

# Needs Assessment

## Assessment of distress, unmet needs, and receipt of care plans among cancer survivors in Georgia

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### ABSTRACT

**Background:** Cancer survivors have distinctive healthcare needs. The Survivorship Working Group of the Georgia Cancer Control Consortium conducted an assessment to understand the physical, psychological, practical, and spiritual needs of adult cancer survivors; patient perceptions regarding patient-provider communications; and their perceived need for services.

**Methods:** In 2014, a convenience sample of Georgia cancer survivors completed a paper or online survey about the presence of and distress associated with unmet physical, emotional, spiritual, and practical needs, and receipt of assistance in those areas. They were also asked about receipt of cancer treatment and survivorship care plans.

**Results:** Survivors were primarily female, married, White, and within 5 years of treatment. High proportions reported moderate to extreme levels of distress with depression (32.7%), anxiety (32.1%), stress (30.2%), and fear of recurrence (28.2%). Many reported no receipt of assistance in emotional needs such as changing relationships and defining a new normal and physical needs such as intimacy and body image. Fewer than half (48%) reported having received a cancer treatment summary from their physician and only 37% received a survivorship care plan. Of those who received either, 98% reported that the information was helpful.

**Conclusions:** Cancer survivors in Georgia who responded to the survey had unmet needs, especially related to physical and mental health. More widespread adoption of guidelines of the Commission on Cancer, including the use of distress screening tools, would assist providers in addressing identified needs directly or through referrals. A limitation is that the racial and ethnic minority participation of 20.1% is insufficient to generalize results to all cancer survivors in Georgia. Subsequent surveys would benefit from targeted approaches to reach diverse and underserved survivors.

**Key words:** cancer survivors, needs assessment, unmet needs, distress, psychosocial, quality of life

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### INTRODUCTION

An estimated 14.5 million cancer survivors live in the United States (American Cancer Society [ACS], 2015a). In Georgia, there are currently 355,870 survivors (ACS, 2015a). Within the decade, the numbers of people who will survive cancer 5 years post-diagnosis are predicted to increase to 37% (de Moor et al, 2013). In Georgia's statewide cancer plan, a focus on cancer survivors has been identified as a priority for the state (Georgia Department of Public Health, 2014). An Institute of Medicine report on survivorship defines four goals for improving survivorship care: 1) prevention and detection of new cancers; 2) surveillance of cancer spread and recurrence; 3) interventions to handle the consequences of cancer and its treatment; and, 4) coordination between cancer specialists and primary care providers (Hewitt, Greenfield, & Stovall, 2005). With the growing numbers of cancer survivors,

consideration should be given to mechanisms to ensure clinical, social, physical, and emotional support for these individuals (Stein, Syrjala, & Andrykowski, 2008; Yabroff, Lawrence, Clauser, Davis, & Brown, 2004).

Although needs of cancer survivors have been assessed in research and practice, there is little knowledge about unmet needs (Harrison, Young, Price, Butow, & Solomon, 2009). These needs among cancer survivors have been defined as instances where perceived needs do not meet the level of service or support for achieving optimal wellness (Sansone-Fisher et al., 2000). Evaluation of the literature on unmet needs can yield insights into areas of focus for survivorship programs. A review of survivors found that many reported unmet needs in communication and informational needs, physical needs, finances, relationships, and emotional needs (Harrison, Young, Price, Butow, & Solomon, 2009). These needs were greatest and most diverse during the treatment

period. For those who were 5 to 10 years post-treatment, survivors reported physical and psychosocial problems associated with their cancer (Foster & Fenlon, 2011; Jefford et al., 2008). A qualitative study that focused on the unmet needs of cancer survivors who were 2, 5, and 10 years post diagnosis found that the top five unmet needs centered on these themes: physical (38.2%), financial (20.3%), education (19.5%), personal control (16.4%), and challenges with systems of care (15.5%) (Burg et al., 2015). Breast cancer survivors reported more unmet needs than survivors of other cancers, and younger survivors described more unmet needs than older ones. Furthermore, a systematic review of interventions related to needs of survivors found that efforts in only 3 out of 9 studies reduced unmet supportive care needs of survivors (Richardson et al., 2011). More research has been recommended to explore areas of needs and to assess, longitudinally, supportive concerns for survivors (Carey et al., 2012).

The purpose of the present study was to understand the physical, psychological, practical, and spiritual needs of adult cancer survivors in Georgia, to identify support services and resources available to these individuals, and to develop new strategies or programs for addressing these needs. Furthermore, we explored receipt of assistance for their needs and unmet needs (defined as “not getting any help”) for the survivors by gender, income level, and other demographic factors in order to understand the systems of care that would best meet the needs of survivors.

## METHODS

In Georgia, healthcare providers, public health professionals, non-profit leaders, and advocates have a long-standing history of collaboration in assessing and enhancing the quality of cancer survivorship care. The development of strategies, programs, and resources to serve the state’s growing numbers of cancer survivors occurs through shared activities and individual efforts of organizations, including the Georgia Department of Public Health (GDPH), the Georgia Center for Oncology Research and Education (Georgia CORE), the Andrew Young School of Policy Studies at Georgia State University, the Regional Cancer Coalitions of Georgia, the American Cancer Society, the Georgia Society of Clinical Oncology, and the Emory University Rollins School of Public Health. Representatives of these and other organizations serve as members of the Georgia Cancer Control Consortium (GC3), the Cancer Survivor Leadership Council, and the Cancer Survivorship Connection Advisory Board, each of which is chaired by a cancer survivor.

Initial efforts to enhance care for cancer survivors in Georgia began in 2002 with the creation of the Cancer Survivor Leadership Council (CSLC). Later, survivorship was introduced as an intersectoral issue to guide development of the Georgia Cancer Plan, developed by the GC3 under the auspices of the GDPH. Three surveys

designed and conducted in Georgia have identified survivorship needs, gaps, and opportunities and have guided the development of survivorship resources in the state. The two surveys by the Commission on Cancer (CoC)-accredited facilities were implemented by Georgia CORE to assess knowledge of national standards, use of survivorship care plans (SCPs) and treatment summaries, and availability of survivorship resources. The third survey of a broad spectrum of needs of cancer survivors was designed and implemented in 2014 by the GC3 Survivorship Working Group with the Emory University Rollins School of Public Health.

This survivorship assessment tool, derived from published cancer survivor instruments, was pilot-tested in the fall of 2013 with 74 individuals, 28% of whom were racial and ethnic minorities. Based on key learnings from the pilot test, a final instrument was developed and approved by the Institutional Review Board of Emory University in 2014. To ensure that it could be completed by individuals with limited access to the internet or with low technological proficiency, the survey was adapted to both on-line and paper formats.

## Recruitment

Inclusion criteria for the survivorship needs assessment were: 1) cancer survivors who had completed treatment and 2) who lived in the state of Georgia. Based on a strategy developed by members of the GC3 Survivorship Work Group, broad dissemination occurred via electronic mail, regular mail, social media, newsletters, and flyers through stakeholders with direct access to cancer survivors, including 40 CoC hospitals, 16 survivorship-focused non-profit organizations, five regional cancer coalitions, and the 18-member Cancer Survivorship Connection Advisory Board. The initial request to complete the survey was sent electronically to survivors, followed by reminder emails every two weeks over a fourteen-week period to encourage survey completion. Stakeholders also promoted completion of a paper version in support groups and by newsletters. Participants were asked to read an informed consent and then complete the survey. On request, Georgia CORE mailed the paper surveys and pre-paid return envelopes. The data were collected from September to December 2014.

## Instrument

The survey included sections about patient demographics; cancer type and history; overall health history; lifestyle behaviors; interactions with healthcare professionals; experience with physical, emotional, spiritual, and practical needs; and sources of support. Items assessed were age, gender, race/ethnicity, education level, marital status, income, employment, insurance status, type of cancer, treatment received (e.g., chemotherapy, surgery, radiation), time since cancer diagnosis, other chronic illnesses, and time since the last doctor visit. Physical health and mental health status and days of poor physical/mental health were determined through use of BRFS questions (Centers for

Disease Control and Prevention, 2015). Survivors provided three types of information about physical, emotional, spiritual, and practical needs. They rated if, since their cancer diagnosis, the need/problem caused them distress on a scale of 0=no to 5=extreme distress, if they ever needed help for this problem (Yes, No, Don't Know), and if they got the help that they needed on a scale of 1=didn't get any of the help needed to 4=got all of the help needed.

For provider communication, they were asked about communication with a healthcare provider after completion of cancer treatment in relation to time spent, decision-making, opportunities to ask questions, and assistance in dealing with feelings of uncertainty on a scale of 1=never to 4=very often (National Cancer Institute, 2015). In addition, related to survivorship care planning, survivors reported if they received a cancer treatment summary or an SCP and if they found the information helpful. Survivors also selected methods in which they received information and listed the top three most important resources.

### Statistical Analyses

For analyses, data were exported from RedCAP to SPSS 23.0 (IBM, 2013). More than 960 survivors started the survey. Data reported here are for the 729 who completed

90% or more of the questions. The dataset was cleaned by removing duplicates and recoding responses to variables that were miscoded (e.g., types of cancer, treatment types). Participant characteristics, cancer treatment, health communications, and support services were summarized by use of descriptive statistics. For the survivors, their needs, levels of distress, and receipt of assistance were described with percentages and means. Fisher exact tests were performed to explore differences for receipt of help across areas of needs and income levels (i.e., <\$20,000, \$20-39,999, \$40-74,999, and \$75,000 or greater), and statistical significance was defined as p values  $\leq 0.05$ .

## RESULTS

The sample of survivors in Georgia was mostly female, White, married, insured, had incomes of \$40,000 or more, and lived in a metropolitan area (Table 1). They included survivors of breast (55.4%), blood (12.6%), prostate (9.4%), and skin cancer (7.5%) and were diagnosed on average at 53 years old. The treatments received were primarily surgery (73.1%), radiation (60.4%), and chemotherapy (60.1%). Most were less than 1 year (36.3%) or between 1-5 years (44.6%) post-treatment.

**Table 1. Characteristics of participants**

<b>Sociodemographics</b>	
<b>Age, Mean (SD)</b>	58.2 (11.6)
<b>Gender, n=717</b>	N (%)
Female	562 (78.4)
Male	155 (21.6)
<b>Race, n=706</b>	
White	584 (82.7)
African American/Black	111 (15.7)
Other	11 (1.6)
<b>Hispanic, % Yes</b>	5 (2.8)
<b>Marital status, n=729</b>	
Single/Living with partner	76 (10.4)
Married	474 (65.0)
Separated/Divorced/Widowed	179 (24.6)
<b>Metro-Atlanta, % Yes, n=710</b>	76.2
<b>Education, n=726</b>	
High school or less	8 (1.3)
High school/GED	72 (9.9)
Some college	247 (34.0)
College/Graduate school	399 (54.8)
<b>Income, n=567</b>	
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)
<b>Employment, n=720</b>	
Working	392 (54.4)
Unemployed/Retired/Student	328 (45.6)
<b>Health insurance, % Yes, n=725</b>	700 (97.0)

<b>Sociodemographics</b>	
Health characteristics	
<b>Cancer, n=720</b>	
Breast	399 (55.4)
Blood	91 (12.6)
Prostate	68 (9.4)
Skin	54 (7.5)
Colon/Rectal	36 (5.0)
Head & Neck	32 (4.4)
Endometrial	26 (3.6)
Melanoma	21 (2.9)
Ovarian	20 (2.8)
Liver	3 (0.4)
Lung	19 (2.6)
Thyroid	19 (2.6)
Kidney	11 (1.5)
Cervical	9 (1.3)
Bladder	8 (1.1)
Pancreatic	6 (0.8)
<b>Age diagnosed, n=699</b>	52.5 (12.1)
<b>Treatment received, n=699</b>	
Surgery	511 (73.1)
Radiation therapy	422 (60.4)
Chemotherapy	420 (60.1)
Hormone therapy	148( 21.1)
Bone marrow transportation	34 (4.9)
Immunotherapy	21 (3.0)
None	15 (2.1)
Other	15 (2.1)
<b>Time since last treatment, n=688</b>	
Less than 1 year	250 (36.3)
1-5 years	307 (44.6)
5-10 years	72 (10.4)
More than 10 years	59 (8.7)
<b>Distance from cancer treatment facility, n=714</b>	
Less than 10 miles	243 (34.0)
10-20 miles	248 (35.7)
20-50 miles	171 (23.9)
Over 50 miles	52 (7.3)

Most reported other chronic conditions, with hypertension, high cholesterol, joint problems, and gastrointestinal problems being greater in frequency (Table 2). In terms of quality of life, only 13% reported being in fair or poor

physical or mental health; 27.8% indicated that they had less than 5 days of poor health that kept them from their usual activities in the past 30 days. 91.9% had visited a doctor in the last year.

**Table 2. Health status and doctor's visit**

Chronic Condition	N	N (%)
High blood pressure	701	276 (39.3)
High cholesterol	698	262 (37.5)
Joint problems	702	253 (36.0)
Gastrointestinal	702	199 (28.3)
Anxiety	703	188 (26.7)
Depression	698	182 (26.1)
Osteoporosis	705	97 (13.8)
Asthma	701	92 (13.1)
Diabetes	700	70 (10.0)
Heart disease	697	64 (9.1)
Chronic lung disease	700	27 (3.9)
Kidney disease	699	22 (3.1)
<b>Physical health status</b>	716	
Excellent		133 (18.6)
Very good/Good		492 (68.7)
Fair/Poor		91 (12.7)
<b>Mental health status</b>	713	
Excellent		216 (30.3)
Very good/Good		408 (57.2)
Fair/Poor		89 (12.5)
<b>Days physical health poor/past 30 days</b>	693	
None		386 (55.7)
Less than 5		197 (28.4)
5-10		52 (7.5)
10-15		26 (3.8)
More than 15		32 (4.6)
<b>Days physical health poor/past 30 days</b>	699	
None		378 (54.1)
Less than 5		194 (27.8)
5-10		65 (9.3)
10-15		24 (3.4)
More than 15		38 (5.4)
<b>Days poor health kept from usual activities/past 30 days</b>	694	
None		425 (61.2)
Less than 5		158 (22.8)
5-10		60 (8.6)
10-15		23 (3.3)
More than 15		28 (4.1)
<b>Time since visited a doctor for check-up</b>	712	
Last year		654 (91.9)
1-2		33 (4.6)
2-5		19 (2.7)
5 or more years		6 (0.8)

Survivors reported that providers often gave them a chance to ask questions (62.1%) and involved them in the healthcare decision-making (55.5%) (data not shown). Many reported that the provider understood how to manage issues faced by survivors (Mean=7.27, SD=2.3) (data not shown).

Table 3 presents the spiritual, practical, physical, and emotional/mental health needs; level of distress; and

assistance provided. Few survivors had spiritual needs, and levels of large or extreme distress were low. A larger proportion did not receive help in the areas of end-of-life thoughts (37.8%) and loss of faith (31.4%). Related to practical needs, work-related issues had the highest prevalence (82.1%), followed by finances (33.5%), insurance (29.1%), and managing their household (28.5%). More than one fourth of survivors reported that they did not

receive any help in the areas of legal issues (38.8%), work-related issues (34.9%), or finances (27.1%).

More than 25% of survivors reported physical health needs. The highest was sleep issues (46.4%) followed by pain, tiredness, tingling, weight gain, and nausea. The three ranked highest in level of distress were sleep, tiredness, and intimacy issues. Many did not get any help for issues relating to fertility (60.4%), body image (51.5%), intimacy (47.0%), memory (45.0%), and weight gain (39.5%). For emotional and mental health needs, the highest reported need was depression (32.7%), followed by anxiety, managing stress, fear of cancer recurrence, and defining a new sense of normal. Areas of largest or extreme distress were fear of recurrence, defining a new normal, and anxiety. More than one fourth reported not receiving any assistance for feelings of isolation (34.0%), changing relationships

with their spouse (31.4%), defining a new normal (31.4%), coping with grief/loss (29.6%), fear of recurrence (29.1%), and having a sense of well-being (28.1%). In summary, survivors reported lower average means of physical needs (Mean=4.18, SD=0.82) and emotional/mental health needs (Mean=4.08, SD=0.99) being met than spiritual (Mean=4.40, SD=0.99) or practical concerns (Mean=4.27, SD=0.91).

There were few significant differences in income levels and areas of spiritual, practical, physical, and emotional needs. Greater proportions of those with less income (<\$40,000) were likely to report that they did not get any help they needed for issues of sexual health ( $X^2=20.3$ ,  $p=0.016$ ) and a sense of well-being ( $X^2=25.8$ ,  $p=0.002$ ). Similarly, those with incomes of less than \$20,000 also reported a higher percentage of not receiving any help in the area of fear of cancer recurrence ( $X^2=17.7$ ,  $p=0.038$ ) (data not shown).

**Table 3. Spiritual, practical, physical, and emotional/mental health needs, level of distress, and assistance provided**

	N	Had this need	Level of Distress <sup>1</sup>			Receipt of help				
			N	Moderate	Large/ Extreme	N	Got all help	Got most	Got some	Didn't get any
<b>Spiritual/Faith Needs</b>										
Religious support	646	88 (13.6)	646	17 (2.6)	6 (.9)	185	87 (47.0)	38 (20.5)	29 (15.7)	31 (16.8)
Loss of faith	640	46 (7.2)	646	14 (2.2)	10 (1.5)	105	37 (35.2)	18 (17.1)	17 (16.2)	33 (31.4)
End-of-life thoughts	640	70 (10.9)	645	67 (10.4)	45 (7.0)	148	43 (29.1)	24 (16.2)	25 (16.9)	56 (37.8)
<b>Practical Needs</b>										
Finances	644	216 (33.5)	647	113 (17.5)	164 (25.3)	277	67 (24.2)	60 (21.7)	75 (27.1)	75 (27.1)
Insurance	639	186 (29.1)	647	98 (15.1)	127 (19.6)	262	77 (29.4)	72 (27.5)	72 (27.5)	41 (15.6)
Work-related	632	519 (82.1)	639	55 (8.6)	102 (16.0)	166	48 (28.9)	24 (14.5)	36 (21.7)	58 (34.9)
Legal	635	66 (10.4)	638	25 (3.9)	28 (4.4)	103	25 (24.3)	11 (10.7)	27 (26.2)	40 (38.8)
Managing household	634	181 (28.5)	643	81 (12.6)	57 (8.9)	238	85 (35.7)	41 (17.2)	71 (29.8)	41 (17.2)
Finding support	632	130 (20.6)	637	51 (8.0)	47 (7.4)	204	61 (29.9)	33 (16.2)	66 (32.4)	44 (21.6)
Connecting to counseling services	630	104 (16.5)	628	29 (4.6)	27 (4.3)	174	50 (28.7)	29 (16.7)	54 (31.0)	41 (23.6)
Ability to return to responsibilities	637	153 (24.0)	639	66 (10.3)	73 (11.4)	223	64 (28.7)	45 (20.2)	67 (30.0)	47 (21.1)
Going to places	638	90 (14.1)	643	33 (5.1)	25 (3.9)	159	73 (45.9)	29 (18.2)	31 (19.5)	26 (16.4)
Staying connected with community	632	52 (8.2)	636	25 (3.9)	18 (2.8)	148	52 (35.1)	30 (20.3)	37 (25.0)	29 (19.6)
<b>Physical Needs</b>										
Tiredness	682	291 (42.7)	688	174 (25.3)	157 (16.8)	365	82 (22.5)	95 (26.0)	111 (30.4)	77 (21.1)
Sleep	679	315 (46.4)	685	176 (25.7)	147 (21.4)	369	114 (30.9)	92 (24.9)	106 (28.7)	57 (15.4)
Memory	673	142 (21.1)	683	146 (21.4)	96 (14.1)	240	36 (15.0)	42 (17.5)	54 (22.5)	108 (45.0)
Pain	680	299 (44.0)	678	102 (15.0)	75 (11.0)	354	165 (46.6)	96 (27.1)	74 (20.9)	19 (5.4)
Neuropathy/ Tingling	679	212 (31.2)	684	87 (12.7)	94 (13.8)	251	67 (26.7)	64 (25.5)	63 (25.1)	57 (22.7)
Thyroid	676	123 (18.2)	678	32 (4.7)	20 (3.0)	144	82 (56.9)	24 (16.7)	15 (10.4)	23 (16.0)
Lymphedema	676	136 (20.1)	678	44 (6.5)	39 (5.7)	164	64 (39.0)	39 (23.8)	26 (15.9)	35 (21.3)
Nausea	677	169 (25.0)	687	41 (6.0)	24 (3.5)	211	116 (55.0)	51 (24.2)	23 (10.9)	21 (10.0)

	N	Had this need	Level of Distress <sup>1</sup>			Receipt of help				
			N	Moderate	Large/ Extreme	N	Got all help	Got most	Got some	Didn't get any
Appetite	676	80 (10.4)	684	35 (5.1)	27 (4.0)	115	39 (33.9)	29 (25.2)	22 (19.1)	25 (21.7)
Swallowing	675	78 (11.6)	683	26 (3.8)	19 (2.8)	106	41 (38.7)	19 (17.9)	23 (21.7)	23 (21.7)
Weight gain	676	171 (25.3)	681	93 (13.7)	101 (14.8)	210	34 (16.2)	41 (19.5)	52 (24.8)	83 (39.5)
Incontinence	671	149 (22.2)	683	67 (9.8)	59 (8.7)	202	62 (30.7)	45 (22.3)	40 (19.8)	55 (27.2)
Intimacy/Sexual	670	141 (21.0)	678	85 (12.5)	112 (16.6)	183	20 (10.9)	23 (12.6)	54 (29.5)	86 (47.0)
Fertility	665	34 (5.1)	666	8 (1.2)	19 (2.9)	53	9 (17.0)	3 (5.7)	9 (17.0)	32 (60.4)
Hair/Skin/body image	673	112 (16.6)	680	83 (12.2)	93 (13.7)	171	29 (17.0)	24 (14.0)	30 (17.5)	88 (51.5)
<b>Emotional/Mental Health Needs</b>										
Talking about cancer with family	656	84 (12.8)	666	71 (10.7)	45 (6.8)	183	47 (25.7)	46 (25.1)	51 (27.9)	39 (21.3)
Caring for family members	650	116 (17.8)	656	61 (9.3)	62 (9.5)	179	54 (30.2)	39 (21.8)	42 (23.5)	44 (24.6)
Changing relations with spouse	650	109 (16.7)	649	69 (10.6)	72 (11.1)	194	41 (21.1)	45 (23.2)	47 (24.2)	61 (31.4)
Managing stress	652	197 (30.2)	657	112 (17.0)	67 (10.2)	293	56 (19.1)	73 (24.9)	103 (35.2)	61 (20.8)
Defining sense of new normal	652	169 (25.9)	657	96 (14.6)	77 (11.8)	245	47 (19.2)	53 (21.6)	68 (27.8)	77 (31.4)
Fear of recurrence	652	184 (28.2)	662	101 (15.3)	155 (23.4)	289	63 (21.8)	55 (19.0)	87 (30.1)	84 (29.1)
Sense of wellbeing	650	135 (20.8)	658	90 (13.7)	59 (9.0)	231	34 (14.7)	58 (25.1)	74 (32.0)	65 (28.1)
Anxiety	652	209 (32.1)	658	79 (12.0)	76 (11.5)	270	52 (19.3)	73 (27.0)	96 (35.6)	49 (18.1)
Depression/Sadness	652	213 (32.7)	658	80 (12.2)	73 (11.1)	273	62 (22.7)	66 (24.2)	89 (32.6)	56 (20.5)
Isolation	650	133 (20.5)	655	49 (7.5)	71 (10.9)	203	23 (11.3)	44 (21.7)	67 (33.0)	69 (34.0)
Coping with grief or loss	644	136 (21.1)	654	64 (9.8)	60 (9.1)	186	34 (18.3)	39 (21.0)	58 (31.2)	55 (29.6)

<sup>1</sup> Distress ranged from 0=No to 5=Extreme

Of the survivors, 48.0% received a cancer treatment summary from a provider, and 36.7% received an SCP. Of the survivors who received either, 97.7% reported that the information was helpful (Table 4). Only 20.5% were offered a survivorship course after they received treatment. Of those

who attended, most indicated that it was useful. For those who looked for information on survivorship (n=507), the most frequently reported resources were online (91.1%), books (65.5%), health care provider/center (59.0%), and family and friends (55.8%).

**Table 4. Cancer survivor information, support, and resources**

<b>Received a cancer treatment summary, % Yes, n=630</b>	303 (48.0)
Information helpful, % Yes, n=300	293 (97.7)
<b>Received a Cancer Care Plan, % Yes, n=635</b>	233 (36.7)
Information helpful, % Yes, n=227	221 (97.4)
<b>Understanding of how to manage issues faced by survivors, 1=No to 10=Complete understanding</b>	7.27 (2.3)
<b>Able to get information and assistance for effects of cancer, 1=Not well to 10=Extremely well</b>	7.27 (2.6)
<b>Looked for information on survivorship and source, % Yes, n=507</b>	
Online	462 (99.1)
Books	332 (65.5)
Cancer center/healthcare provider	299 (59.0)
Family/friends	283 (55.8)
Support group	141(27.8)
Other	18 (3.6)
<b>Class offered for Survivors After Treatment, % , n=623</b>	128 (20.5)
Attended Class, % Yes	59 (47.2)
Usefulness of Class, 1=Not at all to 10=Extremely	

## DISCUSSION

The results for the top unmet needs are consistent with findings from other studies (Harrison et al., 2009; Burg et al., 2015). Although most of the survey respondents reported generally being in good physical and mental health, they were more likely to report physical and emotional/mental health needs, such as depression and anxiety, than other needs. Survivors also reported receiving less assistance in these areas. Thus, it is appropriate that cancer survivorship programs and centers address these perceived needs of survivors.

Survivors also reported co-morbidities with other chronic conditions, such as hypertension, high cholesterol, and joint problems. These included diseases that related to both physical and mental health, such as asthma, heart disease, diabetes, anxiety, and depression. This is consistent with the ages of the survivors and the relatively high burden of chronic conditions across the population in Georgia. These findings, however, emphasize the increasing level of complexity involved in caring for and coordinating care of survivors. They also suggest a need for chronic disease self-management by survivors to address treatment/medications, wellness, information-seeking, mental health management, and psychosocial behaviors in order to live with their cancer diagnosis and treatment and to improve their quality of life (Brady et al., 2013; McCorkle et al., 2011). Both survivors and their caregivers should be educated on the daily behaviors that they should perform to manage their cancer

and treatment, including short and long-term effects (McCorkle et al., 2011).

There were also overall positive ratings of communication with providers. This is relevant since survivors frequently interact with medical staff, especially during treatment. The study found, however, that providers are not adequately addressing issues that are indicators of distress and unmet needs, including fertility, body image, weight gain, and sexuality/intimacy. To address these concerns, survivorship centers could provide counseling and referrals to healthcare providers (i.e., ob-gyn) and community supporters (i.e., physical activity programs). There were moderate to high levels of distress, particularly for physical and emotional health needs, despite the insurance and financial status of the respondents (97% insured or 47% > \$75,000 income).

Another area of support for survivors are SCPs. The present study demonstrates that survivors are not receiving treatment summaries or SCPs at optimal levels. The Institute of Medicine posits that these tools have the potential to increase health and well-being by informing survivors about their diagnosis and treatment and educating them about required surveillance care and follow-up (Hewitt, Greenfield, & Stovall, 2005). A recent evaluation of SCPs found that 90% of survivors were satisfied (i.e., agreed that SCPs were useful, informative, and reassuring, and also increase cancer care knowledge) and that they improved the perceived level of coordination among providers (Palmer et al., 2015). Furthermore, this finding highlights a need to

tailor SCPs to meet the individual concerns of survivors (Keesing, McNamara, & Rosenwax, 2014). In the currently available template options for SCPs (ASCO, Lance Armstrong, Journey Forward) (Rechis et al., 2012; Journey Forward, 2015; American Society of Cancer Oncology, 2015b), there should be greater assessment of these areas of need in addition to recommended surveillance care and behaviors. Some of the concerns related to mental health, such as stress, isolation, and fear of recurrence, should be delineated and not simply categorized as one area. Other physical and social concerns, such as memory, relationships (e.g., intimacy), and fertility issues should also be addressed (Ganz et al., 1996). Moreover, Georgia survivors positively rated post-treatment survivorship classes, yet only a fifth of respondents had this type of support offered to them. These courses, staff, and other participating survivors could offer the social support identified as a need through this assessment (e.g., informational, emotional, and instrumental).

There are limitations to this study. The sample was a convenience sample from CoC-accredited hospitals and multiple survivor-focused organizations in Georgia. Since the survivors were mostly female, those with a mean income of \$40,000, and White, the results are not representative of all cancer survivors. In particular, Black and other minority populations that are more likely to die of cancer in Georgia are under-represented. In addition, the cross-sectional nature of the survey limits our ability to make causal inferences between study variables. Further, since physical needs of survivors were examined individually, exploration of symptom clustering could not be performed.

## CONCLUSIONS

The present research has reinforced the concept that the physical and mental health needs of cancer survivors should be addressed, not only during active treatment but also throughout the continuum of survivorship care (Naughton & Weaver, 2014). Cancer survivorship programs and centers should recognize these needs and consider methods to address them by assessing these areas of needs or distress in SCPs and future physician surveillance visits, as well as by offering advice on emotional coping, wellness, and stress management, and providing mental health services. The present findings support the recommendation of the Commission on Cancer of the American College of Surgeons that would require cancer centers to implement distress screening programs as a criterion for accreditation (Commission on Cancer, 2012). Screening for psychosocial distress and other needs would assist providers in identifying areas of need and in offering and/or referring survivors to appropriate services to reduce distress and improve quality of life.

Several recommendations can be made. Future assessment of cancer survivor needs should focus on developing and implementing strategies to reach more diverse populations reflective of cancer survivors, including men, minority

populations, and rural residents. In addition, there should be concerted efforts to provide training, resources, and assistance for CoC-accredited facilities in meeting the survivorship, navigation, palliative care, and psychosocial distress standards to assist in addressing these identified needs of survivors (Pirl et al., 2014). Furthermore, professional associations and CoC facilities should support the development of multi-disciplinary survivorship care to meet the emotional and mental health needs of survivors and to improve the coordination of care among oncologists, primary care providers, and other specialists, such as mental health professionals. With 60% of Georgia's CoC centers having a survivorship program, these data and future assessments could inform the support services provided to survivors, specifically emphasizing areas of unmet needs (Kirsch, Patterson, & Lipscomb, 2014).

Additional research should explore differences in patient-provider communication; receipt of SCPs; and unmet needs by demographic factors, cancer history, or types of cancer. These data will yield information allowing tailoring of services to specific populations and types of survivors. Future research can also develop and evaluate interventions to reduce unmet needs of various types of cancer survivors.

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