Deep South Cancer Navigation Network
• Edward Partridge MD (PI)

• Innovation Challenge Grant from the Centers for Medicare & Medicaid Services (1C1CMS-331023)

• Triple Aim
  – Better health
  – Better healthcare
  – Lower costs of care

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Presentation Objectives

- Discuss gero-oncology trends in the United States
- Describe the Patient Care Connect (PCCP) Program
- Report distress identified by older cancer survivors
- Discuss the evaluation of the PCCP
- Discuss future trends in values based health care for older cancer survivors
The Silver Tsunami

![Graph showing estimated cancer prevalence by age in the US population from 1975 (216 M) to 2040 (380 M).](image)

**Figure 1: Estimated cancer prevalence by age in the US population from 1975 (216 M) to 2040 (380 M)**

- **1975, 3.6 M**
- **2016, 15.5 M**
- **2040, 26.1 M**

- Dark blue: 85+
- Purple: 75-84
- Green: 65-74
- Red: 50-64
- Light blue: < 50

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*Signifies the year at which the first baby boomers (those born 1946-1964) turned 65 years old.*
Significance

Older cancer survivors

Severity of disease
Severity of treatment

Physiologic effects of aging

Pre-existing Conditions
Pre-existing Condition
New-onset morbidity
New-onset morbidity

The Patient Care Connect Program (PCCP) is a lay navigation program integrated into the care system

- Older adults ≥65 years with cancer
- Cancer treatment or follow up care
- 12 cancer centers in 5 states in southern US

• 12 nurse site managers
• ~40 lay (non-clinical) navigators
Focus of the PCCP

Navigator roles
- Coordinate and address barriers to care
- Empower and support patients and survivors

Navigator activities were guided by frequent distress assessments

Community health advisors

PCCP lay navigators

Lower cost of care
Essentials of the PCCP

PCCP offered as service
- No random assignment to PCCP

Enrollment by
- Referral from providers
- Census reports on hospitalizations and ER visits

Priority given to high acuity cancers and patients
- High acuity cancers such as lung, ovarian, brain, hematologic, head and neck
- Stage 4 cancers and metastatic disease
- High acuity redefined to include comorbidities and higher risk drugs (e.g., warfarin)

Priority also to minority patients and survivors
PCCP Enrollment

PCCP enrolled cancer patients

- 0/1/2013 to 9/1/2015
- Enrolled cancer patients
PCCP Survivor-Centered Care Map

PCCP navigator administers Distress Assessment (DA)

Score < 4

- PCCP navigator evaluates cause of distress
- PCCP navigator offers or survivors request assistance with distress item
- PCCP navigator addresses distress item with appropriate resource

Score ≥ 4 or unrelieved symptoms

- PCCP navigator refers to provider
- Provider addresses distress item
- PCCP navigator repeats DA in 5-7 days

PCCP navigator refers to Site Manager (SM)

SM addresses distress item

PCCP navigator follows up with patient

Assistance request CLOSED only if survivor states no need for further assistance
## Distress Thermometer

### PRACTICAL PROBLEMS:
- Ability to use Phone
- Getting Groceries/Shopping
- Insurance/Financial
- Work
- Child Care
- Housekeeping
- Housing
- Cooking
- Manage Finances
- Transportation

### FAMILY PROBLEMS:
- Dealing with:  
  - Children
  - Partner
  - Family Support
  - Friends

### INFORMATION CONCERNS:
- Lack of Info About (my):
  - Alternative Therapy Choices
  - Diet/Nutrition
  - Home Health
  - Maintaining Fitness/Exercise
  - Prognosis
  - Side-Effects/Treatment(s)
  - Supportive Care
  - Diagnosis/Disease
  - End of Life Issues
  - Legal Issues
  - Performing Medical Procedures
  - Scheduling
  - Side-Effects/Medication(s)
  - Treatment(s)
  - Treatment Decisions

### PHYSICAL PROBLEMS:
- Balance/Walking & Mobility Difficulty
- Body Sores
- Changes in Urination
- Controlling Bowel Movement
- Diarrhea
- Dizziness
- Fatigue
- Feeding Self
- Getting Around: Inside Home
- Getting Around: Outside Home
- Hearing
- Indigestion
- Mouth Sores
- Loss of Appetite
- Moving In/Out of Chair or Bed
- Nausea/Vomiting
- Nose Dry/Congested
- Opening Medication Bottles
- Pain
- Skin Dry/Ichy
- Sleep/Insomnia
- Swallowing
- Swollen Arms/Legs
- Talking
- Tingling Hands/Feet
- Tolleding
- Weight Change

### EMOTIONAL PROBLEMS:
- Adjusting to Changes in Appearance
- Adjusting to my Illness
- Boredom
- Coping with Grief & Loss
- Feeling Depressed or "Blue"
- Feeling Hopeless
- Feeling Lonely
- Fear(s)
- Guilt
- Intrusions (thoughts that appear suddenly and repeatedly that are not welcome)
- Isolation/Feeling Alone
- Isolation/Feeling Alone
- Isolation/Feeling Alone
- Isolation/Feeling Alone
- Loss of Interest in Usual Activities
- Managing Stress
- Nervousness
- Role Changes ("Caring for Family")
- Self-esteem
- Worry

### COGNITIVE PROBLEMS:
- Feeling Confused
- Forgetting
- Poor Thinking
- Memory/Concentration
- Seeing Things/Hearing Things
- Understanding Verbal or Written Words

### OTHER:
- Ability to Read/Write
- Cultural/Religious Needs
- Citizenship
- Lack of Social Support
- Language Barrier
- Post-op Care

### SPIRITUAL/RELIGIOUS CONCERNS:
- Lack of Comfort, Strength or Hope from Spiritual Beliefs
- Facing my Mortality
- Lack of Support from Spiritual/Religious Group
- Loss of Faith
- Trust in God
- Loss of Sense of Purpose
- Meaning of Life
- Relating to God

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Distress Assessment

- Distress thermometer used for assessment
  - \((0 = \text{none}; 10 = \text{extreme distress})\) and item list

- Survivor-centered interventions triggered by distress scores 
  \(>4\) (higher distress)

- And/or by survivors’ request for assistance for specific 
  distress items
10 Most Reported Distress Items

- **Fatigue**: Number Reported 2500, Requested Assistance 1000, Addressed 500
- **Pain**: Number Reported 2000, Requested Assistance 1500, Addressed 1000
- **Functional Mobility**: Number Reported 1500, Requested Assistance 1000, Addressed 500
- **About my treatment(s)**: Number Reported 1000, Requested Assistance 500, Addressed 250
- **Nervous/Anxiety**: Number Reported 750, Requested Assistance 250, Addressed 100
- **Insurance/Financial**: Number Reported 500, Requested Assistance 200, Addressed 100
- **Transportation**: Number Reported 300, Requested Assistance 100, Addressed 50
- **Scheduling**: Number Reported 200, Requested Assistance 100, Addressed 50
- **Nausea/Vomiting**: Number Reported 150, Requested Assistance 50, Addressed 25
- **Breathing**: Number Reported 100, Requested Assistance 50, Addressed 25

Legend:
- Blue: Number Reported
- Purple: Requested Assistance
- Yellow: Addressed
Report of at Least 1 Distress item & Request for Assistance

- At least one distress item
- At least one request for assistance

Common cancers: 37.2
Gynecologic: 34
Head and neck: 36.7
Hematologic: 46.4
Lung: 45.4
Pancreas: 54.2
Other: 36

At least one distress item & Request for Assistance

Oncology Nurse Advisor
Navigation Summit
90.7% requests for assistance were resolved to the patient satisfaction

- Required 1.1 interventions
- Resolved in ~ 11 days
  - Decline in requests over time
    - 18.6 in Q3 2013
    - ~9 in Q2 2015
Navigator Workload

• Mean n=138 beneficiaries per quarter
  – 72 actively navigated
  – 83 high acuity
  – 30 newly enrolled

• Active 57 days per quarter
• Contacts: 3.3 face to face or phone
• Average one contact every 18 days
PCCP Evaluation: Satisfaction

- Surveys of 360 navigated patients
- Random group of beneficiaries identified as potential users of the PCCP
  - 82% were very satisfied or satisfied
  - 88.3% would recommend PCCP to other cancer patients
<table>
<thead>
<tr>
<th>Aspect</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Help with finding the information I needed</td>
<td>72.2%</td>
</tr>
<tr>
<td>Help with learning about disease treatment or side effects</td>
<td>69.4%</td>
</tr>
<tr>
<td>Having the navigator to rely on</td>
<td>67.2%</td>
</tr>
<tr>
<td>Having someone to check on me</td>
<td>66.7%</td>
</tr>
<tr>
<td>Help with sorting out what I wanted and preferred for my medical care</td>
<td>56.3%</td>
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<tr>
<td>Help with understanding doctors’ orders</td>
<td>53.9%</td>
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<tr>
<td>Help with getting in touch with my doctor</td>
<td>53.6%</td>
</tr>
<tr>
<td>Help with preparing for doctor visits</td>
<td>50.9%</td>
</tr>
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Differences in Costs

Data from: Rocque et al. AMA Oncol. Published online January 26, 2017. doi:10.1001/jamaoncol.2016.6307
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Conclusions

The number of older cancer survivors will increase in coming years.

In the PCCP, older cancer survivors

In the PCCP, health care costs and health care use declined for navigated patients compared with matched group of comparison patients.

Lay navigation programs can be expanded as health systems transition to values-based health care.
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