Abstract

Although pheochromocytomas and paragangliomas (PCC/PGL) are rare neuroendocrine tumors (NETs), occurring in 2 to 8 per million people, over 1/3 are reportedly associated with an underlying genetic etiology, which is more than any other cancer type. PCC/PGL tumors develop from chromaffin tissue in the adrenal medulla or extra-adrenal ganglia, respectively. Tumors are usually benign but associated with high mortality and morbidity due to hypersecretion of catecholamines, resulting in hypertension, stroke, even death, and mass effect. PCC/PGL are malignant in approximately 1/4 of cases and metastatic sites vary. To date, more than 10 susceptibility genes have been identified which confer an increased risk in the development of PCC/PGL – von Hippel-Lindau disease (VHL), Multiple Endocrine Neoplasia type 2 ( MEN 2), Neurofibromatosis type 1 (NF1), 5 genes from the succinate dehydrogenase (SDH) complex - SDHA, SDHB, SDHC, SDHD, SDHAF2; TMEM127 and MAX. There are also a number of somatic mutations that have now been identified including HIF2-alpha, ATRX, KIF1b, and PHF2. It is anticipated that additional genes associated with PCC/PGL will be discovered since this aspect of genetics is advancing rapidly. Due to possible prognostic implications for patients with PCC/PGL, and familial implications if positive, genetic testing is appropriate in all patients. Knowledge of genetic predisposition to developing PCC/PGL influences medical management, allowing for proper surveillance of recurrent or metastatic disease, development of additional primary tumors, and other possible associated malignancies. For those who test positive, family members should be referred to medical genetics for screening.

Presenting signs and symptoms associated with PCC/PGL can be confused with other medical conditions and consequently patients may be undiagnosed for many years, particularly if classical symptoms of PCC/PGL are absent. If knowledgeable of PCC/PGL, Oncology Nurses can play a pivotal role in narrowing the differential diagnosis. Since PCC/PGL can be benign or malignant, outcomes are impacted by the extent of the disease, location of the disease, and genetics. This lecture will seek to educate Oncology Nurses on the complexities of these two rare but risky neuroendocrine diseases, enabling them to make proper diagnoses and to plan appropriate interventions.
What are Neuroendocrine Tumors?

- Category of rare tumors arising in different parts of the body from neuroendocrine cells
- Neuroendocrine cells are secretory cells scattered throughout the body. They release hormones & bioactive substances into the blood stream and tissues
- Integration between the nervous system and endocrine system to control critical body functions

What are Pheochromocytomas?
PCC are NETs of the Adrenal Gland

- Chromaffin cell tumors of the adrenal medulla
- Produce catecholamine hormones: Epinephrine (Adrenalin), Norepinephrine (Noradrenalin) and Dopamine.
- Regulate response to stress (“fight or flight response”)
- Hormones secreted into the bloodstream affect the functions of other organs and tissues in your body. BP & HR go up – increase blood flow to essential organs – pupils dilate – gut motility slows alertness, anxiety.
- Cells over-produce and over-secrete catecholamines
- Can potentially increase your heart rate and blood pressure bleeding life threatening when the tumor goes unrecognized or untreated
Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

**What are Paragangliomas?**

PGL are Extra-adrenal PCCs

**Two Types**

1. Sympathetic Nervous System
   - Controls body’s metabolism during action or stress
   - Small clusters of chromaffin cells are distributed throughout the sympathetic nervous system, in the midline of the body from the neck down to the urinary bladder & pelvic organs, controlled by small clusters of nerve cells called ganglion.
   - The adrenal medulla is included and is the only location grossly visible except for the organ of Zuckerkandl, the major repository of chromaffin cells during embryonic development.
   - Tumors can arise from any site where there are normal chromaffin cells. They typically produce catecholamines which may cause symptoms.

2. Parasympathetic Nervous System
   - Opposing functions to the sympathetic nerves
   - Groups of similar cells are associated with cranial nerves at the base of the skull up to the ear.
   - Parasympathetic paragangliomas can also give rise to tumors anywhere they are located in the head and neck to the great vessels that emerge from the heart.
   - Head and Neck PGL (HNPG) tumors differ from PCC and PGL of the sympathetic chain as they rarely over-secrete catecholamines

**Why are PCC/PGL dangerous (risky)?**

YOU MUST SUSPECT IT TO DETECT IT

- Difficult to diagnose - Think Zebras – Not Horses
- Rare, predominantly benign
  - Occur in 2 to 8 per million people. ~1000 new cases diagnosed in US
  - Under reported
  - Autopsy studies report large numbers of tumors are undiagnosed during life
- ~ 40% carry germline mutations. 60% are sporadic
- At PENN: See about 40 new patients with secreting PCC/PGL. 100 in follow up annually
- Symptoms mimic other conditions: Easy to Overlook or Misdiagnosis
  - Hyperthyroidism, hypoglycemia, medullary thyroid cancer, mastocytosis, menopausal symptoms, panic disorder, migraines, carcinoid syndrome, ischemic heart disease, heart failure, stroke, arrhythmia, migraines, anxiety
  - Drugs: monoamine-oxidase inhibitors, sympathomimetic, clonidine withdrawal, cocaine
- Must be astute to diagnose
Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Why are PCC/PGL dangerous (risky)?
Clinical Presentations Vary from Case to Case

• Hormonal Symptoms
  Classic Triad: Headache, palpitations and sweating, associated with persistent or episodic hypertension from elevated levels of circulating metanephrines, are causes for high morbidity and mortality rates.

• Other Common Symptoms
  Tachycardia - Syncope - Anxiety - Tremor
  New-onset hyperglycemia (or worsening of controlled diabetes mellitus)
  Weight changes - Nausea - Pain

• Episodic timing of episodes & duration vary. Volcanic Eruption or Storm

• NO Symptoms or Minimal

• Each patient is Unique

• Early diagnosis has predictive implications because Surgery is the ONLY cure

(Cohen, 2006.)
(Fishbein, 2016.)
(Cohen, Fraker & Townsend, 2006.)

Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Why are PCC/PGL dangerous (risky)?
Management Principles & Obstacles to Early Diagnosis

• Confirm the diagnosis
  Plasma metanephrines first-line screening test. 4X normal
  24-hour urine-fractionated and plasma-free metanephrines have more than 90% sensitivity for PCC/PGL
  Catecholamines for head & neck tumors

• False-positive results are common
  - Foods: Caffeine, chocolate
  - Collection errors: Not fasting, over or under collecting 24 hr urine; improper storage interferes with urine pH

(Fishbein, Orlowski & Cohen, 2013.)

Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Illustration of BP variability in a catecholamine secreting PCC before & after surgical resection

Pre-op

Post-op

Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Why are PCC/PGL dangerous (risky)?

Management Principles & Obstacles to Early Diagnosis

• Confirm the diagnosis
  Plasma metanephrines first-line screening test. 4X normal
  24-hour urine-fractionated and plasma-free metanephrines have more than 90% sensitivity for PCC/PGL
  Catecholamines for head & neck tumors

• False-positive results are common
  - Foods: Caffeine, chocolate
  - Collection errors: Not fasting, over or under collecting 24 hr urine; improper storage interferes with urine pH

(Fishbein, Orlowski & Cohen, 2013.)
Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Why are PCC/PGL dangerous (risky)?

Management Principles & Obstacles to Early Diagnosis

- Imaging – tumor localization challenges
  - CT and MRI for anatomical location
  - Functional imaging Extent of disease
    - Meta-iodo-benzylguanidine (MIBG) Scan
    - Need Thyroid Protection
  - Chromaffin cells express variety of receptors & transporters
    - Octreoscan sensitive for HNPGL and MIBG negative tumors
    - PET scanning
    - PET CT, 18F-FDG-PET preferred for metastatic SDHB function, 18F-Dopa PET
    - Tumor Board discussion to determine best test

(See & F. 2023)

MIBG scan identifies an unresected Organ of Zuckerkandl primary PGL with an area of central necrosis and bone metastases. Physiologic activity is seen in the thyroid, salivary glands, liver, urinary bladder.

MIBG scan identifies metastatic boney disease CT and MRI normal often normal

Why are PCC/PGL dangerous (risky)?

Management Principles & Obstacles to Early Diagnosis

- Surgery is the definitive treatment
- Control BP before & during surgery
- Expert surgical team
- Laparoscopic adrenalectomy for adrenal tumors
- Adrenocortical sparing surgery if possible when concern for bilateral tumors
- Pre-op preparation essential major morbidity associated with tumor removal
- Peripheral alpha blocking with phenoxybenzamine
  - Side Effects: postural hypotension, tachycardia, nasal congestion, GI side effects
  - Prescription drug coverage often a problem
  - Begin ~2 weeks prior to surgery or as soon as diagnosis is confirmed
  - Add a beta-blocker if needed for tachycardia but never until fully alpha blocked as can get unopposed stimulation of alpha receptors
  - Metyrosine in certain cases
- Patient Engagement and Education is essential
  - Medication dosing schedule must be understood and followed
  - BP management

(Pharnobrite, Ochsner C, et al, 2012)

Oncology Nursing Society 41st Annual Congress
April 28–May 1, 2016
San Antonio, TX
Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Paragangliomas can increase surgical risk due to location

Aortocaval mass resection of a 4.0 cm PGL with invasion into wall of vena cava required coordination with vascular surgery. Aorta on left IVC on right. All gross tumor removed with negative margins.

Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Pheochromocytoma Zellballen pattern (balls of cells)

Pathologic classification cannot predict biological & clinical behavior or response to treatment.

Biological & Molecular markers play a role

Paraganglioma – HP

Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Why are PCC/PGL dangerous (risky)?

Malignant potential

World Health Organization (WHO) defines malignancy as the presence of chromaffin tissue in locations other than sites of origin

- About 25% of cases
- PCC ~10% compared with 20 to 25% of extra-adrenal abdominal PGLs
- Most commonly metastatic to: bone, liver, lymph node, lungs
- Found at diagnosis or years later

Treatment options for advanced disease

- Surgical debulking
- Chemotherapy: Cisplatin, Dacarbazine, Vincristine (CDV), Capecitabine & Temozolomide (CAPTEM)
- Somatostatin analogues
- Molecular targeted therapies
- Radiation and Radiotherapy
- MIBG – Peptide receptor-targeted therapy
- Medications to control symptoms of the disease
- Clinical trials & Novel therapies
- Oncolytic virus

(DeLellis et al., 2004.)
(Fishbein, 2016.)
(Fine et al., 2014)
Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Why are PCC/PGL dangerous (risky)?

Genetic predisposition

PCC/PGL have an inherited mutation rate higher than any other cancer type
- Genetic causes found in up to 40% of PCC/PGL

PCC/PGL Susceptibility Genes identified thus far include:
- von Hippel-Lindau disease (VHL)
- Neurofibromatosis type 1 (NF1)
- 5 genes from the succinate dehydrogenase (SDH) complex
  - SDHA
  - SDHB
  - SDHC
  - SDHD
  - SDHAF2
- Transmembrane protein 127 (TMEM127)
- MYC-associated factor X (MAX)

Somatic mutations have been identified including HIF2-alpha, ATRX, KIF1Bb, and PHF2
- Genetics is rapidly advancing
  - Additional genes associated with PCC/PGL expected to be discovered

Genetic Testing

Consider sending all patients with PCC/PGL for genetic testing
If (+), screening family members may lead to early disease detection and better clinical outcomes

Post op testing

- Repeat 24 hr urine and/or plasma metanephrines at 6 weeks then every 6 -12 months after
- Imaging – Personalize timing
  - Rapid body MRI scanning or other imaging modalities for genetic mutation carriers
- Recurrence local or distant metastasis can occur in patients with or without known genetic cause
- Alpha Blocking if needed for procedures. For example, Colonoscopy, Dental, Cardiac

Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

PCC/PGL Susceptibility Genes: where to expect disease, malignancy rate & inheritance

<table>
<thead>
<tr>
<th>Gene</th>
<th>Primary Location</th>
<th>Malignancy Rate</th>
<th>Inheritance</th>
</tr>
</thead>
<tbody>
<tr>
<td>NF1</td>
<td>Adrenal (Bilateral)</td>
<td>12%</td>
<td>AD</td>
</tr>
<tr>
<td>RET</td>
<td>Adrenal (Bilateral)</td>
<td>&lt;5%</td>
<td>AD</td>
</tr>
<tr>
<td>VHL</td>
<td>Adrenal (Bilateral)</td>
<td>5%</td>
<td>AD</td>
</tr>
<tr>
<td>SDHA</td>
<td>Any location</td>
<td>?</td>
<td>AD</td>
</tr>
<tr>
<td>SDHB</td>
<td>Extra adrenal</td>
<td>23%</td>
<td>AD</td>
</tr>
<tr>
<td>SDHC</td>
<td>HNPGL</td>
<td>Low</td>
<td>AD</td>
</tr>
<tr>
<td>SDHD</td>
<td>HNPGL (Multifocal)</td>
<td>&lt;5%</td>
<td>AD/Paternal Inheritance</td>
</tr>
<tr>
<td>SDHAF2</td>
<td>HNPGL (Multifocal)</td>
<td>Low</td>
<td>AD/Paternal Inheritance</td>
</tr>
<tr>
<td>TMEM127</td>
<td>Any location</td>
<td>Low</td>
<td>AD</td>
</tr>
<tr>
<td>MAX</td>
<td>Adrenal (Bilateral)</td>
<td>?</td>
<td>AD</td>
</tr>
</tbody>
</table>

(Chart Adapted from Fishbein & Nathanson, 2012.)
Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Why are PCC/PGL dangerous (risky)?
Tailored treatment plans needed for NETs
• Multidisciplinary, team approach
• Tumor board
• Center with dedicated experts
• Many options and no standard algorithm exists
• Personalize treatment

Favier Amar & Gimenez-Roqueplo, 2015.
Banfield, Green & Ramage, 2005.

Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Pheo Para Clinical Guidelines for Follow-up
April 2014

Unaffected Mutation Carriers
Refer to Medical Genetics (215-662-4744)
Check annual biochemistries
Patients with NF1, vHL, MEN2 have separate screening guidelines

Mutation Positive Abdominal PCC/PGL
s/p complete resection
Check biochemistries at 6 months and 12 months post resection and then annually
Check diagnostic imaging once per year post resection
Individualize clinical management (Tumor board discussion)
Consider post operative MIBG or EBRT treatment for local control

Mutation Negative Abdominal PCC/PGL
s/p complete resection
Check annual biochemistries for life
After 5 years, can have annual follow up with PCP

Mutation Positive HNPGL
s/p definitive treatment (surgery or XRT)
No metastatic disease
Check annual biochemistries for life
Check neck MRI one year after completion of definitive treatment
At year two post treatment, move to unaffected protocol
(*definitive treatment = surgery or EBRT)

Mutation Positive HNPGL
s/p definitive treatment
With metastatic disease
Individualize clinical management
Tumor board discussion

Mutation Positive Abdominal PCC/PGL
Extensive local invasion s/p incomplete resection or vascular invasion into large vessels
Individualize clinical management
Tumor board discussion
Consider post operative MIBG or EBRT treatment for local control

Mutation Positive Abdominal PCC/PGL
With metastatic disease
Individualize clinical management
Tumor board discussion

Oncology Nursing Society 41st Annual Congress
April 28–May 1, 2016
San Antonio, TX
Thursday
Neuroendocrine Tumors and Inherited Cancer Syndromes: Pheochromocytomas and Paragangliomas – Rare But Risky

Summary Points

- PCCs/PGLs can be both benign and malignant. They have high morbidity and mortality, especially when not properly diagnosed or treated.
- All patients should be considered for genetic testing since up to 40% of patients with PCC/PGL have mutations in susceptibility genes.
- Surgery is the only cure for PCC/PGL, but limited control of metastatic disease can follow with treatments, including 131I-MIBG radiotherapy, chemotherapy, and radiation.
- The field of genetics expanding rapidly. Future work is needed to identify predictors of metastatic probability and new targets for therapy.

References

Thank you!
Targeting the Needs of Unique Populations

Adolescent-Young Adult (AYA) Patient Survivorship Program: A Joint Effort Between a Cancer Institute and Community Organization

Alicia Maston Coffin, MS, RN, OCN
Nurse Manager – Pluta Cancer Center / Comprehensive Breast Center
(Former role: Lead Nurse – Judy DiMarzo Cancer Survivorship Program)

Disclosures

• None

Objectives

• Background on AYA cancer survivors
• Problem identification
• Purpose of an AYA survivorship program focus
• Program interventions
• Community collaboration
• Evaluation/Discussion
Estimated Number of Cancer Survivors in the United States From 1971 to 2022

Pediatric Cancers

Overall cure rates for children have now reached 80%

This is largely due to basic science and clinical research!

AYA Defined

- AYA= Adolescent and Young Adult
- Ages 15-39 (or ages 15-29)

- This is a distinct population
  - Distinct diseases
  - Distinct challenges
  - Distinct outcomes
Identification of the Problem

- AYA cancer patients have not enjoyed any significant survival gains over the last few decades
  - Vulnerable population
    - Deficiencies in health-related knowledge
    - Poor adherence to health promotion and screening practices
  - Inferior outcomes and health disparities attributed to:
    - Unique developmental challenges
    - Distinctive styles of learning and communication

Problem Cont.

- There is growing consensus that this population needs more resources and more support from the medical community

- NCCN (National Comprehensive Cancer Network) has developed specific guidelines for this population
  
  http://www.nccn.org/patients/guidelines/aya/index.html
Problem Cont.

- Current recommendations for AYA survivors
  - Lifelong monitoring
    - late effects
    - Impaired health status
    - Premature death

- However....
  - In the previous 2 years:
    - Less than 1/2 had any cancer-related follow up
    - Less than 1/3 received survivorship focused care
    - Less than 1/5 received specific advice on risk reduction or screening

Oeffinger, et al., 2004; Nathan, et al., 2009

Purpose of an AYA Program

- To promote health adherence and satisfaction among AYA survivors by improving engagement in care and preparing them to advocate for themselves
  - Hospital + Community collaboration

AYA Program Interventions

- AYA patient navigator
  - Non-clinical
  - Assist clinical team
    - Survivorship planning
    - Individual and group support
    - Coordinate age-appropriate financial, psychosocial, practical, and educational resources
  - Connects patients to community resources
    - 13thirty
AYA Patient Navigator

- 1 to 1 meetings
  - Improves the AYA’s ability to proactively manage their cancer experiences
    - Identify and meet the unique needs of these patients and families
    - Improve patient / family satisfaction

Community Collaboration

- 13thirty Cancer Connect
  - Community organization providing a comprehensive continuum of support focusing on ages 13-30
    - Parent and sibling support
  - Programs help develop coping skills and self-esteem through:
    - Peer connection
    - Self-advocacy skills-building
    - Self-management tools for long-term health

Evaluation / Discussion

- Implementation Fall 2014
  - 90 AYA patients enrolled
    - 1/3 involved in peer support programs at 13 Thirty Cancer Connect
  - Participants feedback: highly satisfied with program opportunities
- Ongoing evaluation
  - Follow up compliance, surveys, focus groups, patient satisfaction
Questions?

Adolescent – Young Adult Patient Survivorship Program: A Joint Effort Between a Cancer Institute and Community Organization

Alicia Maston Coffin, MS, RN, OCN
Nurse Manager – Pluta Cancer Center/Comprehensive Breast Center

(Former role: Lead Nurse – Judy DiMarzo Cancer Survivorship Program)

Targeting the Needs of Unique Populations

16 Oncology Nursing Society 41st Annual Congress
April 28–May 1, 2016
San Antonio, TX

Thursday
TAKING IT HEAD ON

Susan P. O’Brien, MSN, CNP
Helena C. Viveiros RN BSN OCN
Yvette Rosa RN BS OCN

Taking It Head On:

- an oncology nurse-led team approach to decrease treatment delays and hospitalizations in our head and neck cancer patients.

- Psychosocial Issues
- Transportation
- Noncompliance
- Understanding Disease Process
- Poor Nutrition Weight Loss
- Pain
- Radiation
- Chemo
- Co-morbidities
- Poor Dentition
- G-tube Complications
- Dysphasia
- Post-XRT Effects

- Radiation
- Chemo
- Co-morbidities
- Poor Dentition
- G-tube Complications
- Dysphasia
- Post-XRT Effects

- Radiation
- Chemo
- Co-morbidities
- Poor Dentition
- G-tube Complications
- Dysphasia
- Post-XRT Effects

- Radiation
- Chemo
- Co-morbidities
- Poor Dentition
- G-tube Complications
- Dysphasia
- Post-XRT Effects

- Radiation
- Chemo
- Co-morbidities
- Poor Dentition
- G-tube Complications
- Dysphasia
- Post-XRT Effects

- Radiation
- Chemo
- Co-morbidities
- Poor Dentition
- G-tube Complications
- Dysphasia
- Post-XRT Effects
Clarifying Patient Issues

<table>
<thead>
<tr>
<th>Pre-existing</th>
<th>Treatment</th>
<th>Post Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-morbidities</td>
<td>Chemotherapy</td>
<td>Dysphasia</td>
</tr>
<tr>
<td>Poor dentition</td>
<td>Radiation therapy</td>
<td>Feeding tube complications</td>
</tr>
<tr>
<td>Psychosocial issues</td>
<td>Lack transportation</td>
<td>Post-radiation effects</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>Noncompliance</td>
<td>Lack of transportation</td>
</tr>
<tr>
<td>Poor nutrition/weight loss</td>
<td>Lack of understanding regarding disease process</td>
<td>Noncompliance</td>
</tr>
<tr>
<td>Dysphasia</td>
<td>Mgmt. symptoms &amp; side effects of tx</td>
<td>Pain</td>
</tr>
</tbody>
</table>

Team Members Involved in Care of Patients with Head and Neck Cancer

- Oncology/Radiation RN
- Medical/Radiation Oncologist
- Radiation Therapist
- Surgeons
- Social Workers
- Visiting Nurses
- Dieticians
- Dentists
- Radiologist
- Speech Therapist
- Family/Caregivers

Comprehensive Patient Management and Multidisciplinary Team Implementation

- Chart review to identify cause of treatment delays and hospitalizations
- Speech Therapy Referral
- Biweekly nursing visits
- Collaboration with GI Physicians
Comprehensive Patient Management
Multidisciplinary Team Implementation

- Day surgery algorithm.
- Collaboration with Home Care Services
- Single page education handouts.
- Aggressive supportive care

Bi-weekly Nursing Visits for Patients with Head/Neck/Esophageal Cancer

- New G-tube
- Dysphagia
- CC Chemo-therapy
- Weight Loss

No adverse effects
Continue plan of care
Adverse effects
Notify MD
Initiate nursing interventions.
Completion of treatment without delay or hospitalization

Patient Care Quality Review @ 6 Months

34% absolute reduction in hospitalization and treatment breaks

<table>
<thead>
<tr>
<th>Year</th>
<th>No Treatment Break</th>
<th>Break w/o Hospitalization</th>
<th>Hospitalization</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013-14</td>
<td>30</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>2015</td>
<td>25</td>
<td>20</td>
<td>5</td>
</tr>
</tbody>
</table>
Patient Care Quality Review @ 1 year

Measured Outcomes

- Six month review demonstrated a 34% absolute reduction in hospitalization and treatment delay.
- 1 year review continues to demonstrate reduction in hospitalization and treatment delay.

Take It Away

- Get buy-in from key providers of care
- Coordinate hospital & community based services
- Keep your eyes and mind open as to what is delaying and impacting quality care
- Develop a purpose or statement of goals specific to your patient population
- Don’t stop bringing the team members together.
What is next?

- Community program for oral cancer screening
- Research opportunities to measure quality of life for survivors of head and neck treatment
- Form similar charters for other high risk populations
- Role of advanced practice nurses in post therapy care

Oncology Nurses can have a significant impact on patient outcomes; allowing patients to complete their prescribed course of treatment with minimal delay of treatment and hospitalization.
Estimated Number of Cancer Survivors in the United States From 1971 to 2022

Pediatric Cancers

Overall cure rates for children have now reached 80%

This is largely due to basic science and clinical research!

AYA Defined

- AYA = Adolescent and Young Adult
- Ages 15-39 (or ages 15-29)

- This is a distinct population
  - Distinct diseases
  - Distinct challenges
  - Distinct outcomes
Identification of the Problem

- AYA cancer patients have not enjoyed any significant survival gains over the last few decades
  - Vulnerable population
    - Deficiencies in health-related knowledge
    - Poor adherence to health promotion and screening practices
  - Inferior outcomes and health disparities attributed to:
    - Unique developmental challenges
    - Distinctive styles of learning and communication

Problem Cont.

- There is growing consensus that this population needs more resources and more support from the medical community

- NCCN (National Comprehensive Cancer Network) has developed specific guidelines for this population
  - [http://www.nccn.org/patients/guidelines/aya/index.html](http://www.nccn.org/patients/guidelines/aya/index.html)