Voice of the Survivor

2024-25 assessment of Georgia cancer survivors' needs

GEORGIA CORE
Strengthening Georgia's Cancer Fight

GEORGIA CANCER CONTROL CONSORTIUM

Overview

The Georgia Cancer Control Consortium's (GC3) Survivorship Work Group and Georgia CORE (the Center for Oncology Research and Education) conducted a statewide cancer survivorship needs assessment survey from October 2024 through July 2025 to better understand the needs of Georgia's cancer survivorship community. Building on a similar assessment conducted in 2014,[1] the survey was disseminated via email, newsletters, social media, and in-person events. The updated survey retained many of the original questions while integrating new ones to collect information and garner insight into the physical, mental, practical, and spiritual needs of survivors across the state.

Georgia is currently home to more than 622,000 cancer survivors representing 7.3% of the state's population, including 342,900 women (7.7%) and 279,400 men (6.9%).[2] Survivorship is defined from the point of receiving a cancer diagnosis until the end of life.[3]

Characteristics of Participants

The needs assessment received 206 responses. Most of the survivors in the survey sample were Black (41.7%) or White (48.8%). Among respondents who reported gender (N=170), 146 (85.9%) identified as females and 24 (14.1%) identified as male. The most common cancers reported among the respondents are breast (58.2%), blood (21.3%), lung (5%), colon (5%) and thyroid (5%). Most were diagnosed on average at age 49.6 (range 8-79). Among those who reported their treatment history, 71% were treated with chemotherapy, 60% with surgery, and 57% with radiation.

Table 1. Sociodemographic and Health Characteristics of Survey Respondents (N = 206)

Characteristic	N	%
Total respondents	**206**	**100.0%**
AGE (N=166)		
Mean age (range)	58.3	(15-85 years)
Median age	59.0	
18–39 years	12	7.2%
40–49 years	24	14.5%
50–59 years	46	27.7%
60–69 years	43	25.9%
70 years and older	39	23.5%
AGE AT DIAGNOSIS (N=137)		
Mean age at diagnosis (range)	49.6	(8-79 years)
Median age at diagnosis	50.0	
GENDER (N=170)		
Female	146	85.9%
Male	24	14.1%
RACE/ETHNICITY (MULTI-SELECT; N=168 WHO ANSWERED†)		
White/Non-Hispanic	82	48.8%
Black/African American	70	41.7%
Hispanic	9	5.4%
Multiracial	5	3.0%

Asian American/Pacific Islander	4	2.4%
American Indian/Alaskan Native	2	1.2%
Other	2	1.2%
MARITAL STATUS (N=169)		
Married	97	57.4%
Single (never married)	29	17.2%
Separated or Divorced	26	15.4%
Widowed	12	7.1%
Not married, living with a partner	5	3.0%
EDUCATION (N=169)		
Graduate or professional degree	53	31.4%
College/Bachelor's degree	50	29.6%
Some college or associate's degree	43	25.4%
High school diploma/GED	20	11.8%
Some high school or less	3	1.8%
ANNUAL HOUSEHOLD INCOME (N=168)		
$75,000 or more	65	38.7%
$40,000–$74,999	32	19.0%
$20,000–$39,999	15	8.9%
Less than $19,999	18	10.7%
Prefer not to answer	38	22.6%
EMPLOYMENT STATUS (N=170)		
Employed full time	75	44.1%
Retired	47	27.6%
Employed part time	20	11.8%
Unable to work due to disability	19	11.2%
Unemployed	6	3.5%
Student	3	1.8%
HEALTH INSURANCE (MULTI-SELECT; N=169 WHO ANSWERED)		
Has health insurance	163	96.4%
No health insurance	6	3.6%
HEALTH CHARACTERISTICS		
CANCER TYPE (MULTI-SELECT; N=141 WHO ANSWERED)		
Breast	82	58.2%
Blood (Leukemia, Lymphoma, Multiple Myeloma)	30	21.3%
Lung	8	5.7%
Colon or Rectal	7	5.0%
Skin (Non-Melanoma)	7	5.0%
Thyroid	7	5.0%
Brain	5	3.5%
Endometrial/Uterine	5	3.5%
Head and Neck	4	2.8%

Ovarian	4	2.8%
Prostate	3	2.1%
Cervical	2	1.4%
Other	9	6.4%
TREATMENT RECEIVED (MULTI-SELECT; N=140 WHO ANSWERED)		
Chemotherapy	99	70.7%
Surgery	84	60.0%
Radiation therapy	80	57.1%
Hormone therapy	28	20.0%
Immunotherapy	26	18.6%
Bone marrow transplant	12	8.6%
Other	9	6.4%
CURRENTLY IN ACTIVE TREATMENT (N=143)		
Yes	37	25.9%
No	106	74.1%
TIME SINCE LAST TREATMENT (N=138)		
Less than one year	54	39.1%
1–5 years	35	25.4%
5–10 years	28	20.3%
More than 10 years	21	15.2%
RECEIVED SURVIVORSHIP CARE PLAN (N=101)		
Yes	37	36.6%
No	49	48.5%
Don't know	15	14.9%
RECEIVED TREATMENT SUMMARY (N=100)		
Yes	57	57.0%
No	33	33.0%
Don't know	10	10.0%
DISTANCE TO CANCER CARE FACILITY (N=139)		
Less than 10 miles	41	29.5%
10–20 miles	48	34.5%
20–50 miles	35	25.2%
Over 50 miles	15	10.8%
SELF-REPORTED PHYSICAL HEALTH STATUS (N=143)		
Excellent	21	14.7%
Very good	62	43.4%
Fair	53	37.1%
Poor	7	4.9%

SELF-REPORTED MENTAL HEALTH STATUS (N=142)		
Excellent	29	20.4%
Very good	48	33.8%
Good	35	24.6%
Fair	23	16.2%
Poor	7	4.9%

† Race/ethnicity percentages calculated among N=168 respondents who answered the race question (38 skipped); race is multi-select so percentages may equal to more than 100%.

Satisfaction of Needs Met

The survey examined the complex needs of survivors and the extent to which those needs have been addressed throughout the continuum of their care during and after treatment. The needs are subdivided into four domains: mental, practical, physical, and spiritual. For each domain, respondents rated their level of distress on each item (0 = no distress to 5 = extreme distress) and reported whether they received help for those needs. Table 2 summarizes overall satisfaction of needs met across all four domains.

Table 2. Survivor Needs Satisfaction by Domain

Domain	N	Most/all needs met	Few/none met	Unmet Need with Highest Level of Distress
Physical Health	119	71%	8%	Fatigue (81%)
Mental Health	111	26%	14%	Fear of recurrence (88%)
Practical & Logistical	108	46%	5%	Financial issues (78%)
Spiritual & Faith	107	51%	10%	End-of-life thoughts (51%)

Emotional/Mental Health Needs

The needs assessment results showed that fear of cancer recurrence impacted 88% of respondents. Eighty percent of survivors struggled with defining a new sense of normal, and 77% reported managing stress as an ongoing source of distress. Anxiety (70%), sadness and depression (69%), and loss of a sense of well-being (69%) are impacting survivors at a high percentage. Also, 47.2% of survivors reported emotional distress related to their sexual life.

Only 26% reported that most or all of their emotional/mental health needs are being met, while 14% said few or none are met, making this the least-served domain in the needs assessment. Of note, 11.5% of survivors reported 15 or more days of poor mental health per month.

Table 3. Emotional/Mental Health Needs	N	Had this need N (%)	N	Level of Distress[1]		Receipt of Help				
				Moderate N (%)	Large/ Extreme N (%)	N	Got all N (%)	Got most N (%)	Got some N (%)	Didn't get any N (%)
Talking about cancer with family/friends	111	62 (55.9)	111	10 (9)	11 (9.9)	110	15 (13.6)	10 (9.1)	27 (24.5)	11 (10)
Caring for family members	110	45 (40.9)	110	14 (12.7)	9 (8.2)	103	10 (9.7)	5 (4.9)	17 (16.5)	10 (9.7)
Changing relationship with spouse/family	109	59 (54.1)	109	15 (13.8)	12 (11)	106	4 (3.8)	5 (4.7)	16 (15.1)	22 (20.8)
Managing stress	107	82 (76.6)	107	23 (21.5)	17 (15.9)	108	15 (13.9)	12 (11.1)	29 (26.9)	15 (13.9)
Defining a new sense of normal	108	86 (79.6)	108	22 (20.4)	21 (19.4)	107	18 (16.8)	8 (7.5)	25 (23.4)	21 (19.6)
Fear of cancer recurrence	109	96 (88.1)	109	24 (22)	33 (30.3)	110	16 (14.5)	10 (9.1)	24 (21.8)	32 (29.1)
Having a sense of well-being	110	76 (69.1)	110	21 (19.1)	16 (14.5)	107	14 (13.1)	13 (12.1)	26 (24.3)	16 (15)
Anxiety	110	77 (70)	110	16 (14.5)	24 (21.8)	109	15 (13.8)	13 (11.9)	26 (23.9)	13 (11.9)
Sadness or depression	110	76 (69.1)	110	18 (16.4)	15 (13.6)	109	14 (12.8)	12 (11)	25 (22.9)	10 (9.2)
Isolation/feeling alone	110	55 (50)	110	8 (7.3)	21 (19.1)	110	11 (10)	6 (5.5)	21 (19.1)	14 (12.7)
Coping with grief and/or loss	111	68 (61.3)	111	20 (18)	19 (17.1)	108	14 (13)	7 (6.5)	23 (21.3)	16 (14.8)
Emotional state in relation to sex	108	51 (47.2)	108	12 (11.1)	16 (14.8)	107	10 (9.3)	3 (2.8)	10 (9.3)	25 (23.4)

[1] Level of distress scored 0–5: 0 = No distress, 1 = Very small, 2 = Small, 3 = Moderate, 4 = Large, 5 = Extreme distress. Percentages are based on respondents who answered each respective section (Physical n=119; Mental/Emotional n=111; Spiritual n=107; Practical n=108). Percentages may not sum to 100% due to rounding.

Practical Needs

Financial issues were the most common practical concern, reported by 78% of survivors as a source of ongoing distress, followed by the ability to return to previous activities (70%) and health insurance issues (69%). Among survivors who answered the support resources question, 67% reported difficulty finding support resources, with only 5% indicating they had received all the help they needed.

Black survivors said they faced higher distress across food insecurity (41% vs 21% for White/Non-Hispanic), housing (49% vs 24%), employment (54% vs 36%), and counseling access (56% vs 36%). Blood cancer survivors reported the highest health insurance distress of any cancer type at 81%. All surveyed lung cancer survivors reported distress related to household management. Fifteen percent of rural survivors reported that none of their practical needs are met, and their health insurance gap (33%) is nearly double that of survivors in urban settings (18%).

Fifteen percent of survivors reported spending more than $25,000 beyond what insurance covered, rising to 22% for blood cancer survivors.

Table 4. Practical Needs	N	Had this need N (%)	Level of Distress[1]			Receipt of Help				
			N	Mod-erate N (%)	Large/ Ex-treme N (%)	N	Got all N (%)	Got most N (%)	Got some N (%)	Didn't get any N (%)
Financial issues	108	84 (77.8)	108	25 (23.1)	33 (30.6)	106	9 (8.5)	9 (8.5)	28 (26.4)	17 (16)
Health insurance issues	108	75 (69.4)	108	20 (18.5)	22 (20.4)	106	11 (10.4)	21 (19.8)	20 (18.9)	9 (8.5)
Employment	107	46 (43)	107	14 (13.1)	12 (11.2)	104	4 (3.8)	6 (5.8)	6 (5.8)	9 (8.7)
Legal issues	106	31 (29.2)	106	9 (8.5)	7 (6.6)	105	2 (1.9)	2 (1.9)	11 (10.5)	6 (5.7)
Managing household activities	107	77 (72)	107	20 (18.7)	18 (16.8)	105	16 (15.2)	12 (11.4)	23 (21.9)	13 (12.4)
Finding support resources	105	70 (66.7)	105	12 (11.4)	17 (16.2)	106	14 (13.2)	10 (9.4)	31 (29.2)	9 (8.5)
Connecting with counseling services	108	48 (44.4)	108	13 (12)	11 (10.2)	104	14 (13.5)	8 (7.7)	21 (20.2)	8 (7.7)
Ability to return to previous activities	108	76 (70.4)	108	20 (18.5)	26 (24.1)	106	17 (16)	7 (6.6)	20 (18.9)	16 (15.1)
Understanding health-related information	107	53 (49.5)	107	4 (3.7)	9 (8.4)	106	25 (23.6)	18 (17)	13 (12.3)	7 (6.6)
Transportation to necessary places	107	33 (30.8)	107	7 (6.5)	7 (6.5)	106	14 (13.2)	9 (8.5)	6 (5.7)	7 (6.6)
Access to public healthcare services	107	34 (31.8)	107	9 (8.4)	7 (6.5)	105	8 (7.6)	6 (5.7)	11 (10.5)	11 (10.5)
Food insecurity	108	29 (26.9)	108	7 (6.5)	7 (6.5)	106	1 (0.9)	5 (4.7)	9 (8.5)	8 (7.5)
Childcare services	104	3 (2.9)	104	1 (1)	2 (1.9)	103	2 (1.9)	1 (1)	2 (1.9)	5 (4.9)
Isolation and loneliness	108	53 (49.1)	108	11 (10.2)	15 (13.9)	104	5 (4.8)	9 (8.7)	15 (14.4)	15 (14.4)

[1] Level of distress scored 0–5: 0 = No distress, 1 = Very small, 2 = Small, 3 = Moderate, 4 = Large, 5 = Extreme distress. Percentages are based on respondents who answered each respective section (Physical n≈119; Mental/Emotional n≈111; Spiritual n≈107; Practical n≈108). Percentages may not sum to 100% due to rounding.

Physical Needs

The survey responses indicated that many survivors are managing multiple physical symptoms well beyond active treatment. The most prevalent physical challenges reported are fatigue (81%), sleep disruption (80%), and memory/concentration problems (76%). Pain (72%), limitations in physical activity (72%), body image concerns (66%), weight gain (65%), and neuropathy (65%) are also reported as common physical ailments. Forty-two percent of respondents rated their overall physical health as fair or poor. Another 14.5% of survivors reported fertility distress, with 52.9% of those respondents experiencing fertility distress rates at the maximum level of distress (5 rated extreme).

Among comorbidities, 47% reported high blood pressure, 44% reported high cholesterol, 42% indicated gastrointestinal problems, 41% reported anxiety, and 41% reported joint problems. Lung and gynecologic cancer survivors reported the highest physical distress, with 100% of lung survivors indicating fatigue and physical activity limitation. Blood cancer survivors reported the highest memory/concentration distress (92%). Rural survivors reported significantly higher pain and memory problems than their urban peers.

Table 5. Physical Needs	N	Had this need N (%)	Level of Distress[1]			Receipt of Help				
			N	Moderate N (%)	Large/ Extreme N (%)	N	Got all N (%)	Got most N (%)	Got some N (%)	Didn't get any N (%)
Tiredness/Fatigue	119	96 (80.7)	119	27 (22.7)	28 (23.5)	117	6 (5.1)	15 (12.8)	29 (24.8)	22 (18.8)
Sleep issues	119	95 (79.8)	119	31 (26.1)	26 (21.8)	116	12 (10.3)	9 (7.8)	27 (23.3)	26 (22.4)
Concentration/Memory issues	119	90 (75.6)	119	28 (23.5)	20 (16.8)	116	4 (3.4)	6 (5.2)	18 (15.5)	36 (31)
Pain	119	86 (72.3)	119	19 (16)	25 (21)	114	19 (16.7)	19 (16.7)	30 (26.3)	6 (5.3)
Neuropathy/Tingling	119	77 (64.7)	119	19 (16)	22 (18.5)	117	8 (6.8)	16 (13.7)	32 (27.4)	12 (10.3)
Thyroid issues	117	26 (22.2)	117	3 (2.6)	12 (10.3)	115	12 (10.4)	4 (3.5)	5 (4.3)	10 (8.7)
Lymphedema	119	57 (47.9)	119	13 (10.9)	10 (8.4)	118	16 (13.6)	14 (11.9)	10 (8.5)	13 (11)
Nausea/Vomiting	118	48 (40.7)	118	5 (4.2)	8 (6.8)	116	19 (16.4)	14 (12.1)	10 (8.6)	7 (6)
Poor appetite	117	47 (40.2)	117	8 (6.8)	8 (6.8)	113	7 (6.2)	5 (4.4)	16 (14.2)	8 (7.1)
Difficulty swallowing/ eating	118	26 (22)	118	4 (3.4)	7 (5.9)	114	9 (7.9)	4 (3.5)	10 (8.8)	8 (7)
Weight gain	118	77 (65.3)	118	23 (19.5)	21 (17.8)	114	7 (6.1)	12 (10.5)	17 (14.9)	24 (21.1)
Incontinence	118	63 (53.4)	118	8 (6.8)	21 (17.8)	118	9 (7.6)	9 (7.6)	17 (14.4)	15 (12.7)
Sexual/Intimacy issues	116	62 (53.4)	116	10 (8.6)	24 (20.7)	116	5 (4.3)	7 (6)	10 (8.6)	25 (21.6)

Fertility issues	117	17 (14.5)	117	1 (0.9)	10 (8.5)	117	4 (3.4)	2 (1.7)	7 (6)	8 (6.8)
Body image issues	118	78 (66.1)	118	13 (11)	21 (17.8)	116	6 (5.2)	6 (5.2)	16 (13.8)	29 (25)
Eating nutritious foods	116	69 (59.5)	116	17 (14.7)	8 (6.9)	116	15 (12.9)	14 (12.1)	19 (16.4)	9 (7.8)

[1] Level of distress scored 0–5: 0 = No distress, 1 = Very small, 2 = Small, 3 = Moderate, 4 = Large, 5 = Extreme distress. Percentages are based on respondents who answered each respective section (Physical n≈119; Mental/Emotional n≈111; Spiritual n≈107; Practical n≈108). Percentages may not sum to 100% due to rounding.

Spiritual Needs

End-of-life thoughts affected 51% of the respondents. Religious and spiritual support concerns affected 24% of those surveyed, and loss of faith affects 18%. Black survivors reported the highest spiritual needs satisfaction rate (51%) and the lowest rate of few or no needs met (2.6%). Mean faith scores increased throughout the cancer journey, rising from 7.8 before diagnosis to 8.3 afterward. This suggests that spiritual belief may actively support coping for many survivors.

Table 6. Spiritual/Faith Needs	**N**	**Had this need N (%)**	**Level of Distress[1]**			**Receipt of Help**				
			N	**Mod-erate N (%)**	**Large/ Ex-treme N (%)**	**N**	**Got all N (%)**	**Got most N (%)**	**Got some N (%)**	**Didn't get any N (%)**
Religious/Spiritual support	107	26 (24.3)	107	4 (3.7)	5 (4.7)	108	26 (24.1)	7 (6.5)	11 (10.2)	11 (10.2)
Loss of faith	106	19 (17.9)	106	3 (2.8)	3 (2.8)	107	13 (12.1)	5 (4.7)	7 (6.5)	11 (10.3)
End-of-life thoughts	105	54 (51.4)	105	12 (11.4)	9 (8.6)	105	13 (12.4)	9 (8.6)	9 (8.6)	17 (16.2)

[1] Level of distress scored 0–5: 0 = No distress, 1 = Very small, 2 = Small, 3 = Moderate, 4 = Large, 5 = Extreme distress. Percentages are based on respondents who answered each respective section (Physical n=119; Mental/Emotional n=111; Spiritual n=107; Practical n=108). Percentages may not sum to 100% due to rounding.

Health Status and Chronic Conditions

The survey also explored the chronic diseases that cancer patients have in addition to their current or past cancer diagnosis. High blood pressure was the most commonly reported comorbidity at 47%, followed by high cholesterol (44%), gastrointestinal problems (42%), anxiety (41%), and joint problems (41%).

Forty-two percent of survivors rated their overall physical health as fair or poor, and 11.5% reported 15 or more days of poor mental health in the past 30 days. Regarding provider communication, 86% reported their provider always or usually involves them in decision-making, and survivors rated overall provider quality with a mean of 8.2 out of 10.

Table 7. Health Status and Chronic Conditions	N (%)
CHRONIC CONDITIONS (% OF THOSE WHO ANSWERED EACH CONDITION)	
High blood pressure N=134	63 (47.0%)
High cholesterol N=132	58 (43.9%)
Gastrointestinal problems N=131	55 (42.0%)
Anxiety N=134	55 (41.0%)
Joint problems N=133	55 (41.4%)
Depression N=133	38 (28.6%)
Osteoporosis N=128	22 (17.2%)
Asthma N=129	25 (19.4%)
Heart disease N=130	19 (14.6%)
Kidney disease N=131	14 (10.7%)
Chronic lung disease N=130	10 (7.7%)
PHYSICAL HEALTH STATUS N=143	
Excellent	21 (14.7%)
Very good	62 (43.4%)
Fair/Poor	60 (42.0%)
MENTAL HEALTH STATUS N=142	
Excellent	29 (20.4%)
Very good	83 (58.5%)
Fair/Poor	30 (21.1%)
DAYS OF POOR MENTAL HEALTH IN PAST 30 DAYS N=130	
Zero days	40 (30.8%)
Less than 5 days	49 (37.7%)
5–10 days	17 (13.1%)
10–15 days	7 (5.4%)
More than 15 days	15 (11.5%)
DOCTOR/PROVIDER COMMUNICATION (% ALWAYS OR USUALLY)	
Provider gives enough time N=129	88 (68.2%)
Provider involves survivor in decision-making N=129	111 (86.0%)
Provider gives chance to ask questions N=128	109 (85.2%)
Provider explains uncertainty or conflicting information N=128	82 (64.1%)
Overall provider quality (mean score, 1–10) N=124	Mean: 8.2

Cancer Survivor Information, Support, and Resources

Many survivors said they were seeking information regarding the diagnosis and post-treatment options on their own. Eighty-two percent reported seeking survivorship information independently, most commonly through internet searches (38%), family and friends (25%), and books or print materials (24%). Only 29% were offered a survivorship class after treatment, and those who attended such a class rated its usefulness at 6.4 out of 10. Survivors rated their own understanding of how to manage survivorship issues at a mean of 7.3 out of 10 and their ability to access assistance at 6.9.

Table 8. Cancer Survivor Information, Support, and Resources	N (%)
RECEIVED A CANCER TREATMENT SUMMARY N=100	
Yes	57 (57.0%)
No	33 (33.0%)
Don't know	10 (10.0%)
Information helpful — Yes (of those who received) N=64	57 (89.1%)
RECEIVED A SURVIVORSHIP CARE PLAN N=101	
Yes	37 (36.6%)
No	49 (48.5%)
Don't know	15 (14.9%)
Information helpful — Yes (of those who received) N=50	35 (70.0%)
SURVIVOR UNDERSTANDING OF HOW TO MANAGE ISSUES (1=NO TO 10=COMPLETE UNDERSTANDING)	
Mean score	Mean: 7.30
ABILITY TO GET INFORMATION AND ASSISTANCE (1=NOT WELL TO 10=EXTREMELY WELL)	
Mean score	Mean: 6.90
LOOKED FOR INFORMATION ON SURVIVORSHIP AND SOURCE (% YES, N=101)	
Search engine/internet	79 (38.3%)
Books/print materials	50 (24.3%)
Family/friends	52 (25.2%)
Cancer center/healthcare team	44 (21.4%)
Social media	33 (16.0%)
Virtual support group	38 (18.4%)
In-person support group	31 (15.0%)
Regional Cancer Coalitions	18 (8.7%)
Other	8 (3.9%)
CLASS OFFERED FOR SURVIVORS AFTER TREATMENT N=100	
Yes	29 (29.0%)
No	52 (52.0%)
Don't know	19 (19.0%)
Attended class — Yes, at least once (of those offered) N=61	28 (45.9%)
Usefulness of class (1=Not at all to 10=Extremely useful) N=38	Mean: 6.39

Limitations of the Survey

This survey has several limitations that should be considered when interpreting findings. It used convenience sampling through existing networks, and the results may not be generalizable to all Georgia cancer survivors.

The survey was available only in English, limiting accessibility for non-English-speaking survivor communities. Rural survivors are underrepresented relative to their proportion of Georgia's cancer survivor population.

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References

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