Hospital of the University of Pennsylvania

CNS Partnerships in Complex Transitions: Conjoined Craniopagus Twins from Pediatric to Adult Care Facilities

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Clinical Nurse Specialist

March 11, 2017
The Hospital of the University of Pennsylvania (HUP)

- Located in Philadelphia, PA
- 789 bed quaternary academic medical center*

<table>
<thead>
<tr>
<th>Category</th>
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<td>ED Visits</td>
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<td>Physicians</td>
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- Part of the University of Pennsylvania Health System
- Magnet designated since 2007
- Annually recognized as one of the nations best by *U.S. News & World Report* in its Honor Roll of best hospitals.

*Penn Medicine Facts and Figures, 2016*
Objectives

- Identify the issues related to caring for adult patients in pediatric organizations.
- Identify strategies that can be utilized to transition pediatric patients to adult providers.
- Describe communication processes used to support the transition while providing the continuation of safe, quality care.
Conjoined Twins

- 53 year old craniopagus twins.
Clinical History

- Conjoined laterally to the left orbital area, generally facing in opposite directions.
- Small area of shared venous circulation in the superior sagittal sinus.
- Each is an autonomously functioning person.
- The other twin is a healthy middle-aged adult with typical middle-age comorbidities.
- Separate allergies.
Social

  - Received surgical/complex care at the Children’s Hospital of Philadelphia (CHOP) since their early teen years.

- Straightforward medical issues were addressed by their local community hospital.

- Transferred to the CHOP for any complex issues stemming from D’s pediatric congenital disorder.
Challenge

- Caring for two aging patients led CHOP to re-examine the safest setting for the twins to receive specialized care moving forward.
- Exploration of the best hospital setting for the twin’s complex care highlighted the challenges to both pediatric and adult care settings while raising the question of which venue would serve them best.
Adult Patients in Pediatric Organizations

- Is it safe?
- Is it fair to the patients?
- Is it fair to the nurses?
- What happens in an emergency?
- Which venue would serve the twin’s complex care highlighting the challenges to both pediatric and adult care settings?
2008 Initial Talks

- CHOP internal discussions began of the potential transition of twins to the HUP. Teams included:
  - Nursing leadership
  - Social work
  - Transition program
  - Diagnostic center
  - Primary care

- Engaging twins in the CHOP’s care coordination efforts proved to be the biggest hurdle.

- CHOP was their primary hospital and had an aversion to transferring to an adult care setting.

- Ultimately these discussions stopped and interest in the transition process stopped.
2012 Unexpected Hospitalization

- Possible surgery for D restarted the discussions.
- The need for general anesthesia for D’s surgery prompted the CHOP’s team to re-visit the safest care setting for L and D and the need to move the transition process forward.
- Although it was decided that this acute hospitalization was not the right time for transfer to an adult facility, collaboration began between nursing leadership at both the CHOP and the HUP.
Transition

- Nursing partnership between both CHOP’s Clinical Nurse Specialist (CNS) and HUP’s facilitated the partnership and started the discussion between institutions.
  - HUP CNS met the twins and became familiar with the nuances of their care.
  - Twins became more comfortable with the HUP CNS and talk of moving to the adult institution.

- Discussions included:
  - CHOPs nursing care plan.
  - One primary inpatient unit.
  - Primary nursing when L and D were admitted.

- HUP implement the same nursing model.
Partnership Talks

- Broader collaboration across both entities extended to include representatives:
  - Urology
  - General Surgery
  - Orthopedic Surgery
  - Anesthesia
  - Perioperative Teams
  - Social Work
  - Case Management
  - General Counsel Hospital Leadership

- Outcome of extensive initial collaboration:
  - D’s surgery would occur at the CHOP with the HUP teams observing intubation, surgery, and recovery for the HUP’s educational purposes.
  - HUP to accept L and D post-operatively should complications require adult care.
  - Future outpatient follow-up appointments with surgical specialties would occur at the HUP.

- The aim of these plans was to gradually and safely transfer L and D’s specialized care to the adult setting at the HUP.
Backup Plan

- Nursing developed a protocol for emergency admission to HUP.
  - Emergency route from the CHOP to the HUP
  - Elevators
  - Units
  - Beds
2013 Colonoscopy

- Required by L
- Performed at the HUP as out-patients
- Ease into transition
D presented to the CHOP’s Emergency Department with the same orthopedic problem six times.
  • D needed elective orthopedic surgery.

Conversation started up between the CHOP and the HUP.
  • First over email.
  • Multiple meetings with various disciplines.

The transitional plan required 4 months of pre-planning, between 2 unaffiliated medical organizations.
  • Comprehensive transition plan was developed and agreed upon by both institutions.

D would undergo this elective orthopedic surgery at the HUP with extensive support from the CHOP.

CNS communication essential.

I've got your back!
CNSs Drove the Transition Process

- Coordinated efforts of upwards of 85 multidisciplinary staff counterparts at both the CHOP and the HUP.
  - Clinical nurses
  - Social work
  - Physicians
  - Anesthesia
  - Medical team
  - Surgical team
  - Prosthetics for chair
- Operating room simulation with the twins.
  - Physical set up of the operating room.
  - Intubation and induction of anesthesia.
- Numerous collaborative meetings at all levels between hospitals.
  - Preparation for a rapid response should the patients’ condition deteriorate unexpectedly.
  - Meticulous discharge plan for the patients’ durable medical equipment needs and placement post-operatively.
  - Completion of revised Advance Directives for both patients.
# Team List

<table>
<thead>
<tr>
<th>Team</th>
<th>Identified Person</th>
<th>Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgeon</td>
<td>XXXXX  XXXXX</td>
<td></td>
</tr>
<tr>
<td>Admitting Physician</td>
<td>XXXXX  XXXXX</td>
<td></td>
</tr>
<tr>
<td>Physician Assistant</td>
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<tr>
<td>Admitting Plastics Resident</td>
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<td>(4th year Plastics Resident)</td>
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<tr>
<td>Anesthesia</td>
<td>XXXXX  XXXXX</td>
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<tr>
<td>Surgeon</td>
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<td>OR and PACU Leadership Team</td>
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<td>CICU Nursing Leaderships Team</td>
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<td>1083. Staff aware and educated.</td>
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<td>Medicine Consultant</td>
<td>XXXXX  XXXXX</td>
<td>For both twins</td>
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<td>Consult Service</td>
<td>XXXXX  XXXXX</td>
<td>For D</td>
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<td>Pain Service</td>
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<td>Orthotics</td>
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<td>Patient Equipment Coordinator</td>
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<td>Identified 2 striker beds to put together</td>
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<td></td>
<td></td>
<td>Tape mattress with Velcro. (obtained from paint shop)</td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>Hover mat to move them.</td>
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<tr>
<td></td>
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<td>Bring up beds and Hover mat on Tuesday</td>
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<tr>
<td>Team</td>
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<td>Additional Information</td>
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<tr>
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<td>Adopt CHOP’s terminology “Double Resuscitation”.</td>
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<tr>
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<tr>
<td>Rapid Response/Coordinators</td>
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<td>“Double Resuscitation”.</td>
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<td>Clinical Engineering</td>
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<td>IT</td>
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<td>If ICU/Cath lab is needed: Capability to documentation for 2 patients in one room. In progress</td>
</tr>
</tbody>
</table>
Lessons Learned

- Establish dialogue early as possible.
- Connecting with the CNS.
- Connecting complimentary teams from CHOP and HUP (meetings).
- Meeting twins.
- CHOP nursing support the first 2 day shifts.
Conclusion

- A CNS-driven collaboration model established a safe transition for conjoined twins who required complex care.
  - Working in the three spheres of influence, CNSs are the drivers for transitions in care.

- Creating inter-organizational process provides a framework for future transitions between organizations.

- Their established plan for admission is used each time they are admitted to the hospital.
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