Changing Health Services Research Priorities in Breast Cancer

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Introduction: decreased mortality rate

Breast Cancer Deaths per 100,000 Women

Source: CDC
Introduction: Increased survival

Early detection

Source: Baeyens-Fernández et al, 2018

Source: SEER Program, National Cancer Institute. Incidence data are from the SEER 9 areas (http://seer.cancer.gov/registries/terms.html). Data are not age-adjusted.
Introduction: treatment breakthroughs

- **1999:**
  - Trastuzumab (Herceptin), first targeted anti-breast cancer drug (HER2)
- **2011:**
  - Aromatase inhibitors approved for prevention
- **2015:**
  - CDK inhibitor palbociclib, a new class of breast cancer treatment introduced
- **2018:**
  - PARP inhibitor, treatment targets BRCA mutations
  - 21-gene-based test (Oncotype DX), guides choice of adjuvant therapy
  - Atezolizumab, first immunotherapy (PD-L1 targeted therapy) for metastatic triple-negative breast cancer
- **2019:**
  - CDK4/6 inhibitor, targeted therapy ribociclib combined with endocrine therapy

Source: ASCO
Objectives

- Describe the past and current health services research (HSR) priorities in breast cancer
- Identify priorities for future research
- Identify top funding agencies for HSR in breast cancer
Methods: Sample

Use "breast cancer" to conduct a search at https://hsrproject.nlm.nih.gov/, and downloaded the xml file. (N=909)

Projects whose initial years are between 2011 and 2019 (N=277)

Final sample (N=250)

Exclusions:
1. Non-research projects (N=20)
2. Not breast cancer related (N=3)
3. Non-NIH funding agencies that only showed up once between 2011-2019 (N=4)

Initial years between 2011 and 2013 (N=81)
Initial years between 2014 and 2016 (N=96)
Initial years between 2017 and 2019 (N=73)
Methods: Past and Current Priorities

• **Word clouds**: Illustrate the most frequent words (major topic areas)
• Input: project titles
• Word exclusions:
  - Common English words:
    • e.g. "among", "via"
  - Generic words for describing research:
    • "breast", "cancer", "women", "understanding", "improving", "methods", "impact", "effect", "population", "populations", "patient", "patients", "study", "research", "health", "care"
Methods: Past and Current Priorities

- **MeSH Terms**: Describe study populations and topics
- **Input**: MeSH Terms
- **Exclusion criteria**:
  - Generic/general terms that don’t describe the topic area of the projects
    - E.g.: “methods”, “Humans”, “Breast Neoplasms”, “diagnosis”, “Health Policy”
- **Selection criteria**:
  - MeSH terms that provide information about the focused population
  - MeSH terms describing the changing topic areas we identified using word clouds
Methods: Identify Future Priorities

Idea → Grants (Average duration: 3.7 years) → Published peer-reviewed article

Where to see ideas that could be funded after 2019?

• (1) The most recent projects
  - Topic Modeling: Further understand the focus of major areas
  - Input: abstracts (2017-2019)
  - Latent Dirichlet Allocation technique

• (2) 2019 San Antonio Breast Cancer Symposium
  - Educational sessions
    • No concurrent sessions
    • Invited speakers by the conference committee
    • Audiences are all participants
    • Important issues and questions identified in clinical practice
Major Areas across Time

2011-2013
- Screening, treatment, outcomes, survivorship, disparities and decision-making

2014-2016
- Major areas: Screening, treatment, outcomes, survivorship, disparities and decision-making

2017-2019
- Major areas: Screening, treatment, outcomes, survivorship, disparities and decision-making

Why not highlight treatment and intervention?
- They are not the true focus: “treatment quality”, “disparity in treatment”
Study Population (MeSH Term)

NUMBER OF PROJECTS FOCUSING ON CERTAIN POPULATIONS

MeSH Term Topics

NUMBER OF PROJECTS ON CERTAIN TOPIC

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FOCUSES OF DECISION-MAKING AREA

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Title vs. MeSH Terms (specific aims)
Top 5 Funding Agencies

Number of Projects by Funding Agency by Time

- National Cancer Institute (NCI)
  - 2011-2013: 40
  - 2014-2016: 41
  - 2017-2019: 45

- American Cancer Society
  - 2011-2013: 9
  - 2014-2016: 5
  - 2017-2019: 10

- Agency for Healthcare Research and Quality (AHRQ)
  - 2011-2013: 9
  - 2014-2016: 14
  - 2017-2019: 4

- Patient-Centered Outcomes Research Institute (PCORI)
  - 2011-2013: 8
  - 2014-2016: 11
  - 2017-2019: 4

- National Institute on Minority Health and Health Disparities (NIMHD)
  - 2011-2013: 2
  - 2014-2016: 5
  - 2017-2019: 4
Understanding the Emerging Areas in 2017-2019

• Topic modeling:
  - Relationships between genetic testing, risk, screening, treatment
    • Germline testing for prevention purpose
    • Genetic testing to guide treatment
  - Relationships between decision-making, screening, treatment
    • Guiding treatment decisions
    • Patient navigation
Priorities in the Conference

- 4 HSR related sessions (12 talks) in 2019
  - One session focused on genetic testing
      - Who should have germline testing for hereditary breast cancer?
      - Alternative practical models for genetic services in the era of increased demand
      - Breast cancer genetic testing: moving from cancer risk assessment to therapeutic biomarker
  - One session focused on personalized radiation decision and guiding the decision
  - Rest talks discussed targeting high risk women for prevention technology uptake and communication challenges for providers
Conclusions

• Major research areas in breast cancer
  - Screening, treatment, outcomes, survivorship, disparities and decision-making

• Future priorities
  - Personalized medicine: germline testing (prevention) → tumor sequencing (treatment decisions)
  - Communication: decision aid → patient navigation, changes on physicians’ side

• Top funding agencies:
  - National Cancer Institute (NCI), American Cancer Society, Agency for Healthcare Research and Quality (AHRQ), Patient-Centered Outcomes Research Institute (PCORI)
Questions & Discussion

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