The GA Cancer Survivorship Workgroup Survey Results

CAM ESCOFFERY, PHD, MPH, CHES
ROLLINS SCHOOL OF PUBLIC HEALTH

Georgia Center for Oncology Research and Education’s Cancer Survivorship: Up Close & Personal
15,533,220: The number of adults and children with a history of cancer alive in the United States as of January 2016

More than one-half (56%) of survivors were diagnosed within the past 10 years

410,740: The number of survivors in GA
Purpose

Aim 1: To understand the physical, psychological, practical, and spiritual needs of adult cancer survivors in Georgia

Aim 2: To identify the existing support services, resources, and to understand access and receipt of care of the services that exist in Georgia

Aim 3: To determine if cancer survivors’ needs are being met by the services in Georgia
Methods

• Georgia Cancer Control Consortium (GC3) Survivorship Workgroup commissioned the survey

• Design: Cross-sectional online and paper-based survey

• Data collection: September - December 2014

• IRB Approval
  • Primary, Emory University IRB
  • Some hospitals also approved protocol
Methods

• Eligibility criteria include:
  1. individuals who are cancer survivors (a cancer survivorship starts from the point of diagnosis of cancer and extends to end of one’s life, ACS, 2013)
  2. are adults (above 18 years of age)
  3. have access to the internet, and
  4. live in Georgia or received cancer treatment in Georgia

• Recruitment
  • Email to cancer survivors through listservs of Georgia CORE partners to complete it online
  • Paper version of survey was available at certain clinics
Survey Instrument

Demographics

Cancer and cancer history (e.g., age of diagnosis, treatment)

Ratings of health (overall physical health, mental health) and comorbid conditions

Wellness behaviors

Interactions with physicians

Experience with physical, psychosocial, religious and practical needs and ratings of needs being met

Information seeking practices

Cancer treatment summaries and care plans
Demographics of Survivors (N~729)

- Primarily female (78%), married (65%), white (83%), and educated (88% some college+)

- Most (80%) were within 5 years of treatment

- Mean age: 58.2 (SD=11.6)

- Most reported other comorbid conditions: hypertension, high cholesterol, joint problems, and gastrointestinal problems
## Cancer Type

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin</td>
<td>8</td>
</tr>
<tr>
<td>Prostate</td>
<td>9</td>
</tr>
<tr>
<td>Blood</td>
<td>13</td>
</tr>
<tr>
<td>Breast</td>
<td>55</td>
</tr>
</tbody>
</table>

**Figure 1. Estimated Numbers of US Cancer Survivors**

As of January 1, 2016

**Male**
- Prostate: 3,306,760
- Colon & rectum: 724,690
- Melanoma: 614,460
- Urinary bladder: 574,250
- Non-Hodgkin lymphoma: 361,480
- Kidney & renal pelvis: 305,340
- Testis: 266,550
- Lung & bronchus: 238,300
- Leukemia: 230,920
- Oral cavity & pharynx: 229,880
- **Total survivors**: 7,377,100

**Female**
- Breast: 3,560,570
- Uterine corpus: 757,190
- Colon & rectum: 727,350
- Thyroid: 630,660
- Melanoma: 612,790
- Non-Hodgkin lymphoma: 324,890
- Lung & bronchus: 288,210
- Uterine cervix: 282,780
- Ovary: 235,200
- Kidney & renal pelvis: 204,040
- **Total survivors**: 8,156,120
Spends Enough Time with You: 3.2\% Never, 1.7\% Sometimes, 12.8\% Often, 55\% Very Often, 1\% I don't know

Involves you in decisions about your health care: 35.1\% Never, 42.1\% Sometimes, 28.9\% Often, 61.9\% Very Often, 1\% I don't know

Gives you a chance to ask the health-related questions that you have: 1\% Never, 8.3\% Sometimes, 28.3\% Often, 0.4\% Very Often, 16.4\% I don't know

Helps you deal with feelings of uncertainty about your health issues or treatments: 31\% Never, 43.2\% Sometimes, 16.4\% Often, 6.6\% Very Often, 2.8\% I don't know

Communication
Summary of Overall Needs

Proportion of Needs Being Met

<table>
<thead>
<tr>
<th>Category</th>
<th>All</th>
<th>Most</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spiritual</td>
<td>63</td>
<td>23</td>
</tr>
<tr>
<td>Practical</td>
<td>52</td>
<td>28</td>
</tr>
<tr>
<td>Physical</td>
<td>39</td>
<td>44</td>
</tr>
<tr>
<td>Emotional</td>
<td>43</td>
<td>31</td>
</tr>
</tbody>
</table>

Legend:
- All
- Most
Having Physical Concerns

% of Respondents Who Experienced Physical Needs

- Sleep: 46.4%
- Pain: 44%
- Tiredness: 42.7%
- Neuropathy: 31.2%
- Weight gain: 25.3%
- Nausea: 25%
- Incontinence: 22.2%
- Memory: 21.1%
- Intimacy/Sexual: 21%
- Lymphedema: 20.1%
Having Emotional Concerns

% of Respondents Who Experienced Emotional Needs

- Depression: 32.7%
- Anxiety: 32.1%
- Managing stress: 30.2%
- Fear of recurrence: 28.2%
- Defining new normal: 25.9%
- Coping with grief or loss: 21.1%
- Sense of wellbeing: 20.8%
- Isolation: 20.5%
Having Practical Concerns

% of Respondents Who Experienced Practical Needs

- Work related: 82.1%
- Financial or Money: 33.5%
- Health Insurance: 29.1%
- Managing household: 28.5%
- Return to responsibilities: 24.0%
- Finding support: 20.6%
Unmet Needs: Greater % Not Receiving Any Help

- Isolation (34.0), defining a new normal (31.4%), change in relations with partner (31.4%), coping with grief (29.6), and fear of recurrence (29.1%)
- Fertility (60%), body image (51.5%), intimacy (47%), memory (45%), and weight gain issues (39.5%)
- Legal issues (38.8%), work-related issues (34.9%), and finances (27.1%)
- End of life thoughts (37.8%) and loss of faith (31.4%)
Understanding of Issues and Late Effects

On a scale from 1 to 10, how well do you understand how to manage the common issues faced by cancer survivors, with 1 being no understanding at all and 10 being complete understanding?

On a scale from 1 to 10, how well are you able to get the information and/or assistance you need to address the late-term and long-term effects of your cancer, with 1 being not well at all and 10 being extremely well?
Receipt of Treatment Summaries and Care Plans

Proportion Received

- **Txt Summary**: 48
- **Care Plan**: 37
Single Most Important THING to Improve Quality of Life for other Survivors

Financial Support
Employment Support
Insurance Support
Attitude
Survivorship
LISTEN
Patience
Transportation

Support Groups
Encourage
Plan
Counseling
TIME
Honesty

Healthy Lifestyle
Team Care

INFORMATION/EDUCATION

FOLLOW-UP CARE

Survivor Programs
Resources

Faith

Compassion
Conclusion

Education and support are needed by survivors:

- Late effects cancer care and wellness behaviors
- Provider and community resources to support survivors and their families

Distress screening is necessary due to high reports of emotional needs not being met: Commission on Cancer (COC)’s requiring cancer centers to implement distress-screening

Care plans are necessary for education about survivorship and late effects

Multi-disciplinary survivorship care would better meet the emotional and mental health needs of survivors, and improve the coordination of care among oncologists, primary care providers, and other specialists
Acknowledgements

Special Thanks: Cassie Frank, Logan Kirsch, Angie Patterson and Nancy Paris

Georgia Cancer Control Consortium’s (GC3) Survivorship Working Group:
Rachel Cannady, American Cancer Society;
Maxine Cochran, Floyd Medical Center;
Jennifer Currin, Memorial Health University Center;
Jennifer Fournier, St. Joseph’s/Candler;
Joan Giblin, Winship Cancer Institute, Emory University;
MaryAnn Heddon, Pearlman Cancer Center;
Marilyn Hill, East Georgia Cancer Coalition;
Ann Hook, Redmond Regional Medical Center;
Mohammad Khalaf, Georgia Health Policy Center, Georgia State University;
Jody Temple, Joan Kines, Harbin Clinic;
Linda Lee, WellStar Health System;
Ann Mertens, Children's Healthcare of Atlanta;
Donna Meyer, Northside Hospital;
Katie Michaud, formerly with Gwinnett Medical Center;
Nausheen Punjani, formerly with Center for Pan Asian Community Services;
Toby Sidman, Georgia Breast Cancer Coalition;
Karen Terry, Memorial University Hospital;
Kim Scott, Cancer Coalition of South Georgia; and
Daniel Thompson, MPH, Tamira Moon, MPH, Georgia Department of Public Health.
Questions

For more information, contact Angie Patterson, GA CORE