Developing a Specialized Pain Rehabilitation Program
Targeting Young Adults who have
Failed to Successfully Launch
into Adulthood Related to Complaints of Pain,
POTS or Other Chronic Symptoms
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Conflict of Interest Disclosure
Authors Conflicts of Interest
A. Connie  No Conflict of Interest
B. Andrea  No Conflict of Interest

Objectives
After attending this session the learner will be able to
1. Identify the problems encountered by young adults who deal with chronic pain/POTS as well as the impact on their families
2. Describe 3 unique programmatic approaches offered for this population
3. List 3 positive outcomes of this pilot program
Definitions

**Chronic pain**
- Non-cancerous pain that lasts 3 months or longer, contributing to impaired functioning and decreased quality of life

**Postural Orthostatic Tachycardia Syndrome (POTS)**
- Orthostatic intolerance as primary symptom, contributes to dizziness, fainting episodes
- Headaches and abdominal pain are common
- Autonomic dysfunction occurs on a continuum

Overview of PRC

- Adult Program began in 1974
- Pediatric Program pilots in 2008 and 2009, full time 2010
- 2 day abbreviated program – PREP
- 3 week intensive outpatient program
- Addresses all types of pain problems along with many chronic symptoms
- M-F 8:00 to 5:00

Focus of PRC

**Goal:** Change focus from symptoms to normal lifestyles
- Decrease “pain/illness behaviors”
- Back to school/work
- Socialization with peers
- Decreased medical utilization
- Improve overall functioning & quality of life
- Discontinue opioid, benzodiazepines, muscle relaxants and sleepers
Specific Components of Each

**Adult**
- More focus on medications and tapers

**Pediatric**
- Behavioral focus
- Significant parent involvement

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**PRC Model**

**Emphasis on Cognitive Behavioral Therapy**
- Stress Management
- Physical reconditioning
- Occupational therapy component
- Relaxation training
- Biofeedback
- Pain management coping skills

**Intensive family involvement**
- Adult: 16 hours typical for total program
- Peds: up to 60 hours total per program

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**PRC YAP Team**
- Medical director
- Clinical Director – Psychologists
- Group providers – CNS and LPCC
- RN Case managers: 1/2 from adult, 1/2 from pediatrics
- Program development: Emily Dresher, MS, RN; Andrea Eickhoff, RN
- Physical Therapy
- Occupational Therapy
- Recreational Therapy
- Supervisors
Challenges Leading to the Development of a YAP Pilot

19-29 year olds don’t fit well in either group
• They don’t like being placed in a “pediatric” group
• Require different group content than younger kids
• Previous attempts to improve care for this age group haven’t been successful in either program
• Parents are over involved, require extra parent components

Inclusion Criteria to Participate in YAP

• Between ages of 19 and 29
• High school graduate or no longer attending HS
• Living with parents/guardians for more than 3 months out of the year
• Financially dependent upon parents/guardians
• A parent/guardian routinely assists with daily activities (grocery shopping, errands, housekeeping, personal hygiene, tending to health-care needs)
• Not married

Goals of YAP pilot

• Getting the “right patient to the right program at the right time”
• Improved clinical care for young adults
• Age appropriate content for young adults
• Include parental support and behavioral strategies
• Promotes specific developmental interventions for each program
Patient Characteristics

Winter Pilot January 2016
- 13 pts started, 12 graduated
- All started at same time
- 13 day program to accommodate college (not necessary)
- Problems:
  - Not long enough
  - Same start time = no successful seniors in group

Summer Pilot July-August 2016
- 22 pts participated, 19 graduated
- Revolving admissions
- 4 weeks of YAP specific content
- 1 Team of YAP pts (12) 2nd Team of non-YAP pts (15)
- Problems:
  - Attempts to balance census btwn teams caused non-Yap pts to be in same team as Yap, content challenges

Comparison of Demographics

Winter Pilot
- 11 Females 1 Male
- Mean age 20.9 (range 18-24)
- Avg pain duration 6 years (2-15)
- From all regions of USA
- At least 1 parent involved throughout

Summer Pilot
- 16 Females 3 Males
- Mean age 21.2 (range 18-26)
- Avg pain duration 6 years (1.5-12)
- From all regions of USA
- 17 YAP’s had parent in attendance throughout

Overall YAP Characteristics

Patients ranged in age from 18-26
- Total of 35 YAP’s started and 31 graduated

Clinical characteristics of young adults
- High medication use – MOST group
  - OTC analgesics, anti-emetics, benzodiazepines
- Developmentally immature

Clinical characteristics of YAP parents
- Overprotective, “concierge” parents
- Desperate but Entitled, Scared but Hopeful
Common Diagnoses from Winter and Summer Pilots

- Fatigue (17)
- Headaches (14)
- POTS (13)
- Abdominal (8)
- Anxiety (7)
- Fibromyalgia (7)
- Dizziness (6)
- Depression (6)
- Insomnia (6)
- Back pain (6)
- Polypharmacy (5)
- Deconditioning (3)

Case Study of Typical Patient
Young Adult Group Content

Traditional PRC content (PT, OT, RT, chronic pain concepts, CBT), plus
- Basic expectations and consequences
- Establish independent identities
- Vocational assessment and planning
- Job search, applications, interviews
- Budgeting
- Sexual health

5 Reasons to Miss Anything

1. Temperature 102.8 or greater
2. Profuse bleeding
3. Protruding broken bone
4. Unconscious
5. Suicidal

Unique Parent Group Components

- 6 hours per week group plus family meetings with staff; need to participate 3 out of the 4 weeks
- Attend a 1½ didactic education course on PRC Concepts
Unique Parent Group Components

Typical PRC content plus
- Age appropriate expectations for a young adult
- Importance of fostering competence & confidence
- “Fake it till you make it” and “Never let your child see you sweat!” Being a parent not a BFF
- Goal of eventual financial independence
- How to use consequences with a young adult

Expectations While in YAP

3 chores every night
- Make bed, clean up after self
- Help prepare lunch for day and evening meal
- Chore to help family – vacuuming, laundry

Social Activities
- 2 out of 5 week nights (can do more)
- 1 activity each day of the weekend
- Everyone participates regardless of symptoms

Expectations While in YAP

- Independence with morning routine
- Respectful behavior
  - To each other, to staff, to peers, to public
  - No eye rolling, sighing, yelling, swearing
- Consequences
  - Discuss expectations before initiating
  - Choose immediate consequence, fitting the behavior (i.e. remove phone for 24 hours)
  - Longer consequences, i.e. don’t pay for phone, car, college, or apartment
Expectations at Discharge

- Productive Activity
  - Scheduled
  - Preferably 8 hours/day outside of home
  - Consistent attendance unless one of 5 reasons
  - No accommodations due to symptoms
  - Transportation plan
- Consistent wake-up times
- Scheduled leisure activities

Expectations at Discharge

- Planned contributions to family tasks
- Financial plan
- If not yet driving, plan to work towards driving or independent transportation
- CBT Counselor – regular sessions for 6 months
- Primary care provider – no specialists for pain/symptoms

Lessons Learned from January Pilot

- Provide young adults more coaching to set up evening/weekend social activities
- More sessions specifically with parents and YAPs together
Lessons Learned from January Pilot

• From a clinical standpoint, program could be at any time of year as they weren’t in school
• Program needs to be longer
• Rolling admission would help group dynamics and staffing burden

Lessons Learned from Summer Pilot

• Length of program needs to coincide with Team 1 (Non-YAP Adult) program which is 3 weeks. Can extend individual YAP’s if necessary.
• Rolling admission works well, YAP’s and parents were at varying points in their programs which gave strength to groups.
** Combined sessions with YAP’s and parents once/week essential
• Parents still struggled with implementation of consequences.

Lessons Learned from Summer Pilot

• MOST group essential
• Positive experience for both YAP’s and Adults to have some groups together such as morning stretch and MOST group.
** Need to encourage social expectations for parents themselves (taking care of their own needs, not those of their young adult children)
• Binder of written information needed for parents with schedules and handouts
Measures Collected on YAP's

- CES-D
- Pain Catastrophizing Scale
- Multidimensional Pain Inventory
- SF-36 Health Survey
- Canadian Occupational Performance Measure (OT)
- 5 minute walk, 50 ft walk at fastest speed, repeated sit to stand, repeated trunk flexion, loaded reach, and timed up and go (PT)
- Parent measures (CES-D, FDI, PCS, MPI, POTS, HSQ-SF-36)

Success Story from January Pilot

19 year old from a Southern State

Success Story from Summer Pilot

18 yr old young woman

“I feel like I have been given a second chance at life. Since graduating I have been doing better than I ever thought possible.

“Before, gently walking on the treadmill was out of the question. Now I go to the gym every day and I run. I have more hope for the future than I have ever had.”

“During my time in PRC my goal of being a nurse was revived, along with many other goals and dreams that had died because of chronic pain and symptoms”

“Maddie”
Nursing Pearls

• Consistency of approach is essential for ALL staff
• These young adults struggled with fatigue and many symptoms as well as pain
• Many struggled with anxiety, medication overuse
• Socially and developmentally “stunted”
• Needed a lot of persuasion to be involved in social activities

Nursing Pearls

Tightrope walk with parents

• Balance of including them in the process while encouraging independence of young adults
• Confidentiality prevents us from pursuing treatment (e.g. CD)
• Often we knew what limits needed to be set and parents were unable/unwilling to change
• We may have planted seeds for change down the road even if we didn’t see change here/now
Future Goals

• 1 Additional YAP pilot offered January and February 2017
  • 3 weeks in length
  • Accrue data on more patients/parents
  • Parent involvement 2 of the 3 weeks
  • Currently have people who meet the YAP criteria who will be scheduling dates in the fall

• Ultimate Goal: Offer an ongoing Young Adult Program simultaneously along with Peds and Adult PRC

References


• POTS Syndrome- Mayo Clinic Retrieved August 12, 2012 from, http://www.youtube.com/watch?v=UgF05LCm&feature=relmfu

• http://www.youtube.com/watch?v=4b8oB757DKc

References


• Bruce B, Ale C, Sperry J, Weiss K, Harrison T, Luedtke C. Can a pediatric pain rehabilitation program achieve and maintain important health outcomes? J PAIN. 2015 Apr; 16(4):S105
