Border Medicine in our Hospitals: Providing Palliative and Complex Medical Care for the Undocumented Patient Population

Rachel Vandermeer, MD
Pediatric Palliative Care
University Hospital

University of Texas Health and Science Center at San Antonio

Objectives

• By the end of this presentation the attendee will be able to
  1. Discuss the ethics and challenges of providing palliative care in a resource limited situation.
  2. Describe the community resources available to medically fragile children who are undocumented.
  3. Review an approach to shared decision making conversations with immigrant families.

Case Presentations

<table>
<thead>
<tr>
<th>Insurance</th>
<th>Standard of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michelle: Mexican Insurance, No American Insurance</td>
<td>Obvious American Standard</td>
</tr>
<tr>
<td>Ana: CSHCN</td>
<td>Standard of care related to goals of care</td>
</tr>
<tr>
<td>Selena: CSHCN</td>
<td>American Standard Unclear</td>
</tr>
<tr>
<td>Leah: Mexican Insurance, No American Insurance</td>
<td>Obvious American Standard</td>
</tr>
<tr>
<td>Roberto: American Medicaid</td>
<td>Obvious American Standard</td>
</tr>
</tbody>
</table>

Medicaid=American Standard of Care

• Inpatient care
• Outpatient care-primary and specialty
• Dental care
• Mental health
• Drugs
• HHN (up to 168 hours for trach/vent)
• DME
• Therapies
• Medicaid Transportation program
  • Car transportation
  • Ambulance transportation
  • In hospital lodging, gas money, meal money
• Hospice (concurrent care)

Case 1:

X American Insurance  ✔ Standard of Care

• Michelle is a 5 mos old previously full term female with h/o intestinal atresia s/p bowel resection and TPN dependence, FTT.

• Born in MX and had prolonged stay in NICU with failure to progress onto NG/oral feeds

• Presented to ER after family left "AMA" from NICU in MX 10 hours earlier.

✔ Neo PICC left in place by medical team in MX, family asked for TPN to be restarted in our hospital

Case 1:

X American Insurance  ✔ Standard of Care

• Started on enteral feeds → large stool output and diarrhea

• IVF and TPN dependent

• Funding??

• Now What??
Case 1:  
American Insurance  ✔ Standard of Care  

Palliative Consult  
Futile care (no funding)  
Please send home on hospice  

Case 1:  
American Insurance  ✔ Standard of Care  

- Middle class family in MX (Mexican IMSS insurance)  
- Large tertiary center in Monterrey MX  
- Life expectancy for SBS in MX only 6-7 mos  
- Family left with BLESSING of Monterrey hospital to seek care in the US  
- Only chance at survival  

“Please give my baby TPN!”  

Case 1:  
American Insurance  ✔ Standard of Care  

- Family called MX consulate representative  
- Spoke with MX pedi surgeon, confirmed life expectancy  
- Can give TPN, but access and infection issue  
- Cannot manage a Broviac  

Justice and Beneficence  

Case 1:  
American Insurance  ✔ Standard of Care  

- Pediatric department opted to provide care  
- Applied for Children With Special Health Care Needs Insurance  
- Stayed admitted until CSHCN funding approved (3 mos total)  
- Did have emergency Medicaid while in house  
- Family moved to Dallas area for follow up care
Emergency Medicaid

- Helps the hospital
- Pays 33c on the dollar (depending on case)
- Does not follow outpatient

Children With Special Health Care Needs (CSHCN)

- Medical, dental and mental health care
  - Outpatient and inpatient
  - Drugs
  - Therapies (speech, physical and occupational)
  - Case management
  - Family support services
  - Respite care
  - Travel to Health Care Visits
  - Transportation of deceased clients

---

Case 2:
- American Insurance GOC = Standard of Care

  - Ana is a 3 yr old F ex 28 weeker with PMH congenital hydrocephalus
  - Admitted with somnolence (days), increased seizures
  - AEDs adjusted, seizures resolved, mental status improved
  - Nurse noticed coughing and gagging with feeds
  - Made NPO, NG placed, swallow study \(\rightarrow\) aspiration with thick liquids and bedside evaluation showed severe dysphagia
  - Mother told Ana would benefit from a GT

Palliative Consult

Care Coordination, Complex Care Clinic

---

Case 2:
- American Insurance GOC = Standard of Care

  - Oral intake had only fallen off during acute worsening of seizures
  - Mother had NO concerns for feeding issues
  - No h/o aspiration or pneumonia
  - 50th-75th percentile on GMFCS Va

Mom enjoys feeding Ana
Case 2: 
√ American Insurance  GOC = Standard of Care

• GOC conversation
• Mom opted for GT, ok with NPO

“If she has a GT then she will get some nursing hours and this will actually help mom.”

Case 2: 
√ American Insurance  GOC = Standard of Care

• Ana has CSHCN
• Mexican citizen
• Mom here on asylum (MX gang violence)

• Called SW, can she get nursing hours??

Case 2: 
√ American Insurance  GOC = Standard of Care

• Social Situation
  • Mom, three children living in dilapidated house owned by uncle (rat infested)
  • Uncle told mom only has two weeks to find new housing
  • Prolonged hospital stay → past two weeks → homeless

  • Homeless + new medical complexity
  • Mom unable to work because no one able to care for Ana

Case 2: 
√ American Insurance  GOC = Standard of Care

• Social Situation = Homeless
  • Shelters (no SSN, would not take medically complex child with nurse)
  • Applied for grant for housing
    • Mom found housing
    • Used all cash to move across town, discharged
    • Nursing initiated, new housing concerns per nursing
    • CPS called → “call back when she has medical problems
    • 2/2 living under bridge”
    • First month rent paid
    • Mom had no funding for further rent
    • Moved to Eagle Pass
    • Lost nursing

Case 2: 
√ American Insurance  GOC = Standard of Care

• Fell off the grid...
  • “if it is not broke...don’t fix it...”

  • Living in family house (first Eagle Pass, now Kyle)
  • Mom working during day (three family members taking care of Ana)
  • Mom offering oral tastes and hopes for Ana to take more oral feeds
  • Now overweight...
Case 2:
- American Insurance
- GOC = Standard of Care

| Disparity in care offered in the two countries | US-GT placed early
| Limited funding | Mx focus oral feeding
| Family financially destitute | Does increased medicalization further negatively impact finances?

Who is supposed to pay for her care?
- nursing
- transportation
- transportation

Does non-maleficence

Case 3:
- American Insurance
- GOC = Standard of Care

Selena is a 10 yr old F born FT and healthy until T&A at age 7 with resultant anoxic event and severe neurologic impairment

Admitted for aspiration pna and acute on chronic respiratory failure

Unable to wean continuous bipap

CSHCN

Palliative Consult

GOC conversation

Medical
- Continuous bipap
- Less alert over past several months
- Trach versus continuous bipap and comfort

Social
- From Honduras
- Mom here on asylum visa
- Child product of rape
- Mom with new partner, works 12-15h/day
- Mom 9 mos pregnant
- CSHCN
- Known limited nursing hours

Family meeting!!

Trach requires rigid care

No consistent nursing

End of life

Mom opted for continuous bipap with limited available nursing AND hospice, OOH DNR

HICCUP

CSHCN-No concurrent care

Home with limited HHN hours, CCC follow up and OOH DNR
**Children With Special Health Care Needs (CSHCN)**

- Takes MONTHS to get
  - Write letter of necessity, multiple physician signatures
  - “matter of life and death”
- Limited number nursing hours (up to 400/YEAR)
- Can get skilled nursing visits
- DME usually covered
- Less therapy hours than Medicaid
- Ambulance transportation NOT easy to obtain
- Hospice coverage
  - Difficult to get concurrent care

**Case 4:**

- **X American Insurance**
- **Standard of Care**

  - Leah is a 7 yr old F with relapsed X2 pre B cell ALL

  - Admitted with acute relapse and neutropenic fever.

  - Here from MX on traveler’s visa with mother visiting grandmother for Christmas holiday.

  - Middle class family in MX, IMSS insurance in MX

  - Treated at age 2 and remission until 1/2016 - treated in MX

**Palliative Consult**

**End of life, GOC conversation (Hospice)**

**Case 4:**

- **X American Insurance**
- **Standard of Care**

  - Emergency Medicaid (on visa)

  - Neutropenic fever treated

  - Started on chemo regimen

  - BMA with MRD high

  - Dad’s trip to the US...precarious
    - Emergency Medicaid = visa violation??
    - Criminal action??

  - LACK of funding (needs BMT)
  - Would not be able to get appropriate TX and BMT in MX
  - Chemo possible, but no next step  suffering
  - Recommended hospice

**Case 4:**

- **X American Insurance**
- **Standard of Care**

  - Emergency Medicaid (on visa)

  - Neutropenic fever treated

  - Started on chemo regimen

  - BMA with MRD high

  - Dad’s trip to the US...precarious

  - Emergency Medicaid = visa violation??

  - Criminal action??

  - LACK of funding (needs BMT)
  - Would not be able to get appropriate TX and BMT in MX
  - Chemo possible, but no next step  suffering
  - Recommended hospice
Case 4: X American Insurance ? Standard of Care

- Further discussion about medical options
- Chemo option may be a possibility...
- BMT possible with CSHCN
- CSHCN application submitted 30 days ago!!

Case 4: X American Insurance ? Standard of Care

- The GREAT GAMBLE
  - Tolerated chemo very well
  - Bone marrow cleared
  - CSHCN did NOT come through
  - Able to locate charity BMT

Case 4: √ American Insurance √ Standard of Care

- Disparity in care offered in the two countries
- Limited funding
- Family financially destitute

| Disparity in care offered in the two countries | US-BMT for 2x relapsed MX-no BMT in this case |
| Limited funding | Who is supposed to pay for her care? BMT very expensive (750K - 1mil) |
| Family financially destitute | Compromising family’s financial stability Who is going to pay for housing and food? |

Case 5: √ American Insurance √ Standard of Care

- Roberto is a 5 mos old male ex 26 weeker who developed hepatoblastoma now s/p treatment, CLD of prematurity with O2 dependence and normal neurological development
- Mother and father 18 years, Mexican citizens
- Indigent
- Supported by maternal and paternal grandparents in MX

Case 5: √ American Insurance √ Standard of Care

- Roberto now ready for discharge.
- Cleared from H/O standpoint.
- Goals of family to return to MX
  - O2 stopped and prepare to send to MX
“Why is the palliative doctor overriding the family’s goals of care?”

Shared Decision Making Continuum

<table>
<thead>
<tr>
<th>Case 5:</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>v American Insurance v Standard of Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disparity in care offered in the two countries</td>
<td>US-O2 and synagis, great prognosis</td>
<td>MX no O2 and synagis, ?prognosis</td>
<td></td>
</tr>
<tr>
<td>Family financially destitute</td>
<td>Compromising family’s financial stability Who is going to pay for housing and food?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social isolation</td>
<td>Young parents separated from support system</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Non-maleficence (Autonomy? Advocacy...)

What can I get on the Border: Texas-Side??

- Hospice
- Charity
- CSCHN if no other HHN
- Medicaid
- FYI-concurrent care hard
- DME
- CSCHN
- Medicaid
- HHN
- Hit or miss even with Medicaid
- Not CSCHN

What can I get in MX???

- End of life...
  - O2 concentrator
  - Family left CC deposit $2000 with DME company
- Most equipment must be paid for out of pocket
- Can get almost anything though...

- Keep Visa status in mind if family crossing back and forth and child NOT American citizen (CSHCN...)

- Medical letters-dangerous!

Conclusions

- Should you? Can You?
- Can You? Should You?

Medical Information

Family Values

Shared decision

Family Resources

Institutional Resources
Thank You!!

Questions??