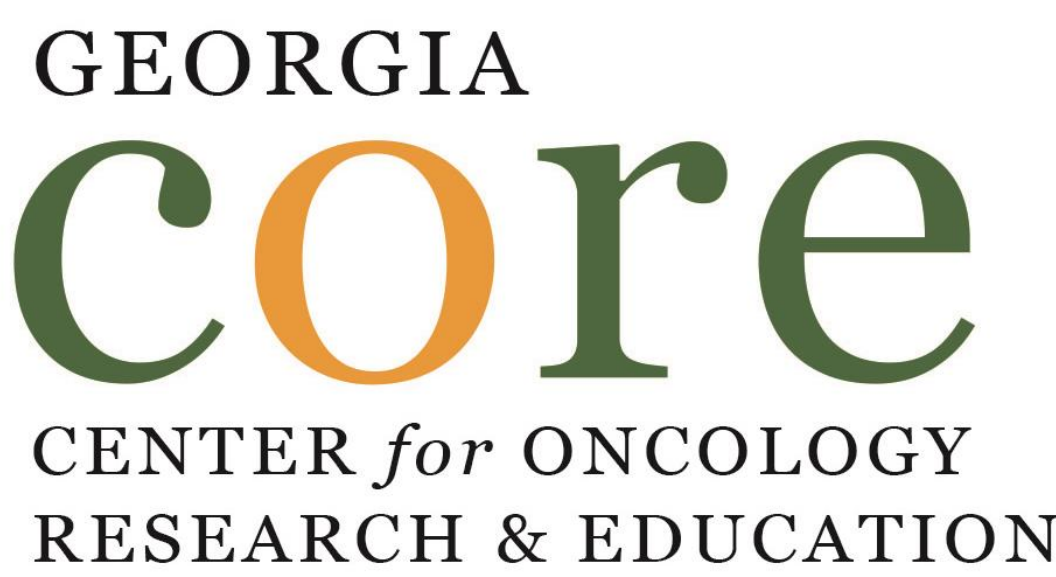


# Unmet Needs and Distress Levels for Georgia's Survivors

Angela K. Patterson<sup>1</sup>; Cam Escoffery, PhD, MPH, CHES<sup>2</sup>; Mohammad Khalaf, MPH<sup>3</sup>; Joan Giblin, MSN FNP-C AOCN<sup>4</sup>; Karuna Ramachandran, MA, EdM<sup>5</sup>; Rachel Cannady<sup>6</sup>

1. Georgia Center for Oncology Research and Education, Inc., Atlanta, GA; 2. Rollins School of Public at Emory University, Atlanta, GA; 3. Formerly with Georgia Health Policy Center, Georgia State University, Atlanta, GA; 4. Winship Cancer Institute at Emory University, Atlanta, GA; 5. Center for Pan Asian Community Services, Atlanta, GA 6. American Cancer Society, Atlanta, GA.



## BACKGROUND

An estimated 14.5 million cancer survivors live in the United States<sup>1</sup>. In Georgia, there are currently 355,870 survivors<sup>1</sup>. It is predicted that the number of survivors 5 years post diagnosis will increase to 37% within the decade.<sup>2</sup>

Georgia has a long standing history of collaboration to assess and enhance the quality of survivorship care in the state with leaders from the Georgia Department of Public Health (DPH), Georgia Center for Oncology Research and Education (Georgia CORE), Andrew Young School of Policy Studies at Georgia State University, Regional Cancer Coalitions of Georgia, American Cancer Society, Georgia Society of Clinical Oncology (GASCO), and the Emory University Rollins School of Public Health, among others. Representatives serve as members of the Georgia Cancer Control Consortium (GC3), who leads the Cancer Control Plan.

One of the eight priorities of the plan is focused on Survivorship. In 2013, the GC3 Survivorship Working Group (SWG) began work on a statewide survivors' needs assessment to understand the physical, psychosocial, practical and spiritual needs of adult cancer survivors. While needs of cancer survivors have been assessed, there is less knowledge about unmet needs<sup>3</sup>.



## METHODS

The GC3 SWG and the Rollins School of Public Health developed a cross-sectional survey using National Comprehensive Cancer Network (NCCN) and Commission on Cancer (CoC) guidelines. The survey was approved by the Institutional Review Board (IRB) of Emory University in 2014.

### Survey Methodology

- 76 items
- Recruitment & Dissemination
  - Adult cancer survivors who had completed treatment and live in the state of Georgia.
  - Distributed through survivorship programs of the CoC hospitals (n = 40), 16 Survivorship-focused non-profit organizations, and 5 Regional Cancer Coalitions via email, social media and mail.
- 740 responses received September - December 2014.
- Respondents resided in 48% of Georgia Counties (n=159)
- Treated at 72% of CoC hospitals (n=40)

## RESULTS

Respondents were primarily female (78%) married (65%), college-educated (55%) and insured (97%). 83% were White, 16% were African American and 3% were Hispanic. 36% of respondents were within 1 year of treatment; 45% were 1 - 5 years post treatment.

A high proportion of survivors reported moderate to extreme levels of emotional distress with: depression (32.7%), anxiety (32.1%), stress (30.2%), fear of recurrence (28.2%) and defining a "new normal" (25.9%).

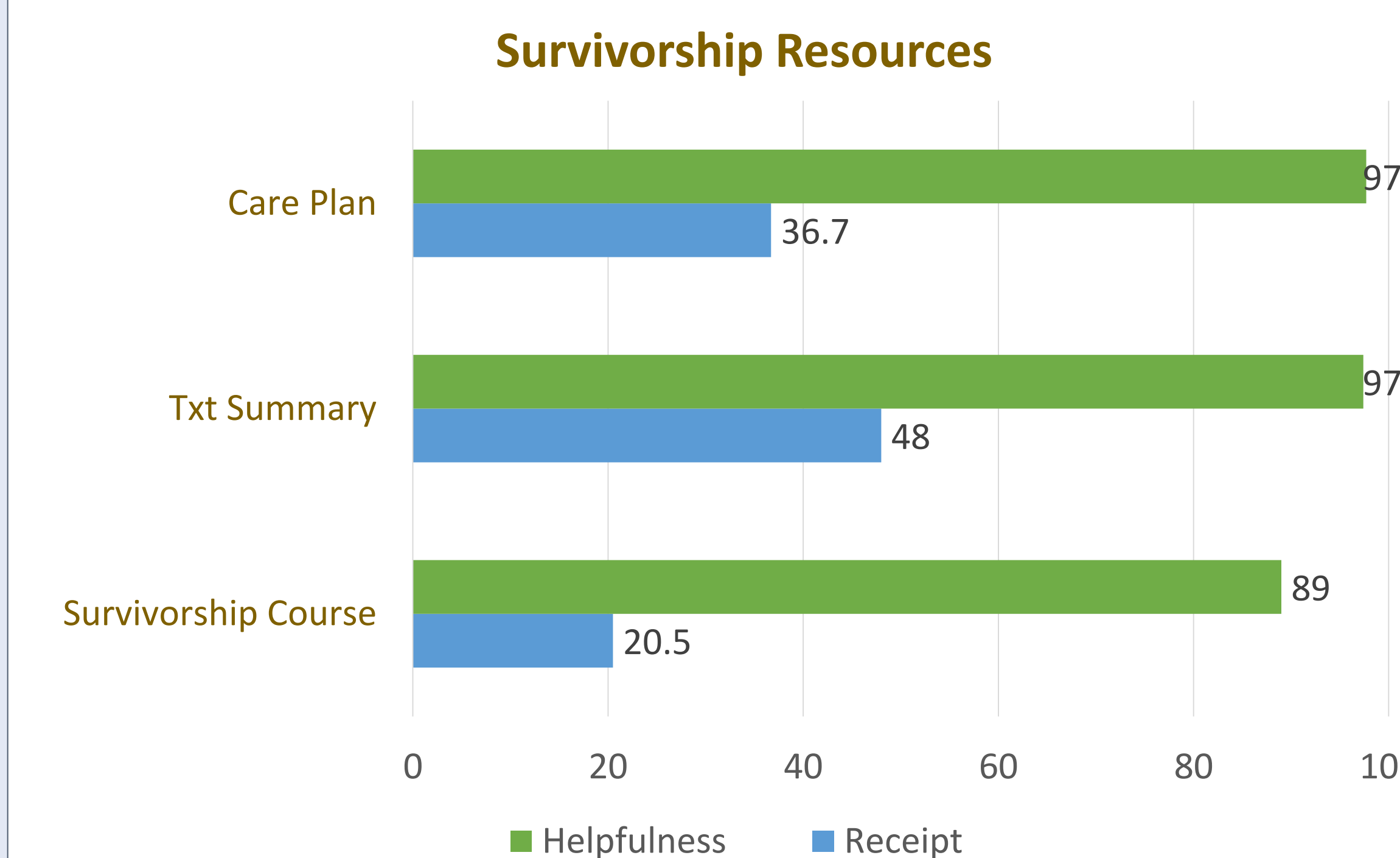
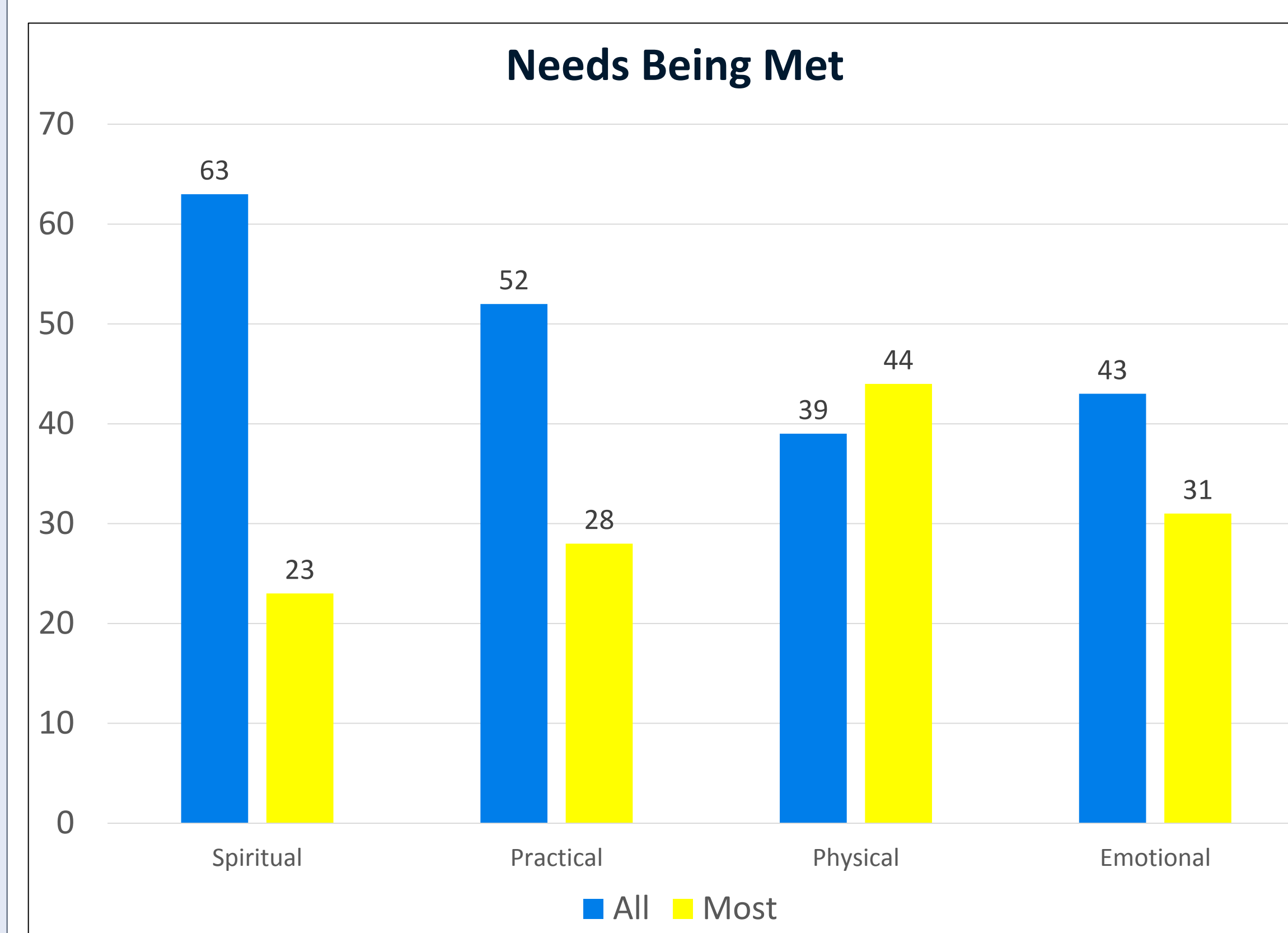
Over 50% of survivors reported receiving little or no assistance from providers for these needs. Only 37% received a survivorship care plan (SCP) and 98% of those who received it reported it was helpful.

Table 1. Characteristics of Participants

Sociodemographics	
Age, M (SD)	58.2 (11.6)
Gender, n=717	
Female	562 (78.4)
Race, n=706	
White	584 (82.7)
African American/Black	111 (15.7)
Other	11 (1.6)
Hispanic, % Yes	5 (2.8)
Marital Status, n=729	
Single/Living with partner	76 (10.4)
Married	474 (65.0)
Separated/Divorced/Widowed	179 (24.6)
Metro-Atlanta, % Yes, n=710	76.2
Education, n=726	
High school or less	8 (1.3)
High school/GED	72 (9.9)
Some college	247 (34.0)
College/Graduate school	399 (54.8)
Income, n=567	
Less than \$20,000	57 (10.1)
20,000-39,999	83 (14.6)
40,000-74,999	159 (28.0)
75,000 or more	268 (47.3)
Employment, n=720	
Working	392 (54.4)
Unemployed/Retired/Student	328 (45.6)
Health Insurance, % Yes, n=725	74.8 (97.0)
Health Characteristics	
Most Common Cancer, n=720	
Breast	399 (55.4)
Blood	91 (12.6)
Prostate	68 (9.4)
Skin	54 (7.5)
Colon/Rectal	36 (5.0)
Age diagnosed, n=699	52.5 (12.1)
Time since last treatment, n=688	
Less than 1 year	250 (36.3)
1-5 years	307 (44.6)
5-10	72 (10.4)
More than 10	59 (8.7)

## Emotional/Mental Health Needs, Level of Distress, and Assistance Provided

	Level of Distress <sup>1</sup>		N	Receipt of help			
	Moderate	Large/Extreme		Got all help	Got most	Got some	Didn't get any
Talking about cancer with Family	71 (10.7)	45 (6.8)	183	47 (25.7)	46 (25.1)	51 (27.9)	39 (21.3)
Caring for Family members	61 (9.3)	62 (9.5)	179	54 (30.2)	39 (21.8)	42 (23.5)	44 (24.6)
Changing relations with spouse	69 (10.6)	72 (11.1)	194	41 (21.1)	45 (23.2)	47 (24.2)	61 (31.4)
Managing stress	112 (17.0)	67 (10.2)	293	56 (19.1)	73 (24.9)	103 (35.2)	61 (20.8)
Defining sense of new normal	96 (14.6)	77 (11.8)	245	47 (19.2)	53 (21.6)	68 (27.8)	77 (31.4)
Fear of recurrence	101 (15.3)	155 (23.4)	289	63 (21.8)	55 (19.0)	87 (30.1)	84 (29.1)
Sense of wellbeing	90 (13.7)	59 (9.0)	231	34 (14.7)	58 (25.1)	74 (32.0)	65 (28.1)
Anxiety	79 (12.0)	76 (11.5)	270	52 (19.3)	73 (27.0)	96 (35.6)	49 (18.1)
Depression/Sadness	80 (12.2)	73 (11.1)	273	62 (22.7)	66 (24.2)	89 (32.6)	56 (20.5)
Isolation	49 (7.5)	71 (10.9)	203	23 (11.3)	44 (21.7)	67 (33.0)	69 (34.0)
Coping with grief or loss	64 (9.8)	60 (9.1)	186	34 (18.3)	39 (21.0)	58 (31.2)	55 (29.6)



## CONCLUSIONS

Results demonstrate the psychosocial needs of cancer survivors in the state. However, several racial and ethnic minority groups and people from socioeconomically disadvantaged backgrounds were significantly underrepresented in this study. Further research is needed to expand the study sample by working with community organizations and CoC hospitals to develop a more targeted approach to reaching individuals with limited English proficiency, limited access to technology and other minority populations.

Knowledge of areas of distress and unmet needs for survivors, including racial and ethnic minorities and the socioeconomically disadvantaged, can inform providers' practices to guide survivors towards evidence-based approaches such as SCPs and utilize community resources to implement culturally and linguistically competent services that address their needs.

One important resource launched in 2014, Georgia's [Cancer Survivorship Connection](#) (CSC) is the first statewide comprehensive online portal that provides evidence-based survivorship information and resources for Georgia survivors, caregivers and healthcare professionals.

The site will be enhanced to insure survivorship resources are available and highlighted to address the unmet needs.



## REFERENCES

1. American Cancer Society. Cancer Treatment & Survivorship Facts & Figures 2014-2015. American Cancer Society. 2015.
2. de Moor JS, Mariotto AB, Parry C, Alfano CM, Padgett L, Kent EE., et al. Cancer survivors in the United States: prevalence across the survivorship trajectory and implications for care. *Cancer Epidemiol Biomarkers Prev.* 2013;22(4):561-570.
3. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer.* 2009;17(8):1117-28.

## CONTACT INFORMATION

Angela K. Patterson  
Vice President  
Georgia Center for Oncology Research and Education, Inc.  
(404) 584-0657 [Apatterson@georgiacore.org](mailto:Apatterson@georgiacore.org)

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