It Takes a Village: Innovative roles of peers, health coaches, and parents in supporting positive development and healthcare transition for youth with chronic conditions.

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Department of Psychiatry and Behavioral Health

Learning Objectives
1. Describe the 5Cs model of Positive Youth Development (PYD) and the role of PYD in healthcare transition for youth with chronic conditions.
2. Delineate practical strategies for operationalizing core PYD components through incorporation of peer, parent, and health coach interventions.
3. Formulate a personal action plan for implementing PYD-based supports for youth with chronic conditions.

Diagnosis | Life Expectancy
--- | ---
Cystic Fibrosis | 37 years
Sickle Cell Disease | 66 years
Congenital Heart Disease | 85% reach adulthood
Down Syndrome | 55 years
Hemophilia | 60 years
Spina Bifida | 80% reach adulthood

500,000+ youth with special health care needs “graduate” from pediatric care annually

↑ Organ rejection (Watson, 2005; Annunziato, 2007; Foster 2011; Andreoni, 2013)
↓ Diabetes control (Kohler, 2009)
↑ Symptoms in rheumatoid arthritis (Worats, 2005)
↓ Congenital heart disease follow-up (Yeung, 2008)
↑ Adverse effects in cancer survivors (Condren 2005)
How does it work for youth with physical illness after they turn 18 years old at Duke?

- 55% LOST
- 23% Active in Adult Care
- 22% Active in Peds

All patients in the analysis had at least 2 visits in a pediatric specialty clinic after age 15 (CF, diabetes, IBD, Lupus, HIV, SCD)

Sickle Cell Disease

- 202 patients
- 78 (39%) lost to follow-up

Your Experiences

Peer Mentors  Coaches  Parent Navigators

PYD and Transition

Your Experiences

Peer Mentors  Coaches  Parent Navigators

PYD and Transition
Most children with chronic illness will grow-up to be adults

While many do well the following are domains of concern

- Health
- Educational
- Vocational

What can be done?
Competence: Abilities/skills as well as a positive view of one's abilities/skills in domain specific areas, including social, academic, cognitive, and vocational.

Confidence: An internal sense of overall positive self-worth and self-efficacy.

Connection: Positive bonds with people and institutions that are reflected in bidirectional exchanges between the individual and peers, family, school, and community, in which both parties contribute to the relationship.

Character: Respect for societal and cultural rules, possession of standards for correct behaviors, morality, and integrity.

Caring: A sense of sympathy and empathy for others.

Growing Up Sick Study: Overview

Examine the effects of growing up with a chronic illness on youth development

1. Does PYD differ between youth with and without chronic physical illness?

2. Do similar factors that relate to PYD for healthy youth, also relate to PYD for youth with chronic physical illness?
Growing Up Sick Study: Results

 Recruited, N=465
 Youth with COCI, 51% (n=236)
 Survey completed, N=340
 Youth with COCI, 51% (n=173) excludes misclassified

 Demographics
 43% male
 15y avg age
 Race/ethnicity
 48% White
 40% Black
 12% Other

 Growing Up Sick Study: PYD Results

 No statistically significant differences

<table>
<thead>
<tr>
<th></th>
<th>Youth with COCI</th>
<th>Comparison</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall PYD</td>
<td>72.0</td>
<td>72.4</td>
<td>ns</td>
</tr>
<tr>
<td>Competence</td>
<td>59.7</td>
<td>63.5</td>
<td>ns</td>
</tr>
<tr>
<td>Confidence</td>
<td>69.5</td>
<td>73.2</td>
<td>ns</td>
</tr>
<tr>
<td>Caring</td>
<td>82.5</td>
<td>81.1</td>
<td>ns</td>
</tr>
<tr>
<td>Connection</td>
<td>74.3</td>
<td>70.9</td>
<td>ns</td>
</tr>
<tr>
<td>Character</td>
<td>74.5</td>
<td>73.2</td>
<td>ns</td>
</tr>
</tbody>
</table>

Same factors for both groups related to PYD

- Intentional Self Regulation
- Hopeful Future Expectations
- God Locus Health Control (COCI)

How to Address

- Youth Programs - ATLAS
- Coaching

Big 3 Components of PYD Programs

- Youth participation in and leadership of activities,
- Skill-based programming in the context of
- Sustained and caring adult-youth relationships.
**PYD Systematic Review**

- 10,721 titles reviewed
- 394 abstracts reviewed
- 14 programs identified
  - 3 comprehensive (included all 3 components)
  - 4 mentoring focused
  - 7 youth leadership focused
- Few well evaluated


**Comprehensive Programs**

<table>
<thead>
<tr>
<th>Programs (condition)</th>
<th>Leadership</th>
<th>Skill-based</th>
<th>Mentorship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bay Area Positives (HIV)</td>
<td>Youth run organization, serve as peer supporters</td>
<td>Education regarding health and services</td>
<td>Professional staff mentor youth</td>
</tr>
<tr>
<td>Youth Health (HIV)</td>
<td>Youth plan and run programs</td>
<td>Self-advocacy and health promotion</td>
<td>HIV + staff mentor youth</td>
</tr>
<tr>
<td>Chronic Illness Peer Support Program (Mixed)</td>
<td>Youth co-facilitate support group and plan other activities</td>
<td>Group sessions focus on skills for living with a chronic illness</td>
<td>Sustained relationships with peers and staff</td>
</tr>
</tbody>
</table>

**Mentor Focused Programs**

<table>
<thead>
<tr>
<th>Programs (condition)</th>
<th>Leadership</th>
<th>Skill-based</th>
<th>Mentorship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take Charge (physical disability)</td>
<td>Youth learn to navigate community and work environment</td>
<td>Youth matched with mentors in the community for 10 months</td>
<td></td>
</tr>
<tr>
<td>Diabetes Sponsorship Program (diabetes)</td>
<td>Mentors teach youth with diabetes during teachable moments</td>
<td>Youth and mentors meet biweekly for 10 months</td>
<td></td>
</tr>
<tr>
<td>Camp Ability (Spina Bifida Summer Camp)</td>
<td>Focused teaching around Spina Bifida self-care</td>
<td>Sustained relationships with adult counselors at camp (annual)</td>
<td></td>
</tr>
</tbody>
</table>

**Youth Leadership Programs**

<table>
<thead>
<tr>
<th>Programs (condition)</th>
<th>Leadership</th>
<th>Skill-based</th>
<th>Mentorship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Outward Bound Programs (Diabetes)</td>
<td>Participants serve as leaders in the outdoors on sailing trips</td>
<td>Youth learn to navigate diabetes</td>
<td></td>
</tr>
<tr>
<td>Adolescent Asthma Action program (Asthma)</td>
<td>10th and 11th grade students teach younger students about asthma</td>
<td>Participants learn about asthma self-management</td>
<td></td>
</tr>
<tr>
<td>Multicomponent Weight Loss Program (Obesity)</td>
<td>Youth participate as leaders in team-based problem solving</td>
<td>Youth learn about weight management and problem solving</td>
<td></td>
</tr>
</tbody>
</table>

**Growing Up Sick Study: Program Participation**

- The same percentage of youth with COCI vs. peers without chronic conditions participate in youth programs and are involved in the same number of programs (on average).

- For youth with COCI, parents report that 45% participate in camps for children with special needs or chronic illness.
### Program Participation

- Socioeconomic factors strongly predict program participation.
- Hispanic youth have lowest rates of participation – **odds ratio of 0.065** compared to whites.
- Black youth had **odds ratio of 0.28** compared to white, non-Hispanic youth for program participation.
- 89% of youth with sickle cell participate in illness specific programs.

### ATLAS Transition Programs Pyramid

- **ATLAS** N=15
- **Transition Clinic** N=100
- **Transition Coach** N=??
- Universal approach at Duke Health for all young adult patients N=??

### Group Mentoring Programs

- **STAR program at Dartmouth** 1998
- **TALC at Brown** - 2005
- **ATLAS Duke program** Pediatric Resident With Gary Maslow Program started Fall 2010 CATCH Grant from AAP
- **UVA** Pediatric Resident Was DVS1 resident and Former STAR College Mentor Program started Fall 2008 CATCH Grant from AAP
- **R-TLClamp University** Program started 2015 CATCH grant AAP

### Programs (condition) | Leadership | Skill-based | Mentorship
---|---|---|---
**STAR** - Dartmouth (mixed) | Learn skills for chronic illness self-management | College students with illness mentor teens with illness
**TALC** - Brown (mixed) | Community outreach through Art, programs for pre-teens with chronic illness, education | Learn skills for chronic illness self-management | College students with illness mentor teens with illness
**ATLAS** - Duke (mixed) | Educate residents, promote transition at Duke | Learn skills for chronic illness self-management and focus on Transition | College students with illness mentor teens with illness

### Youth with COCI Comparison

<table>
<thead>
<tr>
<th>Activity</th>
<th>Without COCI</th>
<th>With COCI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attend school</td>
<td>97.5%</td>
<td>98.7%</td>
<td>ns</td>
</tr>
<tr>
<td>Homebound services</td>
<td>5.7%</td>
<td>0.7%</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>After school programs</td>
<td>43.2%</td>
<td>48.3%</td>
<td>ns</td>
</tr>
<tr>
<td>Youth programs (PYD)</td>
<td>23.4%</td>
<td>24.5%</td>
<td>ns</td>
</tr>
<tr>
<td>School-based sports</td>
<td>28.9%</td>
<td>39.2%</td>
<td>ns</td>
</tr>
<tr>
<td>Non-school sports</td>
<td>26.5%</td>
<td>31.1%</td>
<td>ns</td>
</tr>
<tr>
<td>Religious youth programs</td>
<td>47.8%</td>
<td>46.3%</td>
<td>ns</td>
</tr>
<tr>
<td>Summer camp</td>
<td>55.6%</td>
<td>56.2%</td>
<td>ns</td>
</tr>
<tr>
<td>Support group</td>
<td>8.1%</td>
<td>4.9%</td>
<td>ns</td>
</tr>
<tr>
<td>National foundation for health condition</td>
<td>13.2%</td>
<td>2.8%</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>Make-a-Wish</td>
<td>18.0%</td>
<td>1.4%</td>
<td>p&lt;0.001</td>
</tr>
</tbody>
</table>
Activities from TALC

Monthly Meetings
Individual Creative Projects
  Writing – articles for the newsletter
  Photography – family documentation project
  Drawing – Draw Your Illness

Group Activities
  Produced Newsletter
  Ropes Course as a group
  TALC Jr. program with 10-12 year olds
  Presentations at local high schools
  Presented at Pediatric Grand Rounds
  TALC Summer Leadership Camp

TALC Topics: Diagnosis

TALC Topics: Admission – Doctors and Hospitals

Strategies for nurses:
1. EXPLAIN – Explain what you are thinking clearly and confidently.
2. SPEAK UP - Be assertive, speak up!
3. ASK - Ask questions (make a list).
4. RESPECT - Talk softly, respectfully, every time.
5. PRIORITY - Stick to the subject and know your priorities.
6. KNOW YOUR BODY - Be comfortable with your symptoms and with your doctor.

Top Ten Strategies:
1. LISTEN!
2. Make eye contact and establish a connection.
3. Give clear explanations and warnings.
4. Trust the patient.
5. Don’t underestimate or ignore pain.
6. Ask the patient.
Personal relationship to Illness

“Why are you walking like that?”
Having to tell my father I am in pain.”

“My cousin, Jennifer is 10 yrs old, and she gave me her room over Thanksgiving, because I was sick. This is the picture she drew for me.”

“This is at my dad’s birthday dinner. Everyone else is drinking except for me. I can’t because of lupus/mono liver involvement.”

“Sitting in the tiny little seat in the middle to avoid conflict with brothers who resent all the accommodations made for me.”

“It’s easier not to tell them”
Parent Group

- Chronic illness affects the *entire family*
- Parents meet simultaneously –
  - STAR facilitator was an MSW
  - TALC facilitator is a Triple Board Resident
  - ATLAS facilitator is an MSW
- Highlight for parents when teens and parents mix and both sides get to ask questions

TALC Topics: Moving On

- A topic that ran throughout each meeting was the relationship of each member to their illness.
- The TALC mural was a collaboration describing the group members’ relationship with their illnesses.
- Individual’s relationship to illness came through in their photography as well

TALC Topics: Transitions

TALC/ATLAS: Evaluation

TALC and ATLAS are small scale programs designed to
1) Improve the transition outcomes of teens and college students with chronic illness
2) Serve as an advocacy group within the university, within the community, and within the state
3) Support other residents and medical centers interested in implementing similar programming

TALC Program Evaluation Logic Model

- Inputs (Program based on PYD principles)
  - Youth participation in and leadership of activities
  - Emphasis on development of life skills and illness related skills
  - Environment with sustained caring adult-youth relationships
- Short term Positive Youth Development outcomes
  - Social Connection: Decreased loneliness
  - Competence: Improved self-management, confidence: Increased self-advocacy
- Long term Adult Outcomes
  - Educational Outcomes: High school graduation, College attendance, Program influence on educational choices
  - Vocational Outcomes: Currently employed, Career choice, Program influence on vocational choices
  - Healthcare Outcomes: See adult primary care provider, See pediatric or adult specialist

Positive Assets from Positive Youth Development perspective include connections, competence, confidence, compassion, and character. Proxies were used to examine connections, competence, and confidence.
1st step: Examine degree to which program had features of programs that promote PYD including:
• Youth participate in leadership of activities
• Emphasis on development of life skills
• Creation of an environment with sustained adult ↔ youth relationships

2nd step: Evaluate short-term PYD outcomes
• Survey of adolescents before and after participation
• Assess loneliness, self-management, and self-advocacy

3rd step: Evaluate long-term educational, vocational and healthcare outcomes
• Online survey of all alumni from 5 years of program
• Educational outcomes included high school graduation and college attendance
• Vocational outcomes included current employment and career choice
• Transition outcomes included whether seen in pediatric or adult clinics

Short-term Outcomes

PARTICIPANTS – High School Students
N=20 Mean age 15.4 years (SD=0.3) 25% Male/75% Female
75% White/15% Black/5% Hispanic/5% Other

Medical Conditions: Celiac disease, Cerebral Palsy, Cystic Fibrosis, Diabetes, Epilepsy, Ehler’s Danlos Syndrome, Endometriosis, Inflammatory Bowel Disease, Migraine, Nephelae Myopathy, Sickle Cell Disease, Systemic Lupus Erythematosus, Takayasu’s Arteritis.

<table>
<thead>
<tr>
<th></th>
<th>Pre-TALC mean(SD)</th>
<th>Post-TALC mean(SD)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loneliness (N=20)</td>
<td>44.7(2.0)</td>
<td>39.2(2.0)</td>
<td>0.01</td>
</tr>
<tr>
<td>TRAQs Domain 1 (N=13): Chronic Condition Management</td>
<td>3.1 (0.3)</td>
<td>3.4 (0.3)</td>
<td>0.2</td>
</tr>
<tr>
<td>TRAQs Domain 2 (N=13): Self-Advocacy</td>
<td>3.8(0.2)</td>
<td>4.2(0.2)</td>
<td>0.005</td>
</tr>
</tbody>
</table>

PARTICIPANTS – N=34 (response rate 97%)
High School Alumni – N=16
Mean age = 20.6 years (SD=0.5) 38% Male/62% Female
Mean Years participated = 2.4
August White/13% Black/6% Other

College Mentor Alumni - N=18
Mean age = 24.7 years (SD=0.4) 22% Male/78% Female
Mean Years participated = 2.8

85% White/5% Black/5% Hispanic/5% Asian

Asthma=2, Cancer=5, Celiac=3, Cerebral Palsy=2, Diabetes=4, Ehlers-Danlos=1, Endocarditis=1, Hepatitis=1, IBD=11, Migraine=2, Nephelae Myopathy=1, Sickle Cell=1, Systemic Lupus Erythematosus=4, Takayasu Arteritis=1, Vitiligo=1, Von Willebrand Disease=2.

Long-term Outcomes

ATLAS: Community Advocacy Group

Serve as an advocacy group within Duke Children’s Hospital and within the community

Monthly meetings with a Transition Learning Collaborative including a diverse array of pediatric clinics

FUTURE PLANS:
Have participants educate trainees regarding transition issues
ATLAS mentors will get trained as transition coaches

TALC/ATLAS: Collaboration with other Center

Support other residents and medical centers interested in implementing similar programming

TALC Manual available electronically

Collaboration with other programs to discuss evaluation and programming
TALC 2006-2007: Teen’s Drawing of Illness Changes

Show and Tell: Each person brought an object to represent their illness

Ruth brought this doll to represent Takayasu’s Arteritis

Ruth 2005: High School Sophomore

Sojourner Truth Award for Scholarly Persistence and Dedication

Graduated from the University of Rhode Island in May 2012

Ruth 2012: College Graduate

Adolescents Transitioning to Leadership and Service (ATLAS)

Camp Kaleidoscope - ATLAS Campference
Coaching

Keeping young adults with chronic illness in care

Peer Coach Transition Program

 Adolescents: Ages 16-21

Telephone-Based

1-to-1 Mentoring

Peer Transition Coaches: Ages 18 and up

4 Key Behaviors

1. Managing Health Daily
2. Navigating the Healthcare System
3. Leading Team
4. Planning for the Future
Adaptive Leadership Model

Innovative Web-Based Software

Integrative Health Coaching Model

Adaptive Leadership

<table>
<thead>
<tr>
<th>Key Behavior</th>
<th>Goal</th>
<th>Technical Work</th>
<th>Adaptive Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing Health Daily</td>
<td>Difficulty adhering to medication schedule</td>
<td>Doctor instructs when and how to take medication</td>
<td>Coach helps explore daily routines and how medication schedules can link into daily routines; discusses barriers to adherence</td>
</tr>
<tr>
<td>Navigating Healthcare System</td>
<td>Refilling prescription</td>
<td>Doctor prescribes medication regimen and provides phone number to call for refill</td>
<td>Coach explores techniques to remember to refill prescription; partakes role playing the call to the pharmacy with the patient; explores fear of calling in prescription independently</td>
</tr>
</tbody>
</table>

Innovative Health Coaching

Web-Based Software

Population Health Management

Mentor1to1™ platform supports connection

Program Evaluation

Goals:
1) Measure efficacy of training
2) Evaluate Effects of program on coaches and patients

4 Coaches & 12 Patients Experimental Group
12 Patients Waitlist Control Group
Duke Transition Support Pyramid

ATLAS
N=15

Transition Clinic
N=90

Transition Coach
N=500?

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Patricia Chu
Sharron Docherty, PhD
Nirmish Shah, MD
Clarissa Schilstra, BA
Logan Castrodale

“If you cannot see where you are going, ask someone who has been there before.”
J. Loren Norris
Parents who provide peer-to-peer mentoring, support and coaching to other parents of YSHCN.

Mentorship Resources Navigation

Patient and Family Benefits

- Engagement in care
- Learn about community resources
- Decreased isolation
- Improved advocacy

Parents as transition experts? Qualitative findings from a pilot parent-led peer support group

S. Kingsnorth,* C. Gall,** S. Brennitz† and P. Rigby†

“The conditions (social, economic, and physical) in the environments in which people are born, live, learn, work, play, worship, and age... that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”

Healthy People 2020

“The ‘causes-of-the-causes.’”

Braveman, 2014
Recognizing the Importance of the Social Determinates of Health

“What good is providing routine care, exemplified perhaps by giving an immunization, if a child leaves the office to continue living in poverty, with food insecurity, maternal depression, lack of affordable child care, violence in the home, drug abuse, and other adversities?”

Jack Maypole, MD
Why do two teens with the same pathophysiology experience very different outcomes?

The patient’s experiences and needs should drive our approach, not our clinical comfort zones.

Our mandate as clinicians is not just disease control but thriving.

The whole team is needed.
Questions?