Behavioral and Social Science in Cancer Control Research
August 10, 2017

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Catherine Alfano, Ph.D., American Cancer Society
The Cancer Control Continuum

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Crosscutting Issues

- Communications
- Surveillance
- Social Determinants of Health Disparities
- Genetic Testing
- Decision-Making
- Dissemination of Evidence-Based Interventions
- Health Care Delivery and Quality of Care
- Epidemiology
- Measurement

Adapted from David B. Abrams, Brown University School of Medicine
Overview

- Behavior
- Levels of Analysis
- Methods
- Survivorship

Behavioral Research in Cancer Prevention and Control
A Look to the Future
William M.P. Klein, PhD, Michele Bleeke, MD, PhD, Bradford W. Reise, PhD, Paige G. McDavis, PhD, MPH, Linda Needham, PhD, MPH, BS, Mary E. O'Connell, MA, William T. Reyn, PhD, Stephen H. Taplin, MD, MPH, Gina Tesser, MSW

METHOD: Human behavior is central to the etiology and management of cancer risk and presents several avenues for targeted and sustained intervention. Psychosocial experiences such as stress and health behaviors including tobacco use, nutrition, physical activity, and a healthy lifestyle influence the risk of some cancers and are quite resistant to change. Cancer screening and other health services are misunderstood and even resisted, and vaccination trends vary by area because of the paltry level of information about cancer prevention. Coordination of cancer care in hospitals and community-based settings is often disjointed and ineffective, with little attention paid to the development of new cancer treatments. A growing recognition of cancer survivorship has reinvigorated a fresh view of cancer as a chronic rather than acute disease. Importantly, behavioral research can address a wide variety of processes and outcomes across the cancer care continuum from prevention to end of life care. Here we consider efforts at the behavioral and psychosocial, social and organizational, and health care delivery levels of analysis.

Introduction
Although rates of some cancers have decreased during the past 30 years, others have grown. Cancer remains a leading cause of mortality, with an estimated U.S. economic impact of $240 billion in 2015. It is estimated that in 2015, about 1,600,000 Americans will die of cancer, accounting for approximately 20% of all deaths. The more general health landscape has also evolved substantially. In the late 1990s, Congress passed the U.S. Patient Protection and Affordable Care Act, which signifies a profound shift towards more efficient and effective outcomes and established the Future-Forward Oncogenetic Research Institute (FRORE). The 2009 Family Smoking Prevention and Tobacco Control Act provides the Federal Drug Administration (FDA) with broad authority to regulate the manufacturing, marketing, and distribution of tobacco products. The U.S. Preventive Service Task Force has revised guidelines for mammography, colonoscopy, mammography, and prostate screening. The guidelines call for more thorough decision-making between physicians and patients given the importance of weighing costs and benefits of different screening modalities. Social media and new social networking platforms have added the decision-making process and patient-provider dynamic. The platform for health messages has evolved from print media to websites and mobile applications. Individuals can now obtain access to their genetic profiles (outside of the healthcare system), access personal health records, and share concerns and symptoms with the health of family and friends.

As best two from experts, real-time data on multiple methods of intervention is now available, including multiple methodological tools that can inform decision making. This text is adapted from a 2008 National Research Institute (NRI) report on cancer research development. National Cancer Institute Director Harold Varmus observed in a 2006 Science column that cancer research remains a major area of focus.
Some of the most intractable behaviors significantly contribute to cancer risk.

Adapted from Wolin, Carson, and Colditz, 2010
Smoking and tobacco

- Lung cancer is the number one cause of cancer death for both men and women
- State cigarette excise tax rates vary dramatically
  - MO - $0.17/20-pack
  - NY - $4.35/20-pack
- Geography matters, with the greatest tobacco burden in the South
- Veterans are among the sub-populations with a higher prevalence of smoking
- Approximately 13% young adults use cigarettes
Diet, weight and alcohol use

- Considerable evidence indicates maintaining a healthy lifestyle can potentially reduce cancer-related morbidity.

- Alcohol-related cancer is responsible for 3.5 percent of all cancer deaths.
Physical activity

- Increasing levels of physical activity associated with lower risk of 13 cancers, including colon, breast and endometrial cancer, but higher risk of malignant melanoma
- Higher levels of physical activity associated with a 7 percent lower risk of total cancer

UV exposure and sun protective practices

- Reducing unprotected exposure to the sun and avoiding artificial ultraviolet (UV) light from indoor tanning beds, tanning booths, and sun lamps can lower the risk of skin cancer.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics. National Health Interview Survey. Data are age-adjusted to the 2000 US standard population using age groups: 18-24, 25-34, 35-44, 45-64, 65+.
Crosstalk – a unique approach to behavioral medicine

- Repurpose evidence-based approaches
- Apply basic disciplinary principles
- Apply common behavioral theory and identify common mechanisms
- Optimize study design and harmonize data
Examples of bio-psychosocial factors relevant to cancer control

- Emotion
- Cognition
- Decision-making
- Stress/distress
- Attention
- Motivation
- Genetic predisposition
- Sensory processes
Examples of social & environmental factors in cancer control

- SES/Social determinants
- Discrimination
- Individual/social factors
- Relationships/social support
- Physical/built environment
- Health provider recommendations
- Social and conventional media
- Local, state, Federal policy
- Product availability
Health communication

- Individual level
- Patient-provider communication
- Mass media
- Social media
- Warning labels
- Campaigns

"It is important for the public to understand that the harms of smoking cannot be reduced except by quitting." -- Annette Kaufman, Ph.D.
Behaviors in a health care context

- HPV vaccination
- Cancer screening
- Genetic testing
HPV vaccines prevent cancer

- Human Papilloma Virus (HPV) is a major cause of cervical cancer
- Two safe and effective vaccines are available to protect against infection with the two most prevalent cancer-causing HPV types
- The Advisory Committee on Immunization Practices (ACIP) recommends routine vaccination for HPV at age 11 or 12
Cancer screening

- Colorectal cancer screening
- Lung cancer screening
- Prostate Specific Antigen (PSA) screening
- Melanoma screening
BRCA 1/2 Referral/Testing

- ~30% of eligible breast cancer patients received guideline concordant testing

- ~10 percent of women meeting guideline criteria reported discussion about BRCA 1/2 testing with a provider

- ~30% of women who were BRCA 1/2 tested did not meet NCCN guideline criteria

## The Cancer Control Continuum

### Focus

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Adapted from David B. Abrams, Brown University School of Medicine
The Perfect Storm

- Skyrocketing Costs of Cancer Care & Survivorship
- Provider Knowledge Deficits
- Provider Shortages (ONC, PCP, Nursing)
- Chronic & Late Effects of Cancer (Physical, Psychosocial, Financial, Ability to Work)
- 15.5 Million Survivors +1.7M each year
Improve Care for Smooth Sailing

• Effective, Efficient Care
• Risk-based, personalized
• Patient-centered
• Toxicity prevention or early management
• Optimize function, QOL, longevity
Multilevel influences on Health and Healthcare (Cancer Example)

Multilevel influences on Health and Healthcare (Cancer Example)

Of Behavioral & Social Science

- National Health Policy
  - Medicare reimbursement
  - Federal efforts to reform healthcare
  - National cancer initiatives
  - Accreditations
  - Professional standards

- State Health Policy
  - Medicaid reimbursement
  - Hospital performance data policies (dissemination, visibility, etc.)
  - State cancer plans/programs
  - Regulations/limitations on reimbursement of clinical trials
  - Activities of state-wide advocacy groups

- Organization/Practice Setting
  - Leadership
  - Organizational structure, policies and incentives
  - Delivery system design
  - Clinical decision support
  - Clinical information systems
  - Patient education & navigation

- Provider/Team
  - Knowledge, communication skills
  - Perceived barriers, norms, test efficacy
  - Cultural competency
  - Staffing mix & turnover
  - Role definition
  - Teamwork

- Local Community
  - Community level resources
  - Medical care offerings
  - Population SES
  - Lay support networks
  - Private cancer organizations
  - Local hospital & cancer services market
  - Market structure
  - Level of competition
  - Third party payers/insurance
  - Pay for performance initiatives
  - Managed care penetration
  - Percent nonprofit
  - Specialty mix
  - Local professional norms
  - MD practice organizations
  - Use of guidelines
  - Practice patterns

- Individual Patient
  - Biological factors
  - Socio-demographics
  - Insurance coverage
  - Risk status
  - Comorbidities
  - Knowledge, attitudes, beliefs
  - Decision-making preferences
  - Psychological reaction/ coping

Improved Quality of Cancer Care

Improved Cancer-Related Health Outcomes

Taplin SH et al. J Natl Cancer Inst Monogr 2012;2012:2-10
Rose
Behavioral & Social Science: Rose’s Trajectory

Diagnosis
- Decision making
- Pt-provider communication

Treatment
- Toxicity risk
- Toxicity mechanisms
- Assessment/management
- Adherence
- Caregiver

Follow-up
- Risk-stratified care
- LT adherence
- Prevention
Behavioral & Social Science: Rose’s Trajectory

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EOL decision making

Dx: HF

Diagnosis of 2nth breast cancer
Integrate molecular, genomic, cellular, clinical, behavioral, physiological, and environmental data to:

“…enable better assessment of disease risk, understanding of disease mechanisms, and the prediction of optimal therapy for many more diseases…”
CANCER CARE CHANGES (2)...
BIG DATA & AI

Toward Precision Cancer Surveillance

Collaboration with the Department of Energy

NCI is collaborating with the U.S. Department of Energy (DOE) as part of the inter-agency coordination activities defined in the National Strategic Computing Initiative (NSCI) Presidential Order (July 26, 2016) and announced during Vice President Biden’s Cancer Moonshot Summit on June 25, 2016. The NCI-DOE collaboration has initiated three pilot efforts that will simultaneously impact the future of cancer research and guide future advances in scientific computing. These pilots will characterize and help overcome key precision oncology challenges at the molecular, patient, and population levels during the next three years.

Watson Health

Watson Brings the Promise of Precision Medicine to the Fight Against Cancer

PHILIPS

Philips and PathAI team up to improve breast cancer diagnosis using artificial intelligence technology in 'big data' pathology research

Imagine if your practice could see
1,000,000
patients a day.
CancerLinQ now has more than one million patient records in the system
BIAS IN AI

“The TIME WARP of AI: Study after study has shown that biased machine-learning systems result in everything from job-search ads that show women in lower-paying positions than men to predictive-policing software that perpetuates disparities in communities of color.”
CANCER CARE CHANGES (3)…Transition from Fee-for-Service to Value-based reimbursement

• Testing of novel, bundled payment models
• Search for interventions with
  – “bang for buck” for multiple chronic diseases
• Change practice patterns
ASCO Names Immunotherapy 2.0 as Cancer Advance of the Year in Latest Clinical Cancer Advances Report

Feb 01, 2017

Clinical Cancer Advances 2017: Annual Report on Progress Against Cancer From the American Society of Clinical Oncology

Toxicity from Cancer Immunotherapy


“...hyperactivated T-cell response with reactivity directed against normal tissue”

Checkpoint inhibitors induce autoinflammatory response

IFN-alpha, IL-2 induce fatigue, fever, autoimmunity, neurotoxicity, and myocarditis

Adoptive cell therapy (T cells) induces Cytokine Release Syndrome resembling sepsis

Long-term toxicities???
This 8-year-old is free of cancer — for now — after a ‘breakthrough’ treatment
Precision Medicine, Risk-based Comprehensive Care

Better predict: recurrence, 2nd cancers, chronic & late effects

**FIGURE 1.** A multitude of host- and cancer-related factors influence the risk of morbidity after cancer.

Hudson, 2005, *Cancer*
THANK YOU!
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