Transitions of Care: From Pediatrics to Internal Medicine

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Objectives

- Define transitions of care
- Understand the expert consensus on transitions
- Understand the Shared Management Model
- Define the population
- Define current barriers to transitions
- Understand national data
- Understand the Comprehensive Care Clinic
Definition

Health care transitions is defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centered to adult-oriented healthcare system.

Goal of Transition

The overarching goal for transitional medicine is to provide high quality, coordinated, uninterrupted care which is responsive to the needs and desires of the patient as well as his or her family while enhancing the sense of self-determination and self-advocacy.
Six steps to successful transition

1. Identify a health care provider to help guide through the transition process
2. Identify core knowledge and skills required to provide developmentally appropriate care
3. Prepare up to date medical summary
4. Create a written transition plan by age 14
5. Apply the same guidelines for primary and preventative care for all adolescents
6. Ensure affordable, continuous health insurance

AAP, AAFP, ACP, ASIM, A Consensus Statement of Health Care Transitions for Young Adults with Special Health Care Needs; Pediatrics 2002; 110;1304-1306

Principles of a successful transition

Services need to be appropriate for both chronological and developmental age
Be prepared to discuss common concerns of young people including growth and development, sexuality, mood and mental health, substance abuse, and other behaviors
Enhance autonomy and increase a sense of personal responsibility
Flexible and individualized

Rosen, DS, Transition to adult health care for adolescents and young adults with chronic conditions, Position Paper for the Society of Adolescent Medicine, Journal of Adolescent Health 2003;33:309-311
Transition services: Expect consensus

Providing high quality transition care and support may become the standard of care for all primary care practices

All youth need education, guidance, and planning to prepare to assume responsibilities for their health

Those youth with special health care needs require more individualized approach

AAP; AAFP, ACP; Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011
Getting ready for transition

Every patient should have a transition plan regardless of medical condition
Most successful transitions involve engagement of medical home team, family/caregiver, and the patient jointly
The parents, patient, and both the physician and the receiving physician have their own role

Patient Centered Medical Home

Model of care to strengthen the physician-patient relationship by replacing episodic care based on illness and patient complaints with coordinated care and a long term healing relationship
Joint relationship between the physician, advanced practitioners, nurses, care management, and the patient and family
Implementing the Algorithm

1. Assess for transition readiness
2. Plan a dynamic and longitudinal process for accomplishing transition goals
3. Implement the plan
4. Document progress

Assess for readiness

The provider, family and patient begin discussing realistic goals for transition
Identification of new skills that are required to meet the goals of transition
Proper identification of assessment tools to tract the progress of the patient through the transition process

AAP, AAFP, ACP; Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011
Provider readiness

There should be an explicit office policy that describes the practice approach to and fixed age of transition. Policy should be visible and readily available to patients and their families in a variety of forms.

AAP, AAFP, ACP; Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011

Family readiness

Parents/caregivers have unique perspectives and needs during the transition process. They have specific education needs regarding the differences between pediatric and adult medicine models and their future role in patient care. Require a team approach.

AAP, AAFP, ACP; Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011
Youth readiness

All involved must view the youth as the driver in the transition process

The youth must be ready to begin to assume increased responsibilities for his or her health care needs to the fullest extent possible

Planning

Establishment of individualized goals which may change during the transition process

Creation of a formal, written transition plan that outline specific actions necessary to meet the individualized goals

Plan should be part of the medical record by the age of 14
### The components of the plan

| Combination of patient, family and physician goals | Life skills required to achieve maximum self-management |
| Who will coordinate care through the entire process | The family or other caregiver’s role |
| Time line to accomplish goals | Proposed financing for the youth’s adult healthcare |

AAP, AAFP, ACP; Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011

### Implementing the plan

- Have specific activities that ensure the youth is acquiring the skills needed for self-management
- Need to be flexible during the process
- Continue to implement transition-readiness checklists and track the scores
- Active dialogue with all involved parties, including subspecialists

AAP, AAFP, ACP; Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011
Documentation

Individualized transition plan
Longitudinal readiness checklist demonstrating strengths and weaknesses
Portable medical summary

AAP, AAFP, ACP: Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011

Shared Management Model
Shared Management Model

Developed by Dr Kieckhefer and Trahms in 2000
Has become the model for many organizations in
development of transition services
Based on business labels to express the changing
dynamics in the parent-child relationship


Shifting responsibilities

Children are expected to gradually master the necessary
skills to become managers of their own needs
As the child grows the parents gradually shift from
providing all care to a consultant role
Each party has specific roles
The process must be dynamic

Ultimate Goal

“Planned, systematic approach to a gradual shift in responsibilities from the health care provider and parents to the young person, as developmentally appropriate.”


Young Adult Role

Learning is based on cognitive, developmental and physical readiness
Stepwise approach of increased responsibility
Youth is the pivotal player

Parental Roles

Require the skills for typical challenges of growing up
Special skills related to the youth’s condition and its management
Aspirations for maintaining family life
Dedication to support current and future health outcomes
By working with the child, rather than doing for the child, the parent comes to know when the child has mastered skills at the current level and is ready to move on.

First steps

Identify areas which progress needs to be made
Select a few attainable goals that both the youth and parent find important
Break the goals into small steps that are developmentally appropriate
Prepare a plan to learn and teach these skills with the youth taking the greatest responsibility
Review and evaluate progress
Shared Management Model

Shift in responsibilities from family to young adult to the proper developmental limit.

<table>
<thead>
<tr>
<th>Provider</th>
<th>Parent/Family</th>
<th>Young Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Responsibility</td>
<td>Provides Care</td>
<td>Receives Care</td>
</tr>
<tr>
<td>Support to parent/family &amp; child/youth</td>
<td>Manages</td>
<td>Participates</td>
</tr>
<tr>
<td>Consultant</td>
<td>Supervises</td>
<td>Manager</td>
</tr>
<tr>
<td>Resource</td>
<td>Consultant</td>
<td>Supervisor</td>
</tr>
</tbody>
</table>

Children and Youth with Special Health Care Needs

Defining a population

According to the Maternal and Child Health Bureau (MCHB), children with special health care needs (CSHCN) are those who “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

2005-2006 National Survey of Children with Special Health Care Needs
Cystic Fibrosis (CF) Numbers

Life expectancy continues to lengthen as technologies and understanding of disease grow
Projected that individuals with CF born in the 1990s will live into their 40s and that current birth cohorts will live into their 50s

Tuchman, et al., Cystic Fibrosis and Transition to Adult Medical Care, Pediatrics 2010;125;566.

Nationally

There are over eleven million CSHCN nationwide and growing
Annually 500,000 of these children turn 18
The number of children with special health care needs continues to grow as technological advances allow for longer lifespan

2009-2010 National Survey of Children with Special Health Care Needs
National Data Trends

2009-2010 National Survey of Children with Special Health Care Needs

More youth, more difficulties

Child health
- Condition affects their lives usually to a great deal at a higher percentage
- More youth are missing school

Access to care
- Greater number have unmet family support services, difficulty obtaining a referral, rely on emergency room for care, and are without a personal doctor

2009-2010 National Survey of Children with Special Health Care Needs
Greater impact on families

More families are paying more than $1000 or more for health care a month
Conditions are causing greater financial problems for families
Families are spending greater than 11 hours per week coordinating care
More family members are forced to cut back work or stop working

Pennsylvania

There are approximately 470,000 CSHCN as of 2009-2010 survey results, which is approximately 17% of the population (national average 15.1%)
20.9% of the youth are aged 12-17 years old and 20.7% are between 6-11. Both are above national averages (18.4% and 17.7% respectively)
Pennsylvania Trends

Survival into the middle decades is now commonplace for many disease states that originate in pediatric populations. A larger number of patients older than 18 years old are now being treated in pediatric hospitals where physical facilities and supplies are not designed for adult care and staff are less well trained in adult care.

Inpatient Experience in Pediatric Hospitals

Data collected over a ten year span from thirty freestanding, tertiary care pediatric hospitals

Examined all hospital admission and discharges excluding newborn and OB-GYN admissions

Examined multiple variables, unique patients, discharges, patient-days and charges as well as demographic information


Patient analysis

<table>
<thead>
<tr>
<th></th>
<th>Pediatric (&lt;18 y)</th>
<th>Transitional (18-21 y)</th>
<th>Adults (&gt;21 y)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unique patients (%)</td>
<td>2,083,722 (97.2)</td>
<td>43,157 (2.0)</td>
<td>16,817 (0.8)</td>
</tr>
<tr>
<td>Discharges</td>
<td>3,223,621 (96.4)</td>
<td>85,616 (2.6)</td>
<td>33,957 (1.0)</td>
</tr>
<tr>
<td>Disposition (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>3,114,378 (96.8)</td>
<td>82,604 (96.9)</td>
<td>32,192 (95.1)</td>
</tr>
<tr>
<td>Died</td>
<td>32,818 (1.0)</td>
<td>893 (1.1)</td>
<td>624 (1.8)</td>
</tr>
<tr>
<td>Subacute Care</td>
<td>71,189 (2.2)</td>
<td>1,797 (2.1)</td>
<td>1,039 (3.1)</td>
</tr>
<tr>
<td>Utilization (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatient days</td>
<td>18,719,220 (95.9)</td>
<td>546,848 (2.8)</td>
<td>255,885 (1.3)</td>
</tr>
<tr>
<td>Charges, 2008 US $</td>
<td>126,358,764,252</td>
<td>4,219,567,088</td>
<td>2,059,688,721</td>
</tr>
</tbody>
</table>

Closer look at the data

- Largest increases of unique patients, discharges, patient-days and charges were among transitional patients with average annual increases of 6.9% in discharges, 7.6% in patient days, and 15% in charges which were all significantly greater than the increases in pediatric patients alone (all p<0.001).
- If growth continues, the authors forecast that 12,693 transitional and 3,784 adult discharges will occur in these 30 children’s hospitals in 2012.


Increase in adults treated at children’s hospitals, 1999–2012, according to age group.


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Barriers to Transitions

Barriers to Transition

Limited achievement in improving transitions of care between 2001 and 2006 according to national survey results

Barriers exist at multiple levels from the system end down to the patient and family

AAP, AAFP, ACP; Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011
System Level

Many pediatric hospitals have a policy to no longer allow admission past 18th or 21st birthday\textsuperscript{1}
Also time restraints in clinic setting do not allow for prolonged conversations regarding transitions\textsuperscript{2}

\textsuperscript{1} Tushman, et al., Cystic Fibrosis and Transition to Adult Medical Care, Pediatrics 2010;125;566. \textsuperscript{2} AAP, AAFP, ACP; Clinical Report- Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011

Patient and Family

Trust in the pediatrician or subspecialist and fear of leaving familiar setting of the pediatric care delivery system are seen in both the patient and caregiver
Parents/caregiver have difficulty letting go and allowing the patient autonomy
Pediatric barriers

Poorly informed about consensus statement on transitions
Limited availability of adult providers, both subspecialists and primary providers that are willing to accept CSHCN
Difficulty breaking the bond with family and patient

AAP, AAFP, ACP; Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011 and 2008 AAP Periodic Survey #71

AAP Survey results

“gaps in transition support are due in part to limited staff training; lack of an identified staff person responsible for transition; financial barriers; and anxiety on the part of pediatricians, adolescents, and their parents about planning for their future health care.”

Internist Barriers

Two stage survey conducted between August 2001 and November 2004 of internal medicine providers
Stage one elicited six categories of concern for transitioning patients
Stage two ranked the top concerns in each category

Peter N, et al., Transition from Pediatric to Adult Care: Internists’ Perspectives, Pediatrics 2009;123;417-423

Six categories

Patient maturity
Patient psychosocial needs
Family involvement
Providers’ medical competency
Transition coordination
Health system issues

Highest Ratings

Lack of training in congenital and childhood-onset conditions
Lack of family involvement
Difficulty meeting patients’ psychosocial needs
Needing a subspecialist
Lack of adolescent training
Facing disability/end-of-life issues during youth and early in the relationship
Financial pressures limiting visit time
Families’ high expectations


Proportion of PEDRs and IMRs who were comfortable with inpatient management of childhood-onset chronic disease.


**Culture of care**

Distinct culture of care in pediatric and adult orientated care systems

Patients and family become accustomed to the pediatric system and are reluctant to change

Adult providers often cannot live up to the expectations of the pediatric system

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**Culture of Care**

<table>
<thead>
<tr>
<th></th>
<th>Pediatric</th>
<th>Adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric Disease Knowledge</td>
<td>Common Knowledge</td>
<td>Unfamiliar</td>
</tr>
<tr>
<td>Provider-Patient Interaction</td>
<td>Dependency, Developmentally-Appropriate</td>
<td>Autonomy, Disease focused</td>
</tr>
<tr>
<td>Role of Family</td>
<td>Central</td>
<td>Peripheral</td>
</tr>
<tr>
<td>Coordination</td>
<td>Interdisciplinary with High Level of Psychosocial Support</td>
<td>Multidisciplinary with Limited Social Services</td>
</tr>
<tr>
<td>Need for Primary Care</td>
<td>Important</td>
<td>Crucial</td>
</tr>
</tbody>
</table>

Coming of Age with Diabetes – Patients views of a clinic for under 25 year olds Adopted from Debra Lotstein, MD, MPH
Current Status of Transition Preparation

Structured interview of 17,114 CYSHCN between 12-18 from July 2009-March 2011
Same questionnaire items as 2005-06 survey to see if discussion is occurring and to examine if positive steps have been made since 2005-06 survey

Four Component Measures

1. Transition to adult provider
2. Changing health care needs
3. Maintaining health insurance coverage
4. Taking increased responsibility for self care


Results

Would a discussion on a topic been helpful?

Positive Predictive Factors

Female gender
Non-Hispanic white race
Speaking English in the home
Family income greater than 400% of the federal poverty level
Special health care need that has no impact on activities
Condition other than an emotional, behavioral or developmental condition
Medical home
Continuous insurance coverage
Communication is key

Having a personal physician or nurse increased odds of discussing transition
Physician listened carefully
Physicians helped them feel like a partner
Patient received enough information regarding medical problems
Physician spent enough time with them


Transition clinics and their outcomes
Growing Importance

The National Committee on Quality Assurance in 2011 include specific requirements to address care transitions in primary care
Healthy People 2020 incorporated new public health goal on transition planning
Increased CYSHCN graduating each year requiring a medical home


National rise in transition clinics

Transition clinics are becoming more popular nationally
Many are broken down according to sub-specialty however there has been an increase in general transition clinics for those patients that transcend multiple disciplines
Patient populations

Most common primary diagnosis includes cerebral palsy, developmental delay, Down syndrome, spina bifida, autism, cystic fibrosis, diabetes mellitus among other diagnosis

In many incidents the patients may have four or more subspecialists

Outcomes

Data is scarce overall however there have been anecdotal evidence that shows decreased hospitalization and emergency department visits

Cystic fibrosis data shows improved quality of life scores for those that went through transition process

Some data shows improved HgbA1c levels in teens who go through transition compared to those who do not

Crowley et al., Improving the transition between paediatric and adult healthcare: a systematic review, Arch Dis Child 2011:96,548-553
Comprehensive Care Clinic

Two tiered approach

**Consultative**
- Any medically complex pediatric patient aged 16 years or older. No upper age limit for consult work
- Exclusively work on transitional issues and coordination of care
- Help identify adult subspecialist champions
- Inpatient consultative service is in the works

**Medical Home**
- Any patient over the age of 18 years old
- Complete care in the medical home model
- Combination of primary care and focus on transitional care
Out patient consultant work

Work on transitional issues including improved self management, advocacy, identification of adult providers, guardianship, waiver programs, etc.
Coordination of care for medically complex young adults and co management with primary care physician close to home
One or more visits per year

Multidisciplinary Approach

All patients will be seen by physician and evaluated care management
With time other groups including Pharmacy, Palliative Care, Nutrition, and Psychology will be included at specialized visits once or more times a month
Unique Features

Hour long clinic appointments
Care Management to help with transitional issues surrounding waiver programs, work programs, guardianship versus POA, and other issues
Comprehensive Care Plan sent to patient and referring physician for every patient

Integrated research

Goal for prospective and retrospective studies
Track transitions readiness scores and quality of life scores
Trend hospitalizations, length of stay, emergency room visits, and health care utilization
Improved healthcare delivery with partnership between community physicians and the Comprehensive Care Clinic. Track physician satisfaction scores
First Year Experience

A total of 70 unique patients seen
A total of 171 patient encounters in the first 12 months
A combination of consultant work and medical home work with several patients shifting from one to the other
Mean age was 21 years old with 65% of the clinic patients males
The majority (70%) of patients seen had some form of cognitive impairment including chromosome abnormality and autistic spectrum disease.

Other Resources
Online resources

www.gottransitions.org
National health care transition center with information for youth, families, and health care providers
On going online lecture series focusing on transition specific topics

Specific Clinic Information

http://jaxhats.ufl.edu/
http://www.sickkids.ca/good2go/
http://unckidneycenter.org/hcprofessionals/transition.html
All have links to additional information for patients, families, and healthcare providers
References

1. AAP, AAFP, ACP, ASIM, A Consensus Statement of Health Care Transitions for Young Adults with Special Health Care Needs; Pediatrics 2002; 110:1304-1306
2. AAP, AAFP, ACP, Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011
3. AAP, AAFP, ACP, Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011
6. Tuchman, et al., Cystic Fibrosis and Transition to Adult Medical Care, Pediatrics 2010;125:566.
8. AAP, AAFP, ACP, Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011
9. 2008 AAP Periodic Survey #71
11. Peter N, et al., Transition from Pediatric to Adult Care: Internists’ Perspectives, Pediatrics 2009;123:417-423
14. Crowley et al., Improving the transition between paediatric and adult healthcare: a systematic review, Arch Dis Child 2011;96,548-553
15. Data provided by Dr Alan Friedland, Medical Director, Transition Care Program
17. 2009-2010 National Survey of Children with Special Health Care Needs
18. Additional resources available upon request
Transitioning Pediatrics
at BAYADA Home Health Care
November 1, 2013

BAYADA Pediatrics: A specialty of
BAYADA Home Health Care

➢ Began with specialty pediatric desks in existing
  “mixed service” offices

➢ Opened first pediatric specialty office 1995

➢ With specialized focus, the pediatric population grew

➢ Formal Pediatric Practice developed in 2011
Changes in population serviced

- Increase of children over 18 years in pediatric offices
- Pediatric trained nurses not comfortable providing care to adolescents and young adults
  - Employee claims due to handling and transferring
- 32% of unfilled shifts are ages 13 to 22
- 33% of overtime hours are for ages 13 - 22
Adolescent Care Transition Program

• Develop the team
  Clinical managers
  Pediatric and adult stakeholders
  Rehabilitation nurses
  Parents of adolescents

• Relationship with Geisinger Medical Center

• Transition would begin at age 26

Challenges

• Need to increase staffing for adolescent clients

• Nurses with adult experience need additional training

• Nurses with pediatric experience need additional training and information

• Clients and families need resources to assist with transition – physician and community
Screening tool

1. Client is currently 13 years of age or older.

2. Cognitive ability is appropriate for age or potential for cognitive development beyond baseline is highly unlikely in this client.

3. The client weighs more than 35 kg or 77 lbs.

4. The client does not require assessments for changing growth and development more frequently than every 6 months.

5. The client’s tracheostomy and feeding tube have been in place for > 4 weeks.

6. The client has been maintained on the current ventilator settings for > 4 weeks.

7. The client/family is in agreement to staffing with adult care nurses.

8. State requirements allow an adult skilled nurse to provide care to a pediatric client without training.

9. The adult nurse meets all of the training/competency and orientation requirements (i.e. CPR, single cannula tracheostomy, Child abuse clearances).

Training for nurses with adult experience

- Developed Family Centered Care training

- Developing diagnosis-specific trainings
Training for nurses with pediatric experience

- Advance Directives guidelines
- OASIS training
- Physical/biological changes
- Gender and psychosocial issues

Office/Family resource tool

- Development of a template for offices and families
- Information to be provided
  - State transitional care guidelines
  - Physician and clinic availability
  - Waiver and payer source information
  - Children’s hospitals guidelines
Implementation

- Begin discussions with parents/clients prior to age 18
- Provide resource information and plan for transition
- Always the parent/family/client choice to transition