Delivering Psychosocial Care to Cancer Survivors:
Progress Made & Still to come…

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Update on 2013 IOM Report: *Delivering High Quality Cancer Care*

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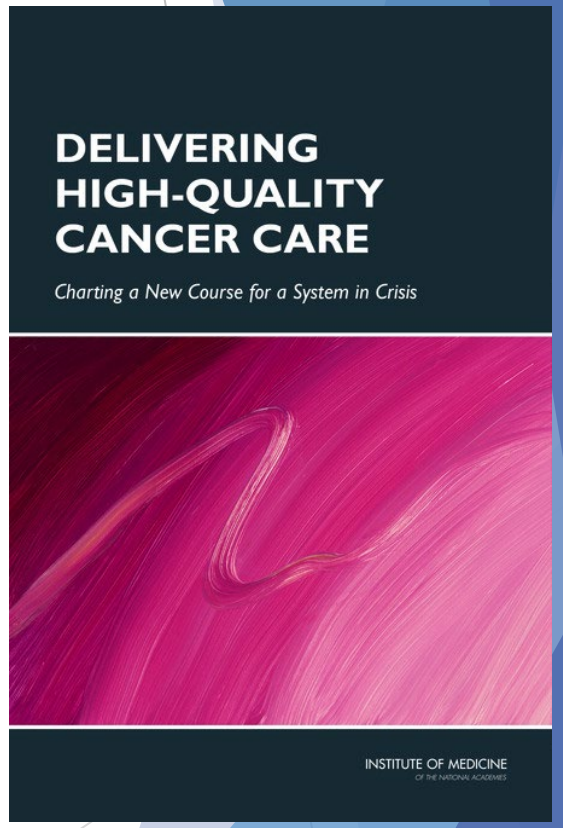
Delivering High-Quality Cancer Care
Conceptual Framework

1. Engaged Patients
2. Adequately Staffed, Trained & Coordinated Workforce
3. Evidence-Based Cancer Care
4. A Learning Health Care IT System for Cancer
5. Translation of Evidence into Clinical Practice, quality measurement, and Performance Improvement
6. Accessible, Affordable Cancer Care



Framework Recommendations
1. Engaged Patient (and family)

Progress made

- Screening for distress increased (NCCN, ASCO, CoC)
- Recommendations and templates for Survivorship Care Planning (SCPs) introduced; mixed uptake (CoC & ASCO)
- Growth in palliative care programs and research (e.g., work of Temel et al)
- Uptake in communication training for oncology staff; Standard setting (see: Sisk et al, Pediatr Blood Cancer, 2023)
- CARE act of 2015 to identify and support family caregivers; growing appreciation of their vital role (see Griffin et al, J Aging Soc Policy, 2022)
- Visible emphasis on patient and community input: PCORI, COE requirements for NCI designated Cancer Centers; PRO-CTCAE (Dueck et al, JAMA Oncol, 2015; CBPR designs

Still to come…

- **Ensure receipt by patients/families of information and resources for psychosocial care**
- Broadening uptake of additional screening to tailor and target care: SDOH, CGA
- **Examination of pathways to care after screening!**
- Revisit support for development and personal delivery of SCPs plans
- **Greater use of peer advocates/support and community resources**

Framework Recommendations
2. Adequately staffed, trained & coordinated workforce

Progress made

- Growing number of primary care providers joining oncology teams (e.g., cardio-oncology)
- Growth in use of EMRs and telehealth to support coordination of and delivery of care
- Oncology patient navigation standards being introduced
- Diverse ASCO educational opportunities abound
- Burgeoning array of survivorship symposia and courses that emphasize whole person care

Still to come…

- **Set staffing standards for delivery of quality psychosocial cancer care**
- Embed relevant teaching about psychosocial impact on and care of cancer survivors to all oncology (from medical students through senior staff); set standards for this knowledge
- Engage/educate primary care providers in delivery of cancer survivorship care
- **CMS proposal to pay for patient navigation in serious illness**
- **Train more oncology mental health providers**

Framework Recommendations
3. Evidence-based cancer care

Progress made

- Growth in guidelines for *psychosocial care* (e.g., ASCO and new ASCO/SIO guidelines for management of anxiety and depression in adults with cancer)
- Pediatric guidelines on psychosocial care (Weiner et al. Psychooncol, 2015; Weaver et al, Palliat Med, 2016)
- Expanded measurement opportunities around psychosocial care delivery by ASCO (QOPI), NCCN, CoC
- Research on risk for and prevention of long-term/late effects increasing; CCSS data of note

Still to come…

- **Examination and dissemination of models for delivery of high quality psychosocial oncology care (e.g., City of Hope)**
- Support for clinical trials among older cancer survivors including assessment of patient-centered outcomes (e.g., work of CARG)
- **(Re)designing psychosocial interventions for dissemination**

Framework Recommendations
4. A learning healthcare IT system for cancer

Progress made

- Expanded SEER System for data collection (pharmacies, pathology)
- Broader use of EHR systems to track patient well-being, populate and deliver Survivorship Care Plans (SCPs)

Still to come…

- Fast paced growth of new inter-connective technologies that holds promise for better coordination of care
- Need for creation of platforms that seamlessly interface with one another; interoperability, usability, meaningful use
- **Come together to decide about a common set of elements to be collected on every cancer patient (incl. pt care and clinical trials): *Demographics, health behaviors, SDOH***

Framework Recommendations
5. Translation of knowledge into clinical practice, Quality Measurement & Performance Improvement

Progress made

- NCI attention to implementation and dissemination science; support for studies to translate research into practice
- Encouragement of investigators to *design interventions for dissemination*

Still to come…

- **Monitoring use of guideline-based psychosocial care (e.g., ASCO/QOPI, NCCN)**
- Creation of quality improvement programs that increase guideline-concordant psychosocial care of cancer survivors and their families
- **Development of national measurement approaches to monitoring well-being & function of cancer survivors over time (NCI cohorts; SEER data collection): *metrics for success!***

Population estimates for poor HRQOL among cancer survivors from the 2010 NHIS as measured by the PROMIS Global 10

Weaver et al, *Cancer Epidemiol Biomarkers Prev* 2012

	Weighted prevalence Adults without Cancer	Weighted prevalence Cancer Survivors	Population Est. for Cancer Survivors (SE)
Physical health score < 1 SD below U.S. population mean	10.2%	24.5%	3,278,000 (184,000)
Mental health score < 1 SD below U.S. population mean	5.9%	10.1%	1,356,000 (122,000)
Physical and mental HRQOL < 1 SD below U.S. population mean	3.5%	7.2%	973,000 (99,000)

Framework Recommendations
6. Accessible, affordable cancer care

Progress made

- Positive impact of ACA health insurance expansion on cancer care access and outcomes ; awareness of 'financial toxicity' for survivors
- Establishment of NCORP, expanding access to clinical trials into the larger community and also affording psychosocial/behavioral research
- Broad uptake of telehealth in response to COVID has had a positive impact on access
- However, progress has been significantly challenged by: smaller than needed workforce, high drug costs, COVID, rapidly growing cancer population

Still to come…

- Continued support for telehealth is warranted
- Building on the chronic illness model for care delivery among survivors (promoting self-management, community-based care)
- ***Partner with community-based organizations to deliver psychosocial care***
- Work to reduce the stigma associated with pursuit of emotional/mental health care
- ***Major initiatives are needed to expand coverage for mental health care across the country***

Why is it Important to Address Psycho-Social Care Needs in Cancer?

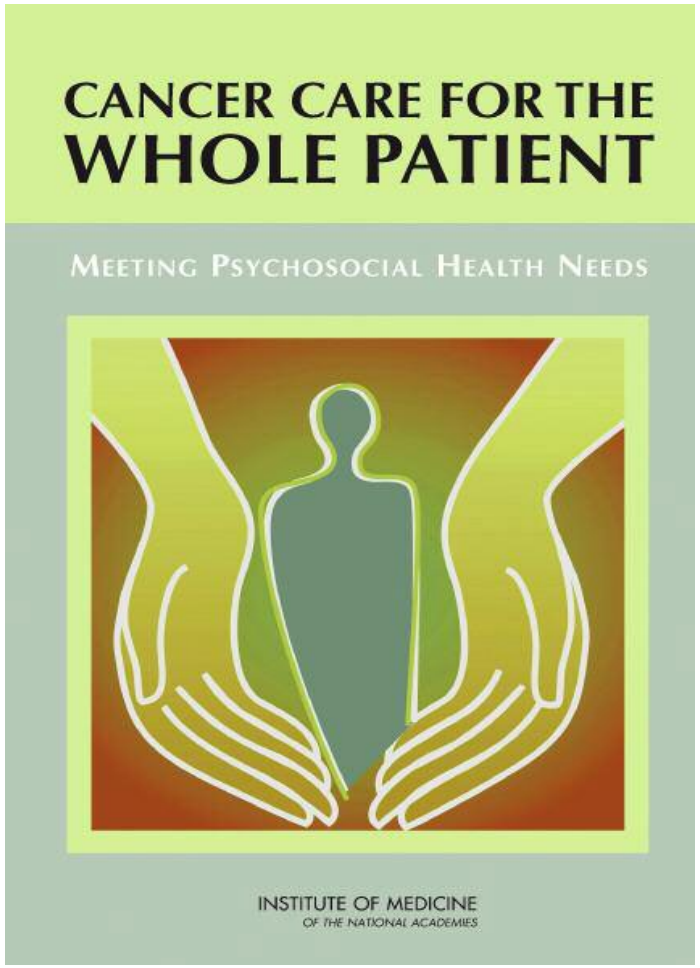
Presence of psychosocial problems can:

- Decrease pursuit of care (contribute to diagnostic and treatment delay)
- Lower treatment adherence
- Decrease chemotherapy effectiveness
- Increase symptom burden and decrease function
- Heighten risk of suicide
- Shorten length of survival
- Raise the financial cost of care (greater resource use & care demands)
- Compromise family health and function

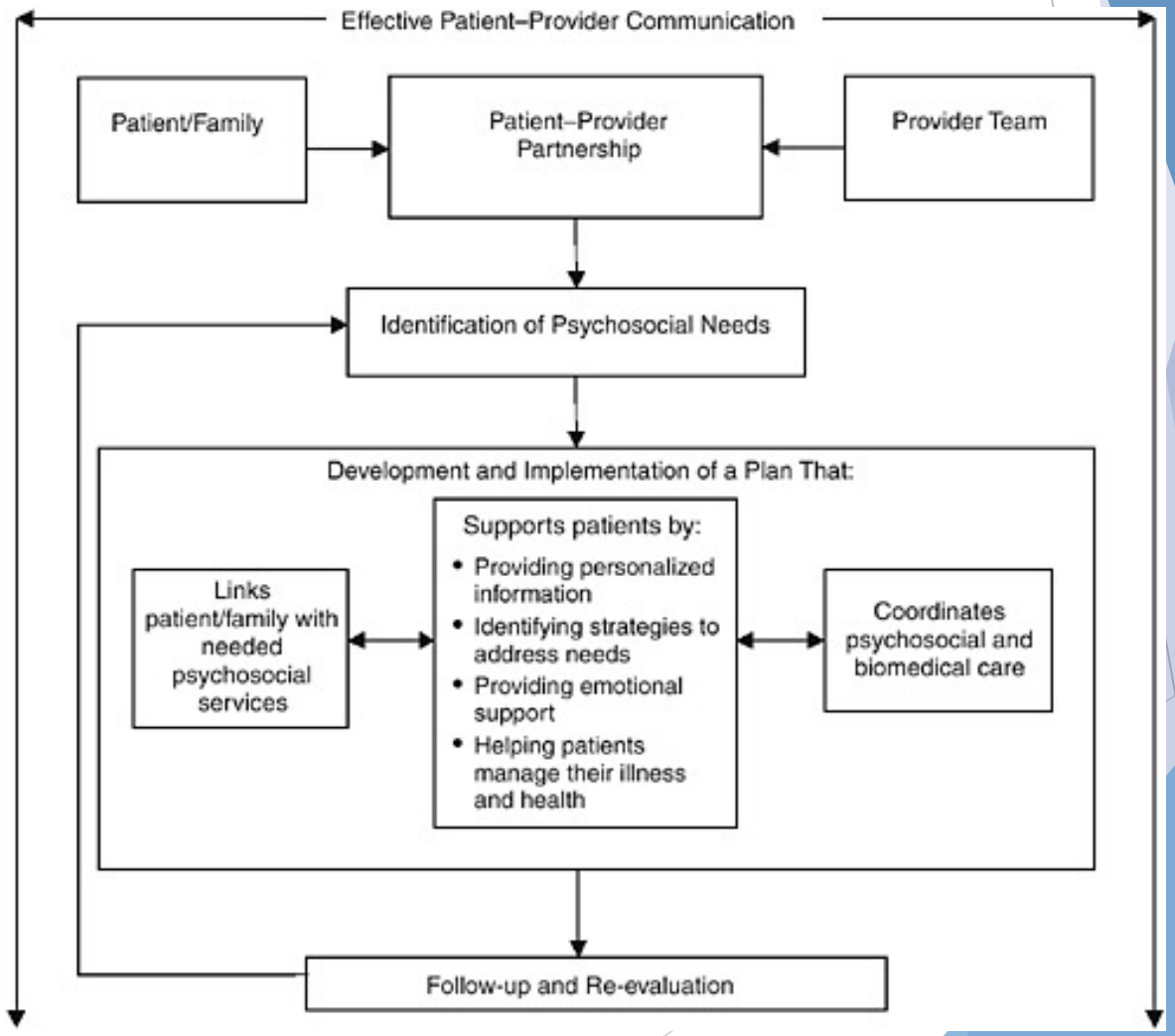
- ***In short, significantly increase the national burden of cancer***

- What we need is a comprehensive and sustained, multiprong, multilevel, & multi-stakeholder approach to tackling barriers to delivery & receipt of psychosocial care
- The biggest challenge to achieving high quality psychosocial cancer care is our *failure to deliver on what we already know.*
- *I believe that together, we can do this!*

Addressing psychosocial care needs of survivors and their families must be part of quality cancer care



IOM, 2007



Thank you!

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