A Tale of Two Worlds:
Ensuring Continuity of Care between Pediatric and Adult Health Care

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Disclosures

I serve as a speaker for Novartis Pharmaceuticals

Consultant/honoraria for Advisory Boards:
  ApoPharma
  Baxter

NONE OF THESE RELATIONSHIPS ARE RELEVANT TO MY PRESENTATION TODAY
Objectives

- Define transition and the patient centered medical home and the impact of the growing population of children with chronic illness surviving to adulthood
- Understand the challenges of transition from multiple perspectives
- Present the key elements in implementing a transition plan here at LBMMC/MCWHLB
- Review Year 1 and 2 data including successes and barriers at LBMMC/MCWHLB
Sickle Cell Disease

- 240,000 children born annually in Africa with SCD; 80% die by their second birthday
- Estimated 80,000 affected in USA; 6900 in CA
- 97% of children in the US survive by age 18
- 1/400 African Americans; 1/3600 Hispanics

Hemoglobinopathies:
- Hgb SS
- Hgb SC
- Hgb Sβ° Thal
- Hgb Sβ+ Thal
Sickle Cell ER visits in California

82% of ER visits are adults
A few patients in a huge area so providers don’t have much experience

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### TABLE II. Visit-Level Descriptive Statistics (Total N = 16,638 Visits)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Categories</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Child: 0–20</td>
<td>2,970 (18)</td>
</tr>
<tr>
<td></td>
<td>0–10</td>
<td>1,185 (7)</td>
</tr>
<tr>
<td></td>
<td>11–20</td>
<td>1,785 (11)</td>
</tr>
<tr>
<td></td>
<td>Adult: 21+</td>
<td>13,668 (82)</td>
</tr>
<tr>
<td></td>
<td>21–30</td>
<td>5,498 (33)</td>
</tr>
<tr>
<td></td>
<td>31–40</td>
<td>3,380 (20)</td>
</tr>
<tr>
<td></td>
<td>41–50</td>
<td>3,183 (19)</td>
</tr>
<tr>
<td></td>
<td>51+</td>
<td>1,607 (10)</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>6,917 (42)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9,669 (58)</td>
</tr>
<tr>
<td></td>
<td>Unknown/inconsistent</td>
<td>52 (0)</td>
</tr>
<tr>
<td>Race</td>
<td>Black/African-American</td>
<td>12,235 (74)</td>
</tr>
<tr>
<td></td>
<td>Other known race</td>
<td>920 (6)</td>
</tr>
<tr>
<td></td>
<td>Asian/Pacific Islander</td>
<td>33 (0)</td>
</tr>
<tr>
<td></td>
<td>White</td>
<td>524 (3)</td>
</tr>
<tr>
<td></td>
<td>Other race</td>
<td>363 (2)</td>
</tr>
<tr>
<td></td>
<td>Unknown/inconsistent</td>
<td>3,483 (21)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Hispanic</td>
<td>2,292 (14)</td>
</tr>
<tr>
<td></td>
<td>Non-Hispanic</td>
<td>12,427 (75)</td>
</tr>
<tr>
<td></td>
<td>Unknown/inconsistent</td>
<td>1,919 (12)</td>
</tr>
<tr>
<td>Expected source of</td>
<td>payment</td>
<td>11,992 (72)</td>
</tr>
<tr>
<td>payment</td>
<td>Public pay</td>
<td>11,992 (72)</td>
</tr>
<tr>
<td></td>
<td>Private pay</td>
<td>2,931 (18)</td>
</tr>
<tr>
<td></td>
<td>Self-pay (no insurance)</td>
<td>1,714 (10)</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>1 (0)</td>
</tr>
<tr>
<td>Disposition</td>
<td>Admit</td>
<td>5,843 (35)</td>
</tr>
<tr>
<td></td>
<td>Discharge</td>
<td>10,795 (65)</td>
</tr>
<tr>
<td>Geographic residence</td>
<td>Los Angeles County (LAC)</td>
<td>6,351 (38)</td>
</tr>
<tr>
<td></td>
<td>Southern California (not LAC)</td>
<td>3,345 (20)</td>
</tr>
<tr>
<td></td>
<td>Northern California</td>
<td>6,664 (40)</td>
</tr>
<tr>
<td></td>
<td>Out-of-state/missing/unknown/homeless</td>
<td>278 (2)</td>
</tr>
</tbody>
</table>

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Wolfson et al et al, Pediatr Blood Cancer 2011, 56(2) 413
Wolfson et al et al, Pediatr Blood Cancer 2011, 58(2) 66

Thomas D Coates, MD
Adults with SCD have inadequate access to expert care.

- The transition from pediatric to adult care (18-30yrs) is associated with a marked increase in ER visits and a significant decrease in survival.
- Most adults with SCD get most of their care in Emergency Rooms.
- There are very few adult providers with special expertise in SCD.
- Most providers have very little experience with SCD and many misconceptions.
- Brain damage from SCD impairs ability of adults to navigate the healthcare system.
- The healthcare system is not setup to deal with rare conditions.

Thomas D Coates, MD
Principles

- “Transfer” to adult facility is a medical handoff that has its own challenges, risks, requirements and idiosyncrasies.
- “Transition” is the process the patient/family undergoes from one life-stage to the next, of which adult care transfer is just one part.
- The pediatric team role is mostly aimed at:
  - Education
  - Readiness assessment
  - Facilitation
“The purposeful, planned and timely transition from child and family-centered pediatric health care to patient-centered adult-oriented health care.”

Society for Adolescent Medicine, 1993
It is not a transition, but a metamorphosis

Julie Kanter, MD
MUSC Children’s Hospital
What happens when patients grow up?
A tale of two worlds: SCD

Pediatric - Under the Sea
- Golden years
- Episodic acute pain
- Opioids acceptable
- Goal: Pain free
- Fewer social problems
- Fewer emotional problems
- Goal to avoid mortality

Adult: A Whole New World
- Turbulent years
- Chronic unremitting pain
- Goal: adjust to pain
- Progressive social problems
- Chronic organ dysfunction
- Goal is symbiosis with disease
Tea or Tai Chi

Pediatric Care

- Nurturing/protective
- Attractive environment
- PFCC
- Universal funding
- Family insurance
- Paternalistic
- More providers
- Centralized

Adult Care

- Informing
- Patient centered
- Unfunded, practical
- Employment based insurance
- Total patient autonomy
- Fragmented
- Fewer providers
Defining the Problem

Youth

- Emotional, social issues
  - Other systems (school, DCFS)
  - Basic needs
  - Parent–child
  - Sensitive svcs
  - No relationship with PCP

- Mental Health

Lack of specialists

- Able & willing to manage
- Accept Medi-cal

(Risky) Adolescent behavior

Limited KSAs

- "Pediatric enabling"
- Adj to illness
- Health literacy

- Cultural/language barriers
Patient Centered Medical Home

- Case Management
- Chronic Care
- Comparative Effectiveness
- Disease Management

Engaged Consumers • Evidenced Based • Health Information Exchange

Hospital Specialtycare
Primary Care
Wellness

Transition

Health Information Technology • Incentives • Medicaid • Medicare

Patient Advocacy • Payment Reform • Physician Directed • Preventive Care • Whole Person Approach
Patient Centered Medical Home

- Goals:
  - Better quality
  - Lower costs
  - Improved care experience
<table>
<thead>
<tr>
<th>Simpler Transition</th>
<th>More Complex Transition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single health condition</td>
<td>Multiple health conditions</td>
</tr>
<tr>
<td>Low risk of future health problems</td>
<td>High risk of future health problems</td>
</tr>
<tr>
<td>No dependence on medical equipment</td>
<td>Reliance on life-sustaining medical equipment</td>
</tr>
<tr>
<td>Rare acute illness, medically stable</td>
<td>Frequent acute episodes, medically unstable</td>
</tr>
<tr>
<td>Few medications</td>
<td>Multiple medications, medication problems</td>
</tr>
<tr>
<td>No cognitive impairments</td>
<td>Profound mental retardation</td>
</tr>
<tr>
<td>No physical impairments</td>
<td>Serious physical impairments</td>
</tr>
<tr>
<td>Mentally healthy</td>
<td>Mentally ill</td>
</tr>
<tr>
<td>No behavioral concerns</td>
<td>Serious behavioral concerns</td>
</tr>
</tbody>
</table>

SOURCE: Adapted from Kelly et al. (2002).
“Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally.”

Department of Health and Human Services,
Health Resources and Services Administration
Maternal and Child Bureau
Children and Youth with Special Health Care Needs (CYSHCN)

- Asthma
- ADHD
- Diabetes mellitus
- Sickle cell disease
- Cerebral Palsy
- Cystic fibrosis
- Chronic kidney disease
- Inflammatory bowel disease
- Congenital heart disease
- Childhood cancer survivors
- Solid-organ transplant recipients

- Spina bifida
- Down syndrome
- HIV-AIDS
- Genetic and neuromuscular disorders
No Longer Just a Childhood Illness

• ~ 11.2 million children (15% of all US children) 0-17 years have special health care needs
  – 500,000 CYSHCN turn 18 and enter adulthood in the US yearly

• Survival rates have increased for children with chronic illnesses
  – >90% survive beyond their 20\textsuperscript{th} birthday
Why Transition is Important

- Failure to recognize and plan transition may result in patients dropping out of care
- Poor transition processes are recognized to have a significant negative effect on morbidity and mortality in young adults with chronic health needs
Consensus Statement on Health Care Transition for Young Adults With Special Health Care Needs

• Goal of Transition:
  - Maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood

American Academy of Pediatrics
American Academy of Family Physicians
American College of Physicians
American Society of Internal Medicine
Healthy People 2020

- U.S. Dept. of HHS
- 10-yr national goals to improve American health
- Increase % of children (including CYSHCN):
  - Receive care in family-centered, comprehensive, coordinated systems
  - Have discussed transition with health care provider
  - Have access to a medical home
To review up to this point...

- CYSHCN are living longer and need a smooth, coordinated transition for improved health outcomes
- We are not doing a great job preparing patients for the transition to adult medicine
- Pediatric and Adult Medicine in great need of communication for this population
Goal: Improved Outcomes
How do we address this problem?

- Education
- Education for patients
- Education for parents
- Education for providers
- Education for hospitals
- Education of the healthcare system
Transition of Care Program

Mission Statement: The purpose of the Transition of Care program is to conduct education, planning, and care coordination with teens and young adults with chronic conditions to increase their health knowledge, skills and abilities, and ensure a smooth transition to adult care.
### Transition and MemorialCare

#### MemorialCare Initiatives (Population Health)

- Seaside Health Plan
- MemorialCare Medical Foundation
- Behavioral Health
- Reduce LOS, costs, readmissions
- Dual eligibles
- Outpatient Village
- Education Center
- Residency Program

#### Transition Program Goals (Healthy Young Adults)

- Access to specialists
- Innovation
- Brand Loyalty
- Pediatrics/Adult Collaboration
- Improved health outcomes, KSAs
- Medical home
- Transition in Education Center
- Transition Clinic
- Education setting for increasing expertise

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**Transition Program Goals**

- **Healthy Young Adults**
  - Access to specialists
  - Innovation
  - Brand Loyalty
  - Pediatrics/A&CA Collaboration
  - Medical home
  - Transition in Education Center
  - Transition Clinic
  - Education setting for increasing expertise
Smooth Transition

Comprehensive Disease Management

Tailored Treatment

Improved Outcomes
Year One Activities

• Conducted needs assessment for pilot populations: type 1 diabetes & sickle cell (interviews, lit review, nat’l transition conference, data analysis)
• Selected and piloted tools (staff checklist, handouts, youth checklist)
• Networking, outreach
• Patient consultation
• Focus 19+ year old patients
• Tracked “rescue group”
• Outpatient Nursing Council sub-committee
Our Patients

Clinical Care for SCD in Our Community

- SCD patients, aged 21-30 at MCH/LBM
  - 51% readmitted within 30 days of ED visit
  - 41% in 14 days

  Tran, H. et al., ASH Dec 2012

- Rescue Group- 9 with SCD aged 19-27
  - 141 hospitalizations and 85 ED visits in 1 year

  Jewell, E. 2013
“Rescue” Group

16 PATIENTS

- Patients with sickle cell disease or type 1 diabetes admitted to adult inpatient units, aged 19-27
- 84% were patients of Miller Children’s Hospital
- 141 admissions and 85 ED visits in one year
- 773 inpatient days, accruing $4,954,144 in charges
- Attempted to link to a medical home & other resources, educated re: managed Medi-cal (navigating the system).
- Limited ability to affect change in one year, transition is just one of many issues
Transition Visit Protocol

**Intro to independence**
- Basic education about disease and self mgmt
- Meet privately
- Set independence goals

**Transition Coordination and Resources**
- Coordinate w/other clinics, agencies
- Continue/reinforce health education
- Meet privately

**Intro to Adult Responsibilities**
- Sign consent/release
- Educate/set goals for additional levels of independence
- Self-assessment
- Life Skills

**Final Transition Activities**
- Review goals
- Education re: adult healthcare system
- Identify adult providers/insurance
- Complete health summary
- Follow-up call
**Documentation**

### Transition Checklist - TRANSITION CHECKLIST

<table>
<thead>
<tr>
<th>Time Taken:</th>
<th>12/17/2014</th>
</tr>
</thead>
</table>

**Values By:** Create Note

- **Transition Provider Checklist**
  - Encourage patient to ask/answer his or her own questions during the visit
  - [Yes] [No]

- **Transition Nursing/Physician Checklist**
  - Meet privately with the patient for part of the visit, discuss sensitive topics
  - [Yes] [No]

- **Transition Psychosocial Checklist**
  - Encourage parent to allow for independence in care with supervision
  - [Yes] [No] [Needs reinforcement]

**Comments:**

- [Text field for comments]

**Visit Notes**

- [Section for visit notes]

**More Activities**

- [Link to more activities]

**Images:**

- [Image with document and checklist]

**Long Beach Memorial Miller Children's & Women's Hospital Long Beach**

**MemorialCare Health System**
CALIFORNIA CHILDREN’S SERVICES
Transition Planning Coordination

Name of CCS Client: ____________________________  DOB: ________

CCS #: ____________________________

Los Angeles County CCS Fax Number:  (800) 924-1154

I. Check one:

☐ Transition Planning was completed by the following CCS approved Special Care Center (SCC) or subspecialty provider (see attached for medical reports):

SCC ____________________________

Or

Subspecialty Provider: ____________________________

☐ Transition Planning was completed by Medical Home or Primary Care Provider: ____________________________
### Impact of Study

- **Research grant awarded: Memorial Foundation**
  - “Youth to Adult Healthcare Transition”
  - Transition Navigator - Erika Jewell, LCSW, 2012
  - $750,000, 3 year grant awarded, 11/2012
  - Transition Navigator - Lauren Partain, LCSW, 2014

- **Development of Transition Program at MCHLB**
  - Pilot populations: Sickle Cell Disease and Diabetes
  - Current: Hematology/Oncology

- **Used in conjunction with other Research endeavors:**
  - “Acute Healthcare Utilization for Patients with Sickle Cell Disease within a Community Based Hospital System” Hung Tran et. al. (2012)
Year 1 Data
Sickle Cell and Diabetes

- 74% of pilot patients received transition services
- 77% of the discharged patients had a follow-up appointment with a new PCP or specialist
- 60% of the patients with diabetes who had fair or poor control decreased their HgA1C after transition services were provided.
- High utilizing patients who received transition services decreased hospitalizations by 9% and emergency room visits by 25%
- Post-discharge follow-up calls found that most (60%) patients encountered insurance difficulties, many didn’t remember receiving transition and some had difficulty working with a new provider.
- Staff and physicians reported greater satisfaction with transition services when compared to the beginning of the program.
1. Implement transition program in additional patient populations (all populations carry over into future years)
   - Type 1 DM and Sickle Cell (2013)
   - Type 2 DM (2014)
   - Cancer/Hemophilia (2015)
   - Cystic Fibrosis (2016)

2. Create a comprehensive education curriculum
   - For staff, physicians, residents (e.g., You Learn module, new hire orientation, Grand Rounds)
   - For patients and families (educational materials, social media, group visits)

3. Align transition activities with larger MemorialCare initiatives, manage and evaluate program, develop model for spreading transition system-wide.
   - CCS Transition to Managed Medi-Cal (?)
   - Seaside and MCMF – training for physicians, establishing adult specialist system to receive transitioning youth
   - Evaluate program and share results, work with national partners, seek funding
Year 2 Data

- Implement a transition program with an additional 125 diabetes (type 2) patients in the Endocrine Clinic.
- 217 active patients received transition services (since 2013), in addition 43 discharged patients received transition services.
- 100% patients completed a post transition visit with a PCP, 61% have seen a specialist (among a group of patients who we could contact for follow-up).
Year 2 Data, cont’d

- 49% patients with diabetes with fair/poor control had improved HgA1C after transition.
- 42% of sickle cell patients had no increase in emergency room visits/inpatient hospitalizations after transition.
- 44% patients scored 80%+ on the transition readiness measure.
- 70% of patients’ charts had documentation of transition services.
- 85% of staff report satisfaction with program.
- 81% of patients report satisfaction with program.
Program Needs

- Building pediatric-adult provider collaboration
- Linking patients to a medical home
- Partnerships with community agencies that serve the population (e.g., LBUSD Regional Center)
- Collaboration with payors, Seaside, MCMF to establish specialty care networks for young adults with chronic illness
- Adolescent Medicine/Transition Clinic
Looking Ahead...

- Expanded to the Hematology/Oncology team to help improve transition outcomes for cancer and hematology patients

- Will add one more disease population at the beginning of 2016

- Awarded a Healthy Tomorrows grant
  o Adding social media and EPIC experts to our team
  o Hiring a physician champion to help build relationships with adult providers and specialists
Looking Ahead…

- Focusing on patient and family transition education, including a transition section on the Miller Children’s & Women’s Website
  - Needs assessment on our teen patients and social media
  - Focus groups of teens and parents who will review new tools and resources
  - Expanding our Transition Task Force to include patients and parents
In Summary

• The importance of successful transition has been well established
• High mortality rate in patients from ages 18-25 y/o
• Focus on creating protocols starting at an early age
• Incorporate planned follow up to ensure transition readiness
• AAP Recommends
  – Providing a medical home
  – Identifying core knowledge and skills
  – Providing a portable medical summary
  – Creating a transition plan
• Communication is essential
Stand up to the Challenge

Do a better job teaching our kids how to navigate the healthcare system and take care of themselves.

Develop effective networks of providers to work with centers to provide quality care.