

# Cancer-Related Disease Trauma: A Public Health Crisis

## Epidemiology, Surveillance, and Treatment

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### OBJECTIVES

There is a linear increase in the number of patients surviving a cancer diagnosis, estimated to exceed 22 million in the U.S. by the year 2030.<sup>1</sup> Epidemiologic data for cancer-related treatment effects (CRTE) are staggering and represent a public health crisis. This research aims to explore evidence to support the introduction of a new term to the medical lexicon to bring this public health crisis to light: cancer-related disease trauma (CRDT).

### METHODS

A review of the literature was conducted to provide a clinical epidemiological view of cancer survivors. In addition, patient-reported outcome (PRO) measures were administered to cancer survivors participating in oncology clinics to complement epidemiological data in describing disease burden.

### RESULTS

While the prevalence of physical and emotional CRTE varied across survivors, the most common physical CRTE included: cardiovascular; pulmonary; gastrointestinal; rheumatologic; endocrine; renal; sensory; neurological; lymphatic; genitourinary; and secondary malignancies.<sup>2</sup> Cancer survivors showed adverse symptoms impacting quality of life 5-years post diagnosis, including sexual health issues (45%), hot flashes (38%), pain (34%), fatigue (24%), and polyneuropathy (21%). Significant gaps in support are reported for menopausal disorders (43%), physical performance (39%), sleep problems (38%), arthralgia (37%), cognitive problems (36%), weight problems (32%), and fatigue (31%).<sup>3</sup> Additionally, behavioral and psychological issues commonly encountered among cancer survivors included emotional distress, body image concerns, infertility, fears of recurrence, financial toxicity, and social isolation.<sup>1</sup> Measuring components of CRDT using PROs in oncology clinics, a significant proportion of cancer survivors showed significant deficits in psychological health (48%), physical functioning (52%), social functioning (68%), cognitive functioning (56%), and financial health (68%).

### CONCLUSIONS

Addressing a gap in cancer survivor care, through vital-sign surveillance of CRDT using standardized PROs, a path forward is provided for updated standard-of-care services for cancer survivors and their health care providers that is delivered through a primary cancer survivor care model.

### Cancer Survivor Clinical Epidemiology

-An expanding number of cancer drugs are producing a more diverse range of potential toxicities, or cancer-related treatment effects (CRTE)

-Most common physical CRTEs include cardiovascular, pulmonary, gastrointestinal, endocrine, renal, sensory, neurological, lymphatic, genitourinary, and secondary malignancies<sup>2</sup>

-Cancer survivors show adverse symptoms impacting quality of life 5-years post diagnosis, including sexual health (45%), hot flashes (38%), pain (34%), fatigue (24%), and polyneuropathy (21%)<sup>3</sup>

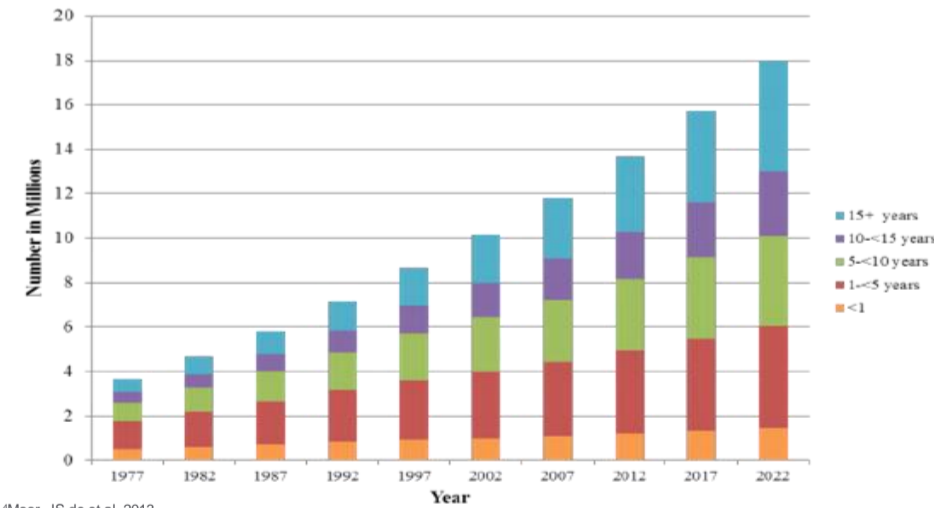
-Significant gaps exist for menopausal disorders (43%), physical performance (39%), sleep problems (38%), arthralgia (37%), cognitive problems (36%), weight problems (32%), and fatigue (31%)<sup>3</sup>

-Other behavioral and psychological issues encountered by cancer survivors include emotional distress, body image concerns, infertility, fears of recurrence, financial toxicity, and social isolation<sup>2</sup>

-CRTE issues tend to be enduring, rather than transitory, leaving many cancer survivors unable to cope with expectations of employers, families, and friends<sup>3</sup>

### Cancer Survivors in the U.S. Increasing Dramatically

-U.S cancer death rates have fallen 33% since 1991<sup>1</sup>



<sup>1</sup>Moor, JS de et al. 2013

### Prevalence of Cancer-Related Disease Effects

Health Problem	Adolescent and Young Adult Cancer Survivors Compared To Cancer-Free Siblings	Health Problem	Adult Cancer Survivors Compared To Cancer-Free Population
Angina	+5,450%	Cardiac Diseases	+147%
Chronic Obstructive Pulmonary Disease	+5,050%	Lung Diseases	+117%
Heart Attack	+3,400%	Neurological Diseases	+275%
Stroke	+2,800%	Psychology/Mental Health	+228%
Arthritis, Gout, Lupus, Fibromyalgia	+459%	Endocrine Disorders	+145%

<sup>1</sup>Librett and Yeates 2017

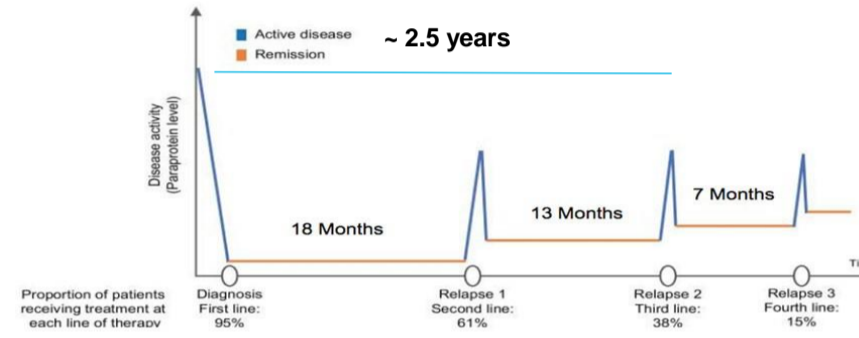
### 3-Year Experience for Cancer-Related Treatment Effects (CRTE): Bone Marrow Transplant (BMT)

**Incidence of multiple myeloma, lymphoma, and leukemia: 3,539<sup>6</sup>**

#### Cancer-Related Treatment Effects from BMT treatment:

-40% of patients experience Grade 3 to 5 chronic conditions resulting from treatment<sup>7</sup>

-55% of patients experience Grade 3 to 4 adverse events resulting from treatment<sup>8</sup>



### Economic Burden of Cancer Survivorship

-Approximately 30% of cancer survivors are disabled and not able to return to work or have decreased ability to work because of limitations in cognitive, mental, and physical functioning<sup>9</sup>

-Upwards of 47% of cancer survivors experience high levels of financial distress<sup>10</sup>

-Using out-of-pocket spending calculations and income ratios, between 28% and 48% of cancer survivors experience financial toxicity<sup>11</sup>

-Using subjective measures, up to 73% of cancer patients are reported to experience financial toxicity<sup>11</sup>

-Job-related income loss due to new cancer diagnosis was estimated to be upwards of \$13,462 per month during a 3-month period<sup>11</sup>

-Recently diagnosed cancer survivors aged 18 to 64 years had average total out-of-pocket medical expenditures of \$17,170 compared with \$6,485 among previously diagnosed cancer survivors and \$3,611 among those without a history of cancer<sup>12</sup>

### Cancer-Related Disease Trauma

-There is a linear increase in the number of cancer survivors, estimated to exceed 22 million in the U.S. by 2030<sup>1</sup>

-The epidemiological data for cancer-related treatment effects are staggering and represent a public health crisis

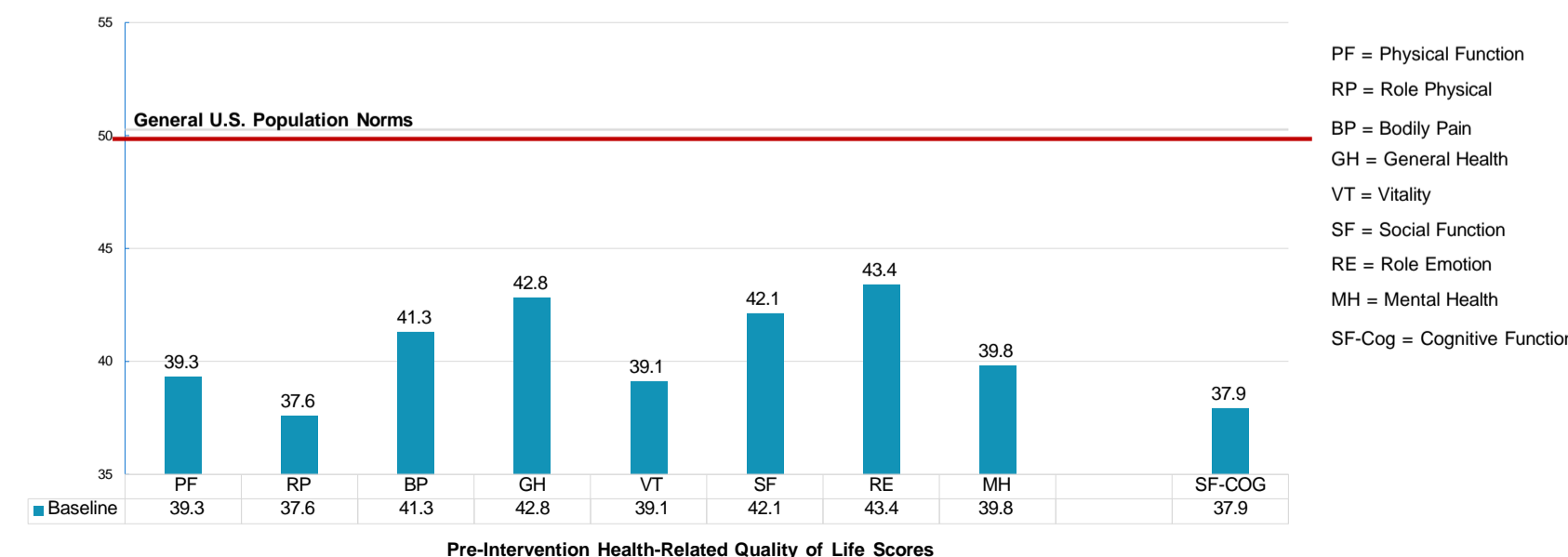
-The term "side-effects" does not adequately describe the profound life changes that can result from a cancer diagnosis and its treatment

-The negative effects of a cancer diagnosis and cancer treatment impact a patient's complete biopsychosocial realm and represent a public health crisis<sup>13</sup>

-To bring this public health crisis to light a new term to the medical lexicon is being introduced: **Cancer-Related Disease Trauma**

-Cancer-Related Disease Trauma is a syndrome that results from a clinically significant reduction of quality of life defined by moderating effects of psychological health, physical health, social health, and financial health

### Cancer Survivors Experience Significant Physical, Social, Role, Cognitive, and Mental Health Burden



PF = Physical Function  
 RP = Role Physical  
 BP = Bodily Pain  
 GH = General Health  
 VT = Vitality  
 SF = Social Function  
 RE = Role Emotion  
 MH = Mental Health  
 SF-COG = Cognitive Function

References

<sup>1</sup>American Cancer Society. Cancer Treatment & Survivorship Facts & Figures 2019-2021. Atlanta: American Cancer Society, 2019. <sup>2</sup>Beckjord EB, Reynolds KA, Rechis R. Psychological Factors and Survivorship: A Focus on Post-treatment Cancer Survivors. In: Psychological Aspects of Cancer. Springer, Boston, MA: 2013:327-346. <sup>3</sup>Schmidt ME, Wiskemann J, Steindorf K. Quality of life, problems, and needs of disease-free breast cancer survivors 5 years after diagnosis. Qual Life Res. 2018;27(8):2077-2086. doi:10.1007/s1136-018-1866-8. <sup>4</sup>Moor JS de, Mariotto AB, Parry C, 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. doi:10.1158/1055-9965.EPI-12-1356. <sup>5</sup>Librett J, Yeates E. Cancer Survivor Plans, Policy, & 572 Environmental Review. State of Utah. 2017. <sup>6</sup>Utah Cancer Registry. Cancer in Utah 2017-2019. <https://uhealth.utah.edu/utah-cancer-registry/>. <sup>7</sup>Bird SA, Boyd K. Multiple myeloma: an overview of management. Palliat Care. 2019;13:1178224219868235. doi:10.1177/1178224219868235. <sup>8</sup>Strauss DU. Long-term survivorship at a price: late-term, therapy-associated toxicities in the adult hodgkin lymphoma patient. Therapeutic Advances in Hematology. 2011;2(2):111-119. doi:10.1177/2040620711402414. <sup>9</sup>Ekwueme DU, Yabroff KR, Guy GP, et al. Medical costs and productivity losses of cancer survivors—United States, 2008-2011. MMWR Morb Mortal Wkly Rep. 2014;63(23):505-510. <sup>10</sup>Chino F, Peppercorn J, Taylor DH, et al. Self-reported financial burden and satisfaction with care among patients with cancer. Oncologist. 2014;19(4):414-420. doi:10.1634/theoncologist.2013-0374. <sup>11</sup>Carrera PM, Kantarjian HM, Binder VS. The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. CA Cancer J Clin. 2018;68(2):153-165. doi:10.3322/caac.21443. <sup>12</sup>Guy GP, Ekwueme DU, Yabroff KR, et al. Economic burden of cancer survivorship among adults in the United States. J Clin Oncol. 2013;31(30):3749-3757. doi:10.1200/JCO.2013.49.1241. <sup>13</sup>Librett J, Kosinski M, Gentile J, et al. Cancer-Related Disease Trauma, A Public Health Crisis. 2022. <sup>14</sup>Sapra A, Malik A, Bhandari P. Vital Sign Assessment. In: Sapra A, Malik A, Bhandari P, eds. StatPearls [Internet]. StatPearls Publishing; 2022. <sup>15</sup>Ayers AA. Competitive Edge: The Importance of Taking Accurate Vitals. Journal of Urgent Care Medicine. <https://www.jucm.com/competitive-edge-importance-taking-accurate-vitals/>. Accessed 05/26/22.

### Primary Cancer Survivor Care Model Developed to Meet Unmet Clinical Needs of Cancer Survivors

-A theoretical model for CRDT reflects the values identified by any cancer survivor who seeks to improve psychological health, physical health, social health, and financial health status

-To accommodate these values in a care program, a patient-reported outcome (PRO) measurement tool was implemented in a community-based cancer survivor clinic that measures vital signs for risk of CRDT

-Patients are tracked for clinically meaningful temporal change over time while capturing the patient's perspectives during clinical visits and between clinical encounters

-These vital signs are a standard component of measurement and assessment for any clinical evaluation<sup>14</sup> and are important to providing quality patient care as they can be an early indication of illness, deterioration, or an impending adverse health event<sup>15</sup>

### Survivor Healthcare (SHC) System for Developing a Quality Primary Cancer Survivor Care Program

#### PATIENT REPORTED OUTCOMES (PROs)

- Collection of Point-of-Care PROs are integrated into electronic medical records.
- SHC PROs are efficiently completed by the patient at clinically relevant intervals.

- SHC PROs are nationally validated, widely published in peer review medical journals, benchmarked, normed, and accepted by CMS and the FDA.

#### APPROACH TO CARE

- Standard-of-care algorithms follow national clinical practice guidelines.
- A multi-disciplinary clinical team specifically addresses cancer related treatment effects.
- Primary cancer survivor care clinicians participate in weekly clinical grand rounds.

#### PROGRAM SCALABILITY

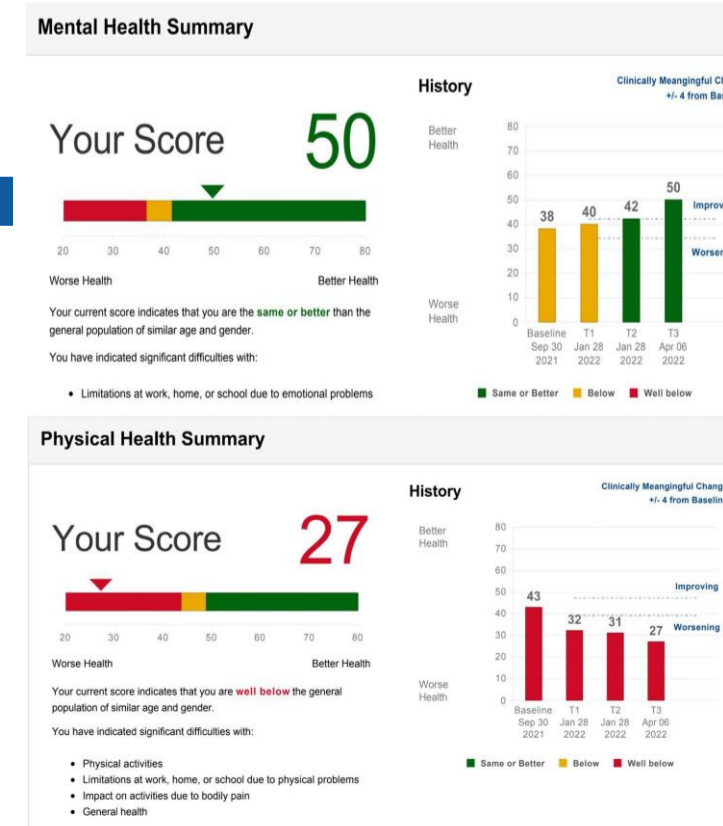
- The clinic hires and trains clinicians who deliver new standard-of-care service lines for cancer survivorship.
- Service-line agreements support the delivery of value-based medicine.
- Virtual environment brings quality clinical care to anywhere in the world.

#### CLINIC QUALITY

- Clinical outcomes are audited through a peer-review research and evaluation process.
- An interdisciplinary clinical team is trained on primary cancer survivor standards-of-care.
- The clinic is supported by a dedicated evaluation, research, and implementation science program.

### Clinic Data

#### Individual level patient trend data



#### Population level patient trend data

