DISPARITIES IN PEDIATRIC CANCER CARE

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PI – South Texas Pediatric MB CCOP

Disclosure
Anne-Marie Langevin MD has no relationships with commercial companies to disclose.

Learning Objectives
1. Recognize the impact of Limited English Proficiency (LEP) in care delivery to patients with chronic illnesses (cancer and others) and advocate for professional translation services.

1. Recognize Healthcare and Provider-related Barriers affecting delivery of care to Adolescents and Young Adults with pediatric-type chronic illnesses (cancer and others)

Background
NCI CCOP/MBCCOP & STP MBCCOP
- Infrastructure grants supporting data management for enrollment of cancer patients on therapeutic and screening/prevention/cancer control trials
- 1983: Community Clinical Oncology Program (CCOP) to engage community physicians in NCI clinical trials and thus improve the incorporation of research results into practice.
- 1990: Minority Based CCOP opens to institutions serving large minority and underserved communities – Birth of the South Texas Pediatric MBCCOP

Background
STP MBCCOP - Catchment Area
- Four COG Institutions
- Four Outreach Clinics
- Population: 4,000,000
- Counties: 47
- Surface: 65,000 Square Miles
**Background**

**STP MBCCOP – Catchment Area**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percent of Total Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 25 years</td>
<td>40%</td>
</tr>
<tr>
<td>25 - 34 years</td>
<td>54%</td>
</tr>
</tbody>
</table>

*Source: South Texas Health Status Review, 2002-2005.*

**Background**

**Transformation of the CCOP/MBCCOP**

- Incorporate emerging science and novel trial designs in cancer prevention and control research
- Maximize community resources to conduct complex clinical trials
- Use epidemiological and biological data from under-represented populations in clinical trials to address disparate clinical outcomes
- Improve clinical trial access and participation among populations under-represented in cancer clinical research
- Build on the success of the CCOP/MB-CCOP programs

**Background**

**Underrepresentation in Clinical Trials**

What are the under-represented groups?

- Racial/Ethnic Minorities
- Adolescents and Young Adults (15 to 39)
- Lower socioeconomic status
- Rural populations
- Elderly

**Background**

**Underrepresentation in Clinical Trials**

Recommendations

1) Facilitate language translation at the NCI and local institutional levels. Include language translation into the institution’s budget to support local needs.

2) Incorporate patient navigation into the MB-CCOP/CCOP infrastructure.

3) Determine particular barriers to clinical trial participation for under-represented populations and conceptualize interventions targeting these barriers.
Background
STP NCORP - Catchment Area

South Texas Pediatric NCORP Catchment Area

<table>
<thead>
<tr>
<th>CATCHMENT</th>
<th>AREA</th>
<th>POPULATION</th>
<th>HISPANIC</th>
<th>AFRICAN AMERICAN</th>
<th>BLACK</th>
<th>OTHER</th>
</tr>
</thead>
<tbody>
<tr>
<td>TEXAS</td>
<td>7,773,907</td>
<td>3,944,017</td>
<td>51.4%</td>
<td>28.3%</td>
<td>15.6%</td>
<td>4.7%</td>
</tr>
<tr>
<td>0 - 14</td>
<td>1,194,739</td>
<td>570,711</td>
<td>61.3%</td>
<td>28.6%</td>
<td>10.1%</td>
<td>0.2%</td>
</tr>
<tr>
<td>15 - 39</td>
<td>3,784,778</td>
<td>1,994,202</td>
<td>58.8%</td>
<td>30.1%</td>
<td>9.3%</td>
<td>1.8%</td>
</tr>
</tbody>
</table>

COUNTIES:
- BEXAR (San Antonio)
- NUECES (Corpus Christi)
- TRAVIS (Austin)
- CAMERON COUNTY (Brownsville)
- Hidalgo County (McAllen)
- Webb (Laredo)

NUECES (Corpus Christi) $48,066 6.2% 17.5% 25.9% 78.2% 19.9%
TRAVIS (Austin) $57,293 5.7% 18.0% 24.8% 86.3% 43.5%
CAMERON COUNTY (Brownsville) $31,080 10.5% 35.5% 48.2% 62.3% 14.5%
HIDALGO COUNTY (McAllen) $33,393 11.0% 34.2% 45.7% 60.2% 15.1%
WEBB (Laredo) $35,974 7.1% 31.3% 42.9% 62.7% 16.7%

Work Poverty Education
- Less than $10,000
- $10,000 to $19,999
- $20,000 to $29,999
- $30,000 to $39,999
- $40,000 or more

CATCHMENT AREA

Population: 7,773,907
Counties: 86
Area (sq. miles): 89,985
STP NCORP Population
- Predominant Young Hispanic Population
- Low SES
- High unauthorized immigration rate

In Texas in 2010
1. 1.8 millions of unauthorized immigrants mostly from Mexico and Central America.
2. Highest rate in the 25 to 34 Age Group
3. ~ 1 million children foreign-born or born to illegal immigrants i.e. members of “mixed families”


STP NCORP – Outreach Clinics

Pediatric Cancer Distribution/Incidence
AGE 0 TO 19

- Carcinoma: 9%
- Germ Cell: 7%
- STS: 7%
- Bone Tumor: 6%
- SNS: 5%
- Kidney: 4%
- Retinoblastoma: 2%
- Liver: 1%
- Leukemia: 25%
- CNS Tumors: 17%

INCIDENCE: 150/1,000,000
CNS/LEUKEMIA/LYMPHOMA = 55% – 60%

Childhood Cancer Survival
Fact To Remember
> 80% of Children Diagnosed with Cancer Will Be Long-term Survivors

Treatment on Study
**“Risk Adapted” Biology Study**
Survival: > 80% to > 90%
4 Consents over 35 wks
Duration of Treatment 2 ½ to 3 years
Side Effects
Adherence with Oral Rx
Post Treatment FU
Impact of LEP on Latino Children’s Health

- Associated with limited health literacy and poverty
- Challenges in accessing care
- Difficulties in explaining symptoms and illness, understanding clinicians’ recommendations, and participating in the development of treatment plans
- Associated with a wide range of negative patient safety and quality outcomes i.e. under or overdosing of medications


Impact of LEP on Latino Children’s Health

The Road to Improvement

- Healthcare system: Accessible + Culturally/linguistically competent
- Consistent use of trained, professional interpreters in the clinical setting.
- Culturally competent and inclusive workforce
- Engagement of community members in the design, implementation, and evaluation of health information and services

A Call to Improve the Health and Healthcare of Latino Children


Hematology Oncology Language Survey

Q2 In what languages can you speak fluently? (Please select all that apply.)

- English
- Spanish
- Other

Hematology Oncology Language Survey

Q3 How satisfied are YOU with using an in-person interpreter during patient interactions?

- Not at all satisfied
- Slightly satisfied
- Moderately satisfied
- Highly satisfied
- Not applicable

Hematology Oncology Language Survey

Q4 How satisfied are YOU with using the phone interpretation service during patient interactions?

- Not at all satisfied
- Slightly satisfied
- Moderately satisfied
- Highly satisfied
- Not applicable

LIMITED AYA PROFICIENCY
DO YOU SPEAK AYA?
Adolescents and Young Adults
Improvement 5-year Relative Survival

Access to Clinical Trials & Treatment Expertise:
Not all AYAs are Created Equal

AYAs with Cancer = Heterogeneous Group Of Patients

Population: AYA with Cancer **

Cancer Type: Pediatric-type

Treatment: Pediatric Team

** AYA < 18 years of age – special considerations

Access to Clinical Trials and Treatment Expertise – Summary Table

<table>
<thead>
<tr>
<th>TREATING TEAM</th>
<th>Adult Oncology</th>
<th>Pediatric Oncology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult-Type Cancer</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Therapeutic Trials</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Biology Studies</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Cancer Control Studies</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Pediatric-Type Cancer</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Treatment Expertise</td>
<td>-</td>
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<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

* No access for AYAs < 18 years of age.

AYA and Cancer: Model of Care and Research

AYA PROJECT
STP MBCCOP Supplemental Grant

OBJECTIVE
Our overall objective was to increase participation of AYAs in the COG studies by developing a recruitment strategy targeting AYAs across providers and healthcare systems.
AYA PROJECT
STP MBCCOP Supplemental Grant

SPECIFIC AIMS:

Aim 1: To recruit and train a dedicated AYA patient navigator/clinical research associate (PN/CRA) who would access AYAs treated by oncological providers across different healthcare systems.

Aim 2: To increase enrollment of AYAs onto clinical trials using the COG registry ACCRN07 as our test clinical trial.

Aim 3: To develop a recruitment model through collaboration and education of providers regarding AYAs with cancer.

METHODS:

Patients and Providers: Patients between 15 and 30 treated by oncologic providers at:
- 1) UTHSCSA outpatient clinics (CTRC and MARC);
- 2) CHRISTUS healthcare facilities;
- 3) Methodist healthcare facilities;
- 4) Bexar county health district facilities.

Protocol: COG registry ACCRN07

RESULTS

Aim 1: To recruit and train a dedicated AYA patient navigator/clinical research associate (PN/CRA) who would access AYAs treated by oncological providers across different healthcare systems.

- PN/CRA Hired on June 1st 2009
- Training and Credentialing with COG and all healthcare facilities completed in April 2010
- Effectively able to start screening and recruiting patients in Mid-July 2009 at UTHSCSA outpatient facilities.

Aim 2: To increase enrollment of AYAs onto clinical trials using the COG registry ACCRN07 as our test clinical trial.

Recruitment of Providers and Clinics:
- 15 providers across diverse oncologic disciplines recruited
- Screening of medical oncology, radiation oncology, hematology and oncologic orthopedics clinic schedules at CTRC
- Screening of clinic schedules at the MARC to include ENT, gynecology/oncology and urology
- Extension to UHS system to access the indigent patient population

Participation in Targeted Adult and Pediatric Tumor Boards
AYA PROJECT

**RESULTS**

**Aim 3:** Develop a recruitment model through collaboration and education of providers and the community in regards to AYA with cancer.

- Partnership with providers and community to increase awareness.
- Collaboration between Medical and Pediatric Oncologists:
  1. Participation in joined tumor board or case conference.
  2. Measures & Activities Leading to Improved Outcomes and Enhanced Knowledge:
     1. Joining additional cooperative group (adult cooperative group for pediatric and COG for medical oncologist).
     2. Creation of physical or virtual treatment units giving access to appropriate treatment expertise and social services.
     3. Joined training program and other education activities.
- Ramphal et al. Cancer 2011

Limited AYA Proficiency

**Do You Speak AYA?**

Improving Outcomes for AYAs with Cancer

**Measures & Activities Leading to Improved Outcomes and Enhanced Knowledge**

**Collaboration between Medical and Pediatric Oncologists:**

1. Participation in joined tumor board or case conference.
2. Joining additional cooperative group (adult cooperative group for pediatric and COG for medical oncologist).
3. Creation of physical or virtual treatment units giving access to appropriate treatment expertise and social services.
4. Joined training program and other education activities.

**Conclusion**

2. Consistent use of trained professional interpreters and navigators in the clinical setting.
3. “Culturally” competent and inclusive workforce
4. Engagement of community members in the design, implementation, and evaluation of health information and services