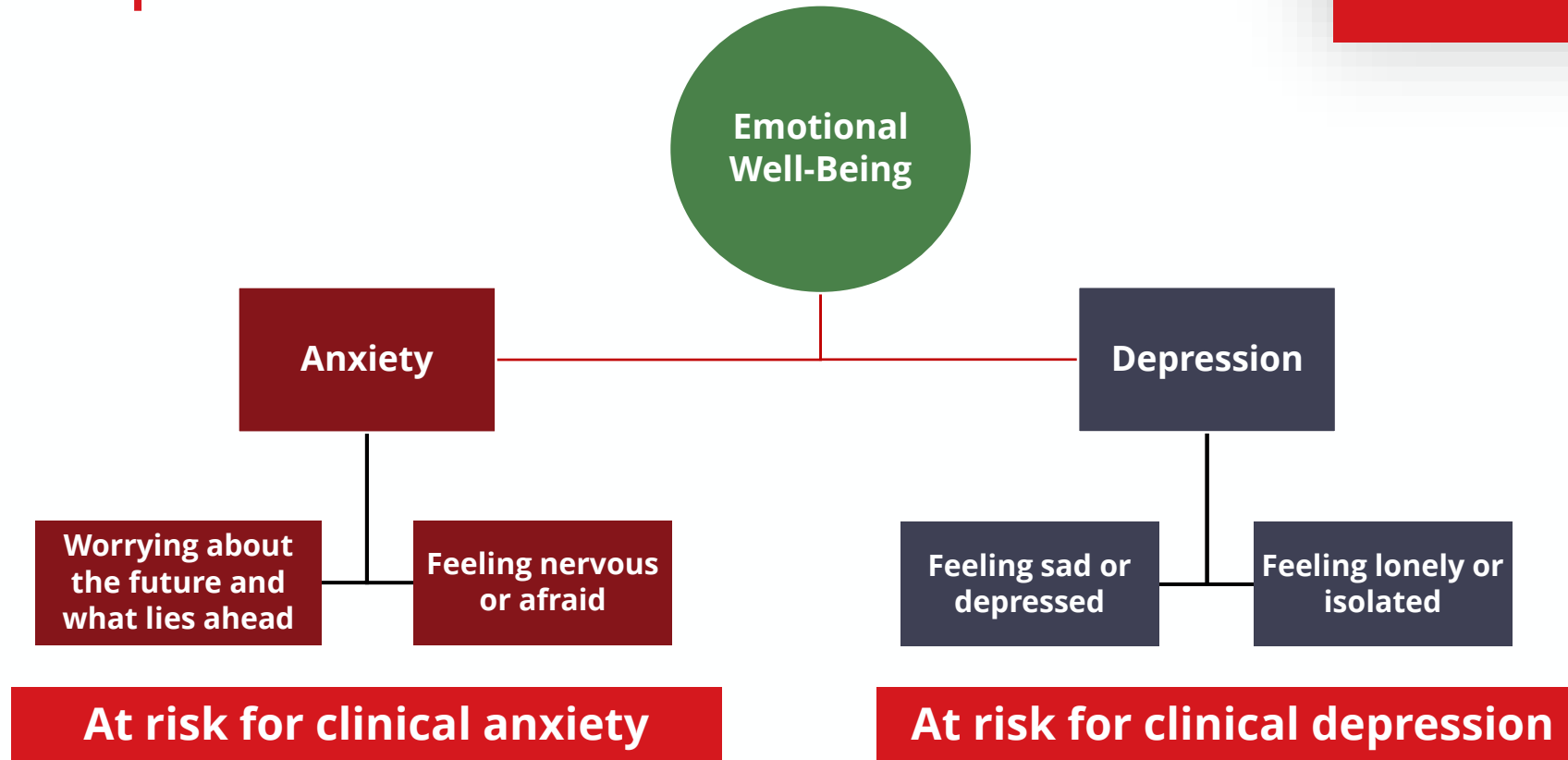
Optional EMR Integration



Distress Screening Process with EMR Integration

CancerSupportSource-Caregiver

Anxiety and Depression Risk Subscales



Flags are triggered for respondents who exceed risk cut-off scores

The 2-item depression and 2-item anxiety risk scales demonstrated **high sensitivity (.87-.95) and adequate specificity (.63-.68)** compared to PHQ-2, GAD-2, PROMIS-Depression 4a, and PROMIS-Anxiety 4a



Initial Screener Development and Testing

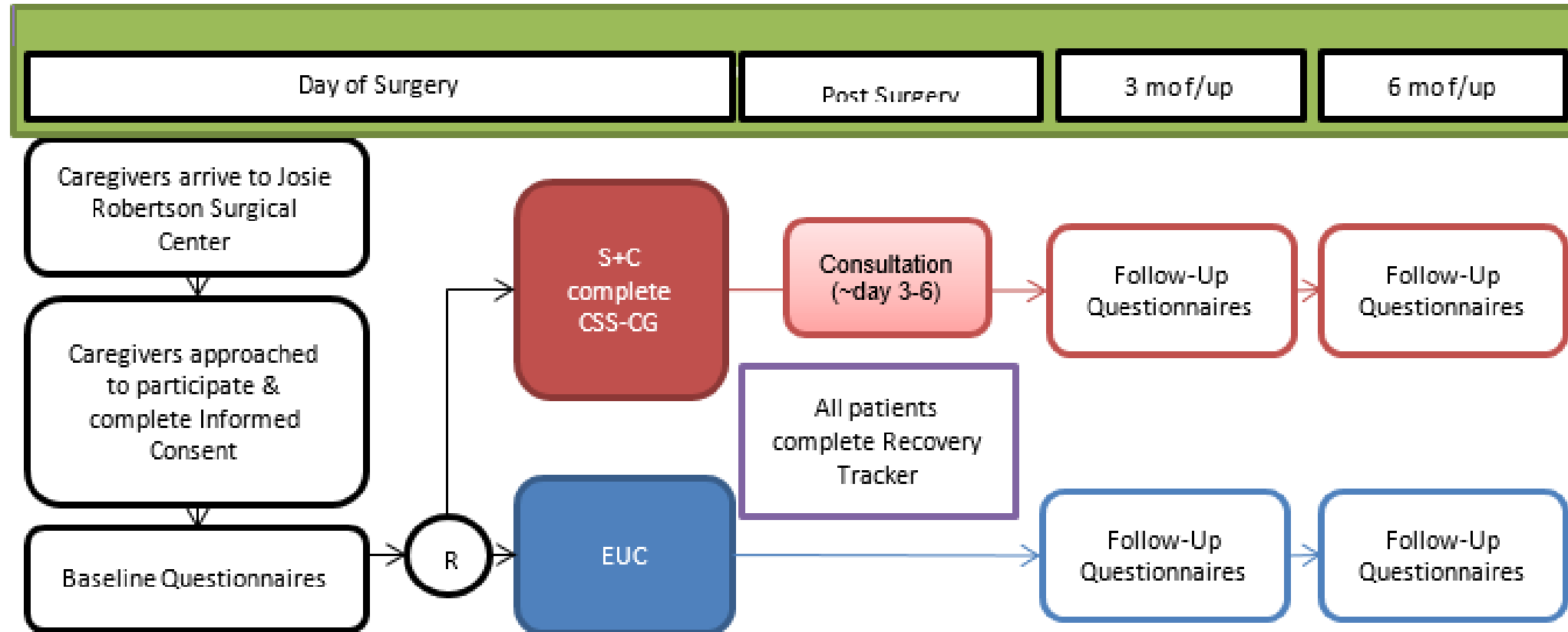
Longacre, M. L., Applebaum, A. J., Buzaglo, J. S., Miller, M. F., Golant, M., Rowland, J. H., Given, B., Dockham, B., & Northouse, L. (2018). Reducing informal caregiver burden in cancer: Evidence-based programs in practice. *Translational Behavioral Medicine*, 8(2), 145-155, doi: 10.1093/tbm/ibx028

Feasibility and Acceptability

Shaffer, K. M., Benvengo, S., Zaleta, A. K., Levine, M., Bellantoni, C., Dannaoui, A., Buzaglo, J. S., & Applebaum, A. J. (2019). Feasibility and acceptability of distress screening for family caregivers at a cancer surgery center. *Oncology Nursing Forum*, 26(2), 159-169. <https://doi.org/10.1188/19.ONF.159-169>

Refining and Validating the Final Screener

Zaleta, A. K., Miller, M. F., Fortune, E. E., Olson, J. S., Rogers, K. P., Hendershot, K., & Ash-Lee, S. (2023). CancerSupportSource™ -Caregiver: Development of a distress screening measure for cancer caregivers. *Psycho-oncology*, 10.1002/pon.6092. Advance online publication. <https://doi.org/10.1002/pon.6092>

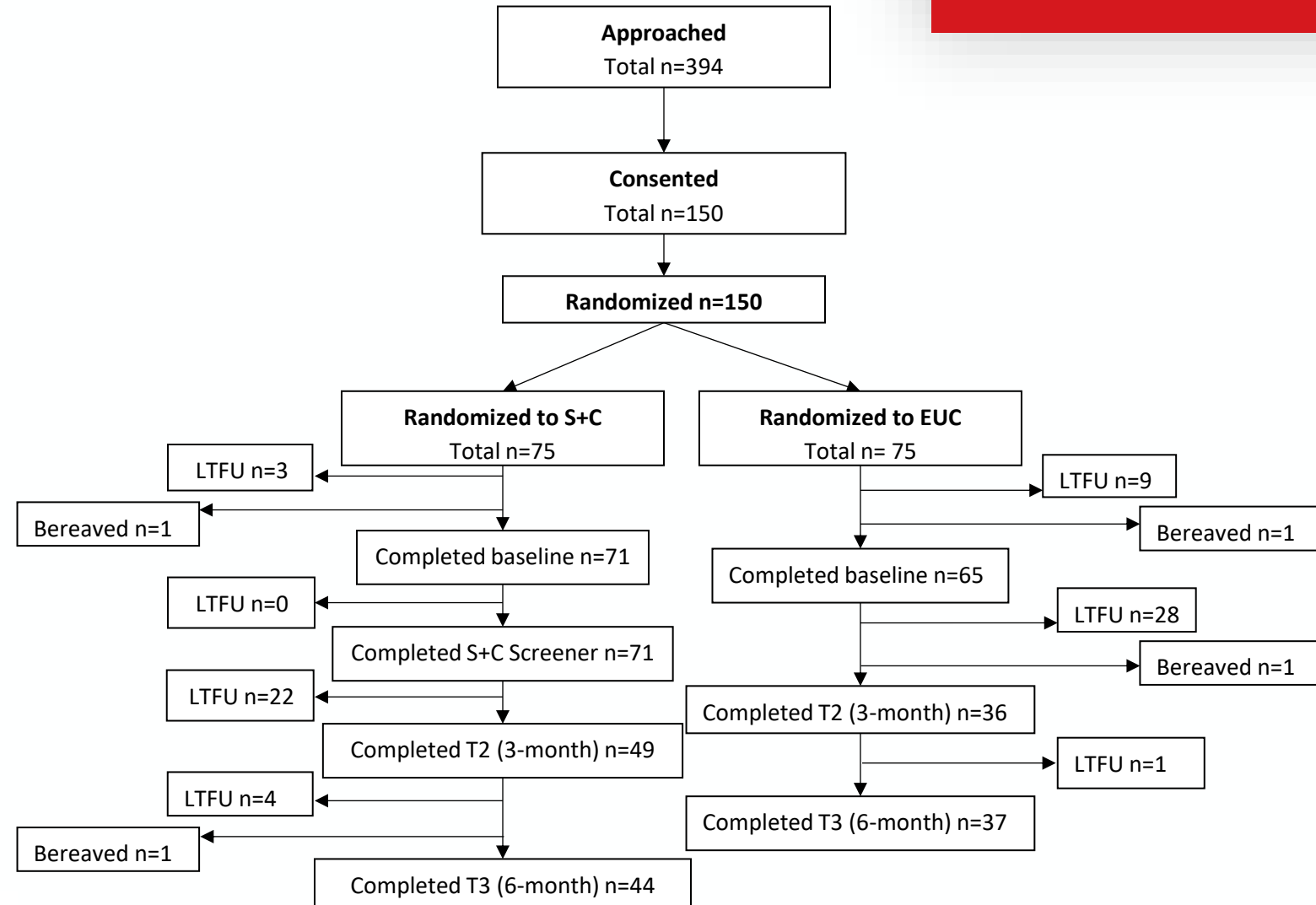


R= Randomization; mo f/u= month follow-up; S+C= Screening + Consultation; CSS-CG= CancerSupportSource-Caregiver distress screening tool; EUC= Enhanced Usual Care.



Record ID	3
Date Called Completed:	<div><div><div>H</div><div></div></div><div><div>31</div><div>Today</div><div>M-D-Y</div></div></div>
Person Completing the Call:	<div><div><div>H</div><div></div></div><div></div></div>
Contact Attempt #1	<div><div><div>H</div><div></div></div><div>Please indicate date & time of call as well as whether you left a voicemail or other notes.</div></div>
Contact Attempt #2	<div><div><div>H</div><div></div></div><div>Please indicate date & time of call as well as whether you left a voicemail or other notes.</div></div>
Contact Attempt #3	<div><div><div>H</div><div></div></div><div>Please indicate date & time of call as well as whether you left a voicemail or other notes.</div></div>
Did you review the support care report with the caregiver?	<div><div><div>H</div><div></div></div><div><div><input type="radio"/> Yes</div><div><input type="radio"/> No</div></div><div>reset</div></div>
Were there any changes in distress?	<div><div><div>H</div><div></div></div><div><div><input type="radio"/> Yes</div><div><input type="radio"/> No</div></div><div>reset</div></div>
Did you have to modify (add, remove, or change) referrals?	<div><div><div>H</div><div></div></div><div><div><input type="radio"/> Yes</div><div><input type="radio"/> No</div></div><div>reset</div></div>
Did you identify any barriers the caregiver has to access requested referrals?	<div><div><div>H</div><div></div></div><div><div><input type="radio"/> Yes</div><div><input type="radio"/> No</div></div><div>reset</div></div>
Outcome of Call:	<div><div><div>H</div><div></div></div><div><div><input type="radio"/> Complete</div><div><input type="radio"/> Lost to follow up</div><div><input type="radio"/> Other</div></div><div>reset</div></div>
Any additional information from the call?	<div><div><div>H</div><div></div></div><div></div><div>Expand</div></div>

Overview of Trial





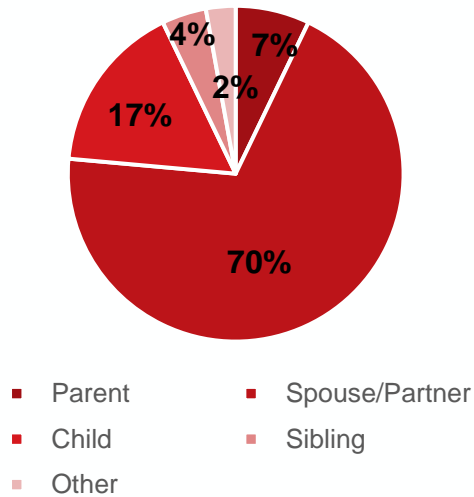
<u>Characteristic</u>	<u>n (%)</u>
Gender	
Male	46 (34%)
Female	90 (66%)
Hispanic/Latino	
Yes	11 (8%)
No	122 (90%)
Race	
White	114 (84%)
Black or AA	9 (7%)
Asian	5 (4%)
Relationship Status	
Single	13 (10%)
Married	101 (74%)
Divorced/Separated	7 (5%)
Widowed	2 (1%)
Education	
HS/ GED	9 (7%)
Some College	22 (16%)
College Grad	104 (76%)

<u>Characteristic</u>	<u>n (%)</u>
Age, M (SD)	52.3 (14.0)
Employment	
Employed	82 (59%)
Self-employed	11 (8%)
Out of work	8 (6%)
A Homemaker	6 (4%)
A Student	2 (1%)
Retired	26 (20%)
Children in home	
0	90 (66%)
1	19 (14%)
2	14 (10%)
3+	8 (6%)
Annual HH income	
<\$25,000	2 (1%)
\$25,000 - \$35,000	4 (3%)
\$35,000 - \$50,000	7 (5%)
\$50,000 - \$75,000	8 (6%)
\$75,000 or more	100 (74%)

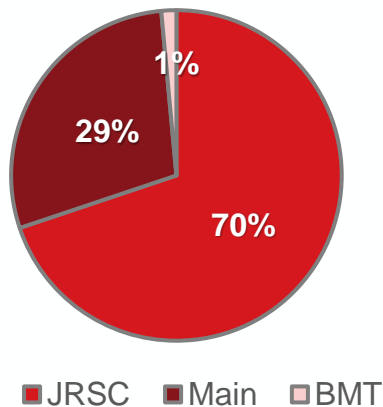


Caregiving Characteristics

Relationship to Patient



Recruitment Site



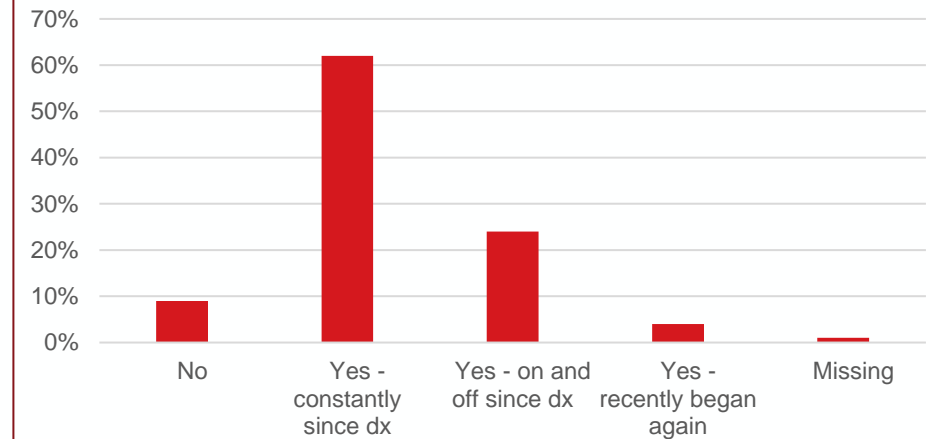
Months Spent Caregiving

Total Months Spent Caregiving	n (%)
<1	5 (4%)
1 to <4	56 (49%)
4 to <8	26 (23%)
8 to 24	17 (15%)
>24	10 (9%)

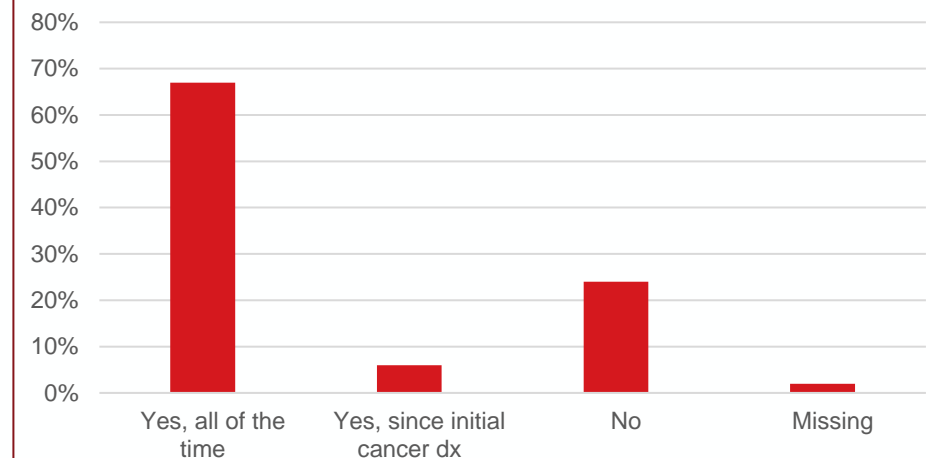
Hours Spent Caregiving

Hours/Day Caregiving	n (%)
<1	6 (6%)
1 to <4	60 (57%)
4 to <8	9 (8%)
8 to <24	18 (17%)
24	13 (12%)

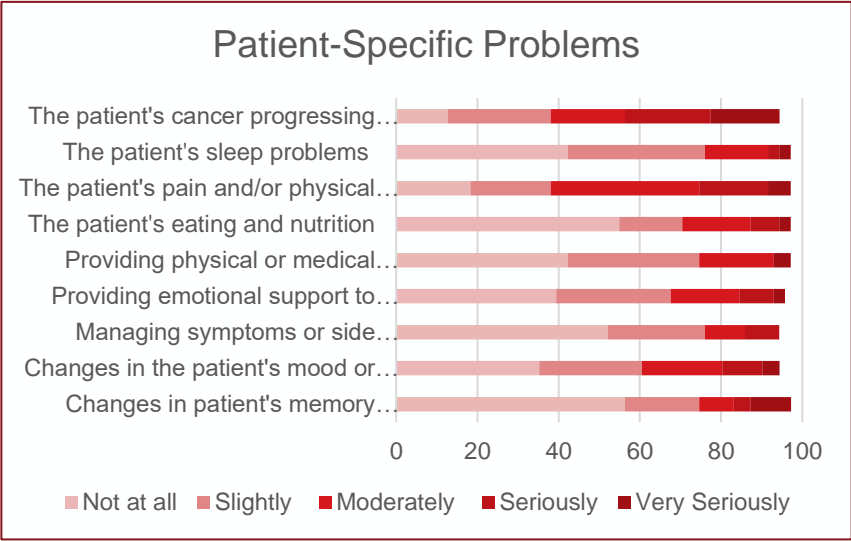
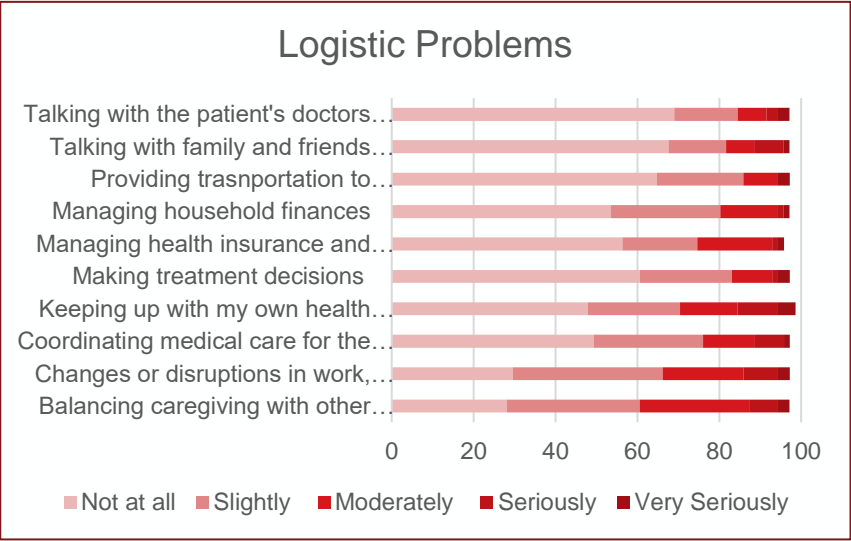
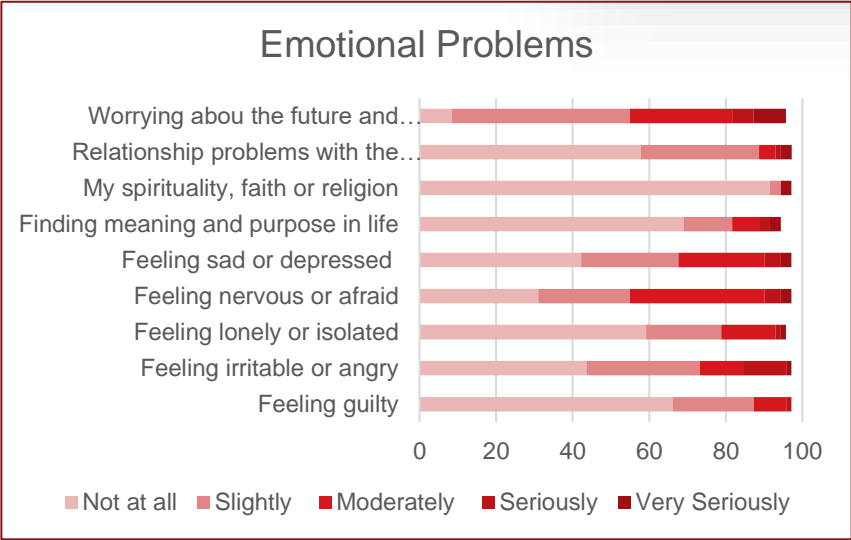
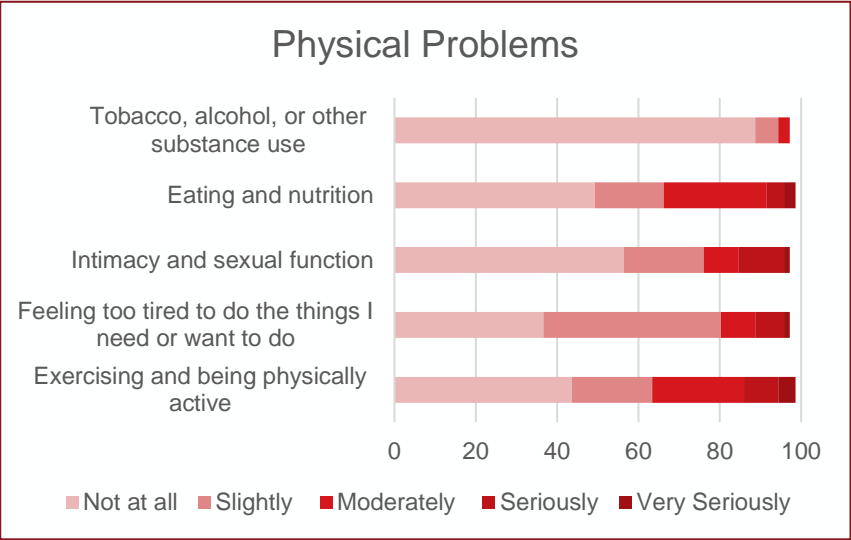
Providing Cancer Care



Living with Patient



Baseline Problem List Responses

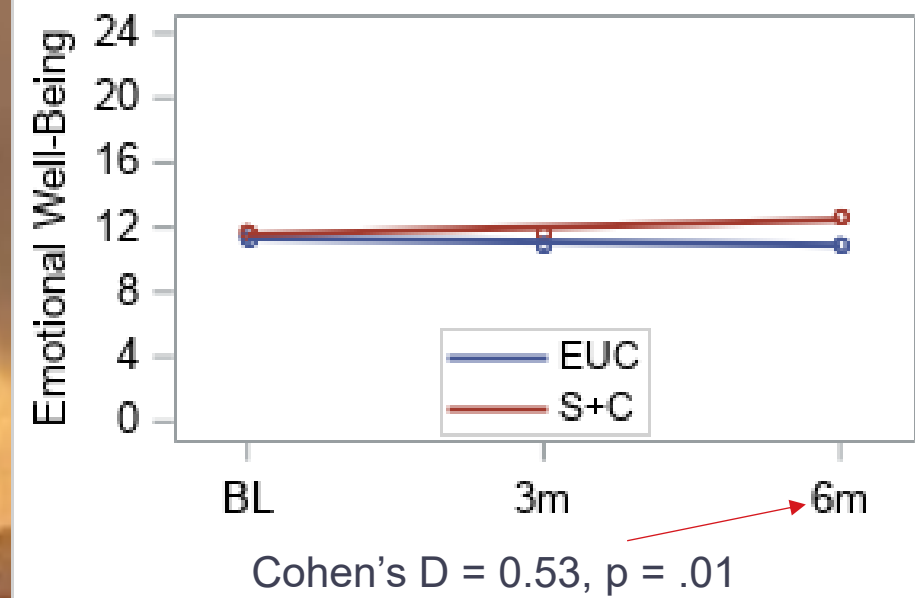




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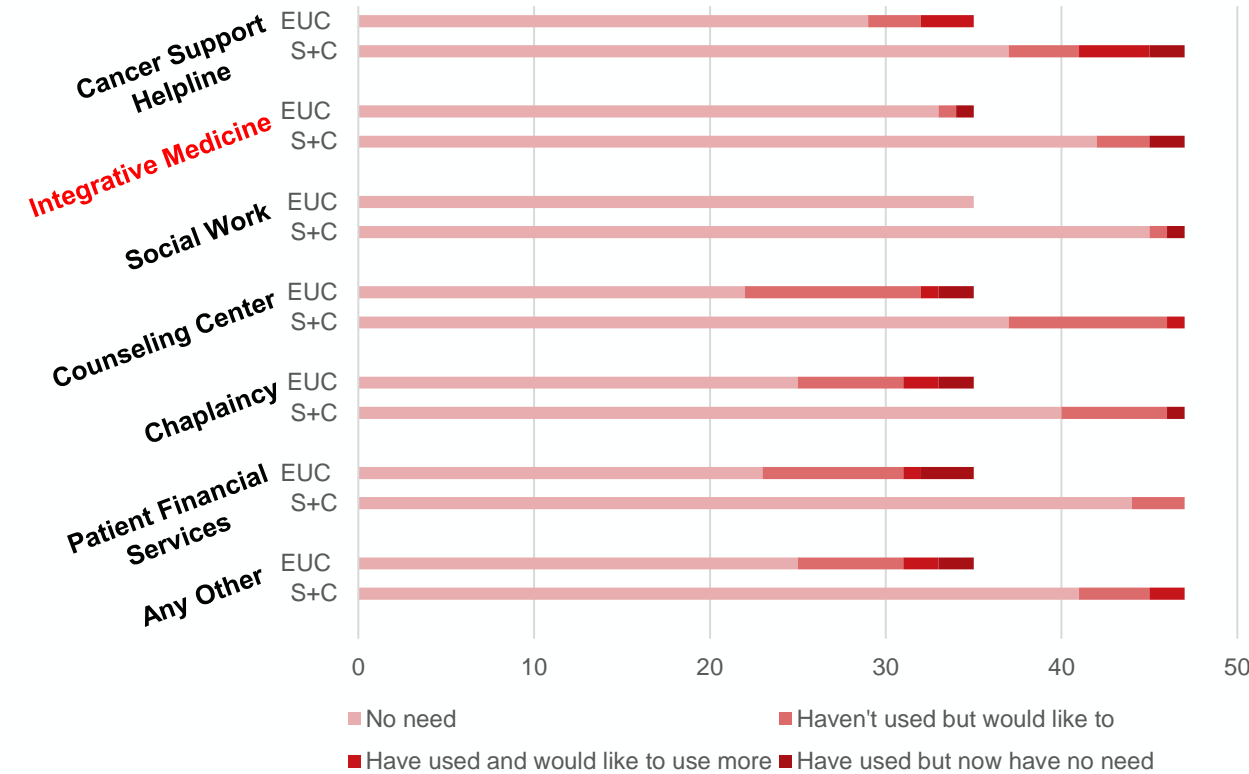
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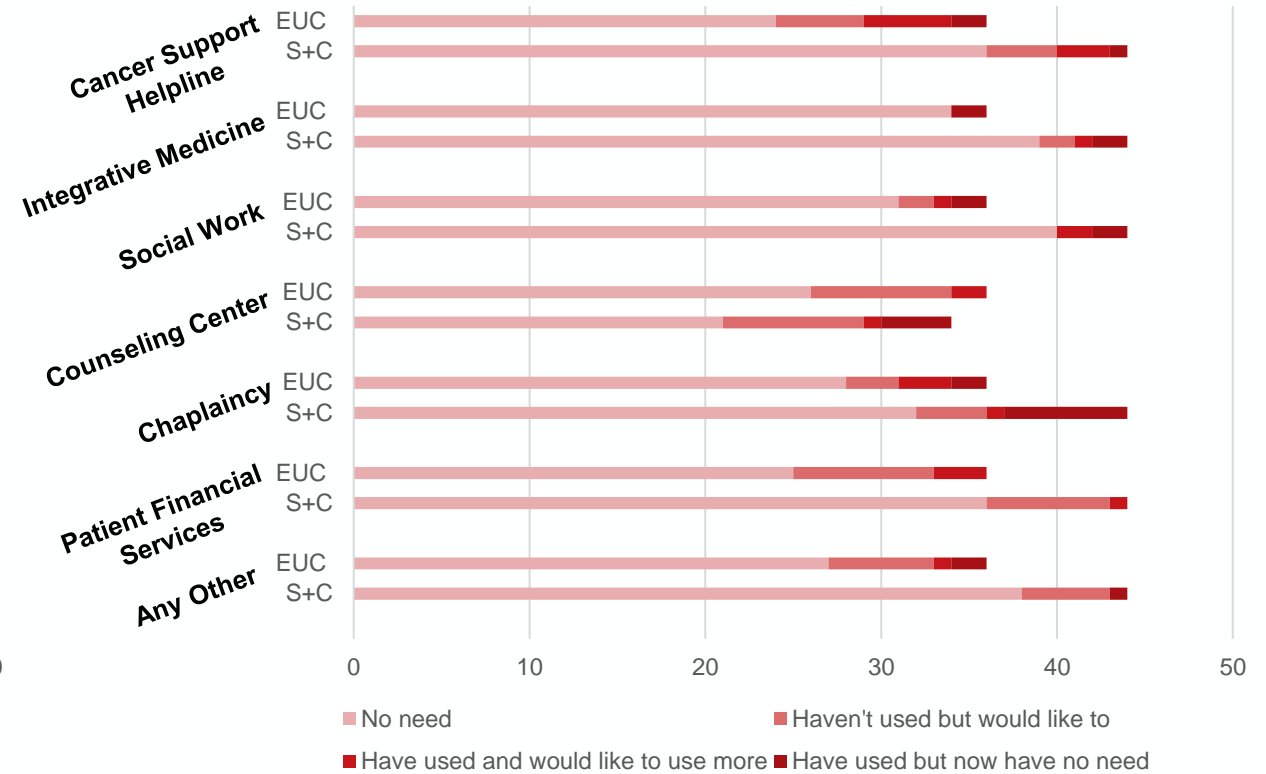


Follow-up Service Use

T2 Service Use



T3 Service Use





Next Steps

- Larger scale trial, more inclusive of higher medical acuity patients and likely longer caregiving trajectories
- Pairing of CSS-CG with CARE Act implementation
 - Requires hospitals to record the name of the family caregiver on the medical record of his or her loved one who is admitted for treatment.
 - Requires caregivers to be informed when his or her loved one is to be transferred or discharged
 - Requires provision of education and instruction to caregivers in the medical tasks he or she will need to perform for the patient at home.
- Integration of the CSS-CG into standard clinical practice to assist in addressing misuse of services and capitalizing on what services already exist in our comprehensive cancer centers



THANK YOU!