Leveraging the Changing Landscape to Improve Mental Health Care for Survivors
Effect of the ACA on Mental Health Care for Survivors

Innovation in a Rapidly Changing Landscape: 8th Biennial Cancer Survivorship Research Conference

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Massachusetts General Hospital
Funding Acknowledgements

- NCI K24CA197382
- NCI CANCORS Statistical Coordinating Center (U01 CA093344) and the NCI-supported Primary Data Collection and Research Centers (U01 CA093332, U01 CA093324, U01 CA093348, U01 CA093329, U01 CA093339, U01 CA093326, CRS 02-164)
- American Cancer Society (MRSG-005-05-CPPB)
- NCI U54 (U54 CA156732)
- Livestrong Foundation
- CCSS (U24 CA55727)
Mental Health Needs

- Across diagnoses, cancer patients are at significantly increased risk for psychological symptoms (Mitchell AJ, Lancet Oncol 2011; Kendall J, Psycho-oncology; 2011).
- > 30% of cancer patients report psychological distress in cancer patients is often reported to be above 30% (Jacobsen PB. J Clin Oncol; 2007).
- 10-25% report depressive symptoms (Pirl, WF. Natl Cancer Inst Monogr; 2004)
- 10-30% report depressive symptoms (Stark & House Br J Cancer; 2000)
## Risk Factors for Psychological Distress after Cancer

*(Recklitis & Bober, Oncology; 2009)*

<table>
<thead>
<tr>
<th>Personal Factors</th>
<th>Disease Factors</th>
<th>Physical Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>• History of mental illness</td>
<td>• Residual disease/recurrence</td>
<td>• Poor health status</td>
</tr>
<tr>
<td>• Economic hardship</td>
<td>• Poor prognosis</td>
<td>• Chronic medical conditions</td>
</tr>
<tr>
<td>• Lack of social support</td>
<td>• Prolonged or intense treatment (eg, bone marrow transplant)</td>
<td>• Chronic pain</td>
</tr>
<tr>
<td>• Life stressors (eg, divorce, unemployment)</td>
<td>• Problems adjusting or adhering to treatment (eg, medication noncompliance, substance abuse, extreme emotional distress)</td>
<td>• Functional limitations (eg, ambulation, communication)</td>
</tr>
<tr>
<td>• Disability</td>
<td></td>
<td>• Difficulties in self-care (eg, dressing, eating, bathing)</td>
</tr>
</tbody>
</table>
Mental Health Service Use Among Adult Cancer Survivors:
Analyses of the National Health Interview Survey

By Maria Hewitt and Julia H. Rowland

Mental health needs and service use in a national sample of adult cancer survivors in the USA: has psychosocial care improved?

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Abstract

Objective: This study aims to estimate and test temporal differences in mental health (MH) need and service use among adult cancer survivors nationally before and after important policy recommendations for psychosocial cancer care.

Methods: Adults (n=58,585) from the National Health Interview Survey, 2005 and 2010, were categorized as having (1) no chronic disease, (2) chronic disease other than cancer, (3) cancer without other chronic disease, and (4) cancer with other chronic disease. In these groups, we compared psychological distress, MH visits, and unmet need for MH services. Survey-weighted logistic regression was used to model these variables as functions of disease status and sociodemographic covariates and the interactions of disease status and survey year.

Results: Whereas the proportion of individuals with psychological distress and MH visits was significantly higher in 2010 versus 2005 for the no chronic disease group, the only group with significantly lower unmet need in 2010 versus 2005 was the cancer with other chronic disease group (5.3% vs. 3.0%, p < 0.05). In adjusted models, cancer survivors with other chronic disease had significantly lower odds of unmet need in 2010 (odds ratio 1.38; 95% confidence interval 0.85, 2.25) than in 2005 (odds ratio 3.32; 95% confidence interval 2.28, 4.83).

Conclusions: We find evidence of MH care quality improvement among cancer survivors between 2005 and 2010, a period that coincides with policy and clinical attention to psychosocial cancer care. These efforts may have reduced, but not eliminated, unmet need for MH services among cancer survivors.

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Previous health policies protections from health status discriminations

- **Americans with Disabilities Act (ADA, 1990)**
  - Prohibits employment discrimination for individuals with disabilities

- **Family Medical Leave Act (FMLA, 1993)**
  - Requires covered employers to provide job-protected and unpaid leave for serious condition

- **Health Insurance Portability & Accountability Act (HIPAA, 1996)**
  - Prevents denying health insurance based on medical conditions.

- Requires insurance companies to cover mental and behavioral health coverage in a way that is equal to or better than coverage for physical health.
- No annual limits or higher co-pays or deductibles for mental health disorders or substance use.
- Applies to most employer-provided health plans and to individual plans

Limitations:
- Medicare exempt
- Health care plan can exclude diagnoses
- Insurance can implement limits on “medical necessity”
Similarly, since 2010, the proportion of adults aware of Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) has remained unchanged. Again, those who have used their mental health benefits are more likely than adults overall to say they have heard of the legislation.
Affordable Care Act (2010)

- ACA established provisions intended to increase access to affordable health insurance
- ACA expands mental health benefits:
  1. Including mental health and substance use disorder benefits in the Essential Health Benefits
  2. Applying federal parity protections to mental health and substance use disorder benefits in the individual and small group markets
  3. Providing access to quality health care
ACA Specific Provisions

- Health care exchanges serving low-income populations
- Medicaid expansion
- No coverage denial for pre-existing conditions
- Staying on parents coverage till age 26
- Primary care visits and preventive care coverage requirements without co-pay
### ACOs and Depression Screening

<table>
<thead>
<tr>
<th>Service</th>
<th>Did not meet benchmark</th>
<th>Met minimum quality benchmark</th>
<th>Met maximum quality benchmark</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting timely care</td>
<td>7</td>
<td>90</td>
<td>100</td>
</tr>
<tr>
<td>How well doctors communicate</td>
<td>7</td>
<td>93</td>
<td>100</td>
</tr>
<tr>
<td>Shared decision-making</td>
<td>21</td>
<td>62</td>
<td>17</td>
</tr>
<tr>
<td>Risk-standardized all-condition readmission</td>
<td>18</td>
<td>81</td>
<td>55</td>
</tr>
<tr>
<td>ACS admissions for heart failure</td>
<td>45</td>
<td>69</td>
<td>7</td>
</tr>
<tr>
<td>% of PCPs qualified for EHR incentive</td>
<td>12</td>
<td>43</td>
<td>7</td>
</tr>
<tr>
<td>Medication reconciliation</td>
<td>25</td>
<td>67</td>
<td>8</td>
</tr>
<tr>
<td>Screening for fall risk</td>
<td>25</td>
<td>91</td>
<td>8</td>
</tr>
<tr>
<td>Pneumococcal vaccination</td>
<td>21</td>
<td>59</td>
<td>20</td>
</tr>
<tr>
<td>Depression screening</td>
<td>21</td>
<td>59</td>
<td>20</td>
</tr>
<tr>
<td>Colorectal cancer screening</td>
<td>25</td>
<td>91</td>
<td>8</td>
</tr>
<tr>
<td>Adults with BP screening in past 2 years</td>
<td>5</td>
<td>56</td>
<td>39</td>
</tr>
<tr>
<td>Diabetes composite</td>
<td>34</td>
<td>58</td>
<td>8</td>
</tr>
<tr>
<td>% with hypertension with BP &lt;140/90</td>
<td>15</td>
<td>80</td>
<td>5</td>
</tr>
<tr>
<td>Coronary artery disease composite</td>
<td>28</td>
<td>62</td>
<td>10</td>
</tr>
</tbody>
</table>

Notes: Benchmarks are set based on the performance of Medicare providers not participating in the Shared Savings Program. ACS = ambulatory care-sensitive. Source: Centers for Medicare and Medicaid Services: [https://data.cms.gov/ACO/Medicare-Shared-Savings-Program-Accountable-Care-O/yuq5-65xi](https://data.cms.gov/ACO/Medicare-Shared-Savings-Program-Accountable-Care-O/yuq5-65xi)

### CWF Report: Percent of ACOs in the Medicare Shared Saving Program meeting Select Quality Benchmarks (2013)
Childhood Cancer Survivor Study

• Funded in 1994
• Retrospective Cohort, diagnosed 1970-1986
• 26 Contributing Centers
• 5-Year Survival (median age=23yrs, range 5-45)
• Leukemia, Lymphoma, CNS, Bone, Wilms, NBL, Soft-tissue sarcoma
• Detailed Treatment Data, Wide Range of Outcomes

20,720 Eligible
Lost (n=3017)

17,703 Contacted
Refusal (n=3189)

14,372 Participants

Health Insurance Study: Used random selection, stratifying by age and health insurance status (uninsured, insured) to survey 698 survivors and 210 siblings in 2011-2012.
Childhood survivors’ familiarity with the ACA and related health policies

![Bar charts showing familiarity with ACA, ADA, FMLA, COBRA, HIPAA for survivors and siblings, and insured and uninsured survivors.](chartimage)

**Fig 2.** Familiarity of (A) survivors of childhood cancer and their siblings and of (B) insured and uninsured survivors with health insurance-related legislation. Multivariable logistic regressions adjusted for current age, sex, marital status, and chronic disease. Models comparing survivors and siblings were also adjusted for insurance status. ACA, Patient Protection and Affordable Care Act; ADA, Americans with Disabilities Act; COBRA, Consolidated Omnibus Budget Reconciliation Act; FMLA, Family Medical Leave Act; HIPAA, Health Insurance Portability and Accountability Act; OR, odds ratio.

Park et al, JCO; 2015
Psychosocial staffing at National Comprehensive Cancer Network member institutions (DeShields, 2015, Psycho-oncology)

<table>
<thead>
<tr>
<th>Professional</th>
<th>0 to 2</th>
<th>&gt;2 to 4</th>
<th>&gt;4 to 6</th>
<th>&gt;6 to 8</th>
<th>&gt;8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical psychologists (n=14)</td>
<td>60%</td>
<td>20%</td>
<td>7%</td>
<td>7%</td>
<td>7%</td>
</tr>
<tr>
<td>Neuropsychologists (n=9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health therapists</td>
<td>7%</td>
<td>14%</td>
<td></td>
<td>71%</td>
<td></td>
</tr>
<tr>
<td>(including Social Workers) (n=13)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case managers (from any discipline) (n=10)</td>
<td>40%</td>
<td>20%</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatrists (n=12)</td>
<td></td>
<td></td>
<td>8%</td>
<td>15%</td>
<td>8%</td>
</tr>
<tr>
<td>Nurses (n=12)</td>
<td></td>
<td></td>
<td>17%</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>Chaplains (n=12)</td>
<td></td>
<td></td>
<td>8%</td>
<td>25%</td>
<td>8%</td>
</tr>
<tr>
<td>Support staff (administrative) (n=12)</td>
<td>50%</td>
<td></td>
<td>25%</td>
<td>8%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Number of Psychosocial Staff (by FTE)
Psychosocial staffing at National Comprehensive Cancer Network institutions (DeShields, 2015, Psycho-oncology)

<table>
<thead>
<tr>
<th>Professional Group</th>
<th>Institutional Funds</th>
<th>Grant Funds</th>
<th>Fee for Service</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologists (n=13)</td>
<td>29%</td>
<td>14%</td>
<td>71%</td>
<td></td>
</tr>
<tr>
<td>Mental Health Therapists (n=6)</td>
<td>17%</td>
<td>17%</td>
<td>83%</td>
<td></td>
</tr>
<tr>
<td>Social Workers (n=17)</td>
<td>17%</td>
<td>0%</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>Psychiatrists (n=13)</td>
<td>36%</td>
<td>14%</td>
<td>64%</td>
<td></td>
</tr>
<tr>
<td>Nurses (n=12)</td>
<td>8%</td>
<td>0%</td>
<td>8%</td>
<td>100%</td>
</tr>
<tr>
<td>Chaplains (n=14)</td>
<td>7%</td>
<td>0%</td>
<td>13%</td>
<td>93%</td>
</tr>
<tr>
<td>Support Staff (n=12)</td>
<td>38%</td>
<td>0%</td>
<td>15%</td>
<td>100%</td>
</tr>
</tbody>
</table>
Mental Health Care Utilization among Lung Cancer Survivors

- Use CanCORS dataset to identify rates of mental healthcare utilization in NHB and NHW lung cancer patients who report depression symptoms (n=1043)
- In-depth interviews with survivors from the Dana-Farber Harvard Cancer Center (n=20)
  - Perceptions of psychosocial services & utilization
Psychosocial Services Utilization from diagnosis to 5-months post diagnosis (n=1043)

Traeger et al., JCO; 2013
Primary Themes

- Patients were not able to differentiate between different types of mental health treatments
- Dearth of conversations about mental health care needs & cancer center resources
- Patients might perceive suggested need for help as a stigma
- Implications: Integrate mental health resources and referrals into cancer treatment
Childhood Survivors’ Perceptions of Mental Health Coverage

(Perez, et al; 2015; IPOS)
Medicaid plans struggle to provide mental health services

By Virgil Dickson | July 4, 2015

At the start of 2014, California's Medicaid program took over management of mental health services from the state's 58 counties. For Inland Empire Health Plan, a Medi-Cal managed-care plan, that meant going from being responsible for behavioral health benefits for 12,000 beneficiaries dually eligible for Medicare and Medicaid to more than a million enrollees.

Mental Health Now Covered Under ACA, but Not for Everyone

Several states are trying new experiments to ensure complete coverage, while others opt out altogether.

By Susan Brink, Contributor | Apr 22, 2016 at 12:11 am
Survivors remain at risk for unmet health care needs & financial burden

- Low incomes and live in states not participating in the ACA’s Medicaid expansion
- Forgo coverage
- Narrow network plans limit where care is obtained
- No coverage for survivor-specific prevention guidelines
Directions in Mental Health Care Delivery for Survivors

- Increased identification of patients through mental health screening
- Diversity of providers & systems delivering care
- Integration of mental care

Increase awareness to facilitate survivors’ access of mental health services