

Developing an Interactive Resident Training Curriculum on Healthcare Transitions and Complex Medical Conditions Arising Out of Childhood for Pediatric and Internal Medicine Trainees

APPD 2019 Annual Spring Meeting

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Welcome!



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We have no disclosures

Objectives

- Recognize the importance of educating pediatric and internal medicine trainees on comprehensive healthcare transition for all youth and caring for children and young adults with chronic conditions arising out of childhood
- Design a needs assessment to identify trainees' knowledge gaps in healthcare transitions and complex medical conditions arising out of childhood
- Design an interactive lecture series focused on healthcare transitions and complex medical conditions arising out of childhood

Outline

- I. Why are these topics important?
- II. What is done at your institution?
- III. Designing a self-assessment
- IV. Brainstorming: Starting this at your institution
- V. Overview of lecture series at Michigan Medicine
- VI. Bringing the lectures to life
- VII. Going beyond the lecture series
- VIII. Resources

Health Care Transitions (HCT)

- Transition is:

Purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems

- National importance:

- Healthy People 2020 Health Objective
- Measurement of Health by Maternal and Child Health Bureau

Youth with Special Health Care Needs (YSHCN)

- Chronic physical, developmental, behavioral, or emotional condition
 - Require health and related services beyond that required by children generally
-
- 90% of children with chronic healthcare conditions survive to adulthood
 - 750,000 children annually in the US

Why is this important?

Significant negative effect on morbidity, mortality, and quality of life for adolescent with special needs when transitions are done poorly

An Area of Need

- National Survey of Children with Special Healthcare Needs:
 - 40% of YSHCN met core transition outcomes
- Limited transition education during residency
 - 4.2% of physicians in one survey study

Over the last 10 years, several national efforts have been made to promote high-quality healthcare transition for both healthy youth and YSHCN; however, several barriers have been identified

Patient Barriers

Family Barriers

Financial/ Legal Barriers

Provider Barriers

Provider Perspective: What are the Barriers?

Time

Subspecialist Coordination

Funding/Reimbursement

Support Staff

Knowledge

- Lack of skills and knowledge
 - » healthcare transition process and planning
 - » available community resources that support the YSHCN population during this time of need
 - » complicated conditions arising from childhood



What interested you in this
workshop?

Current Practices

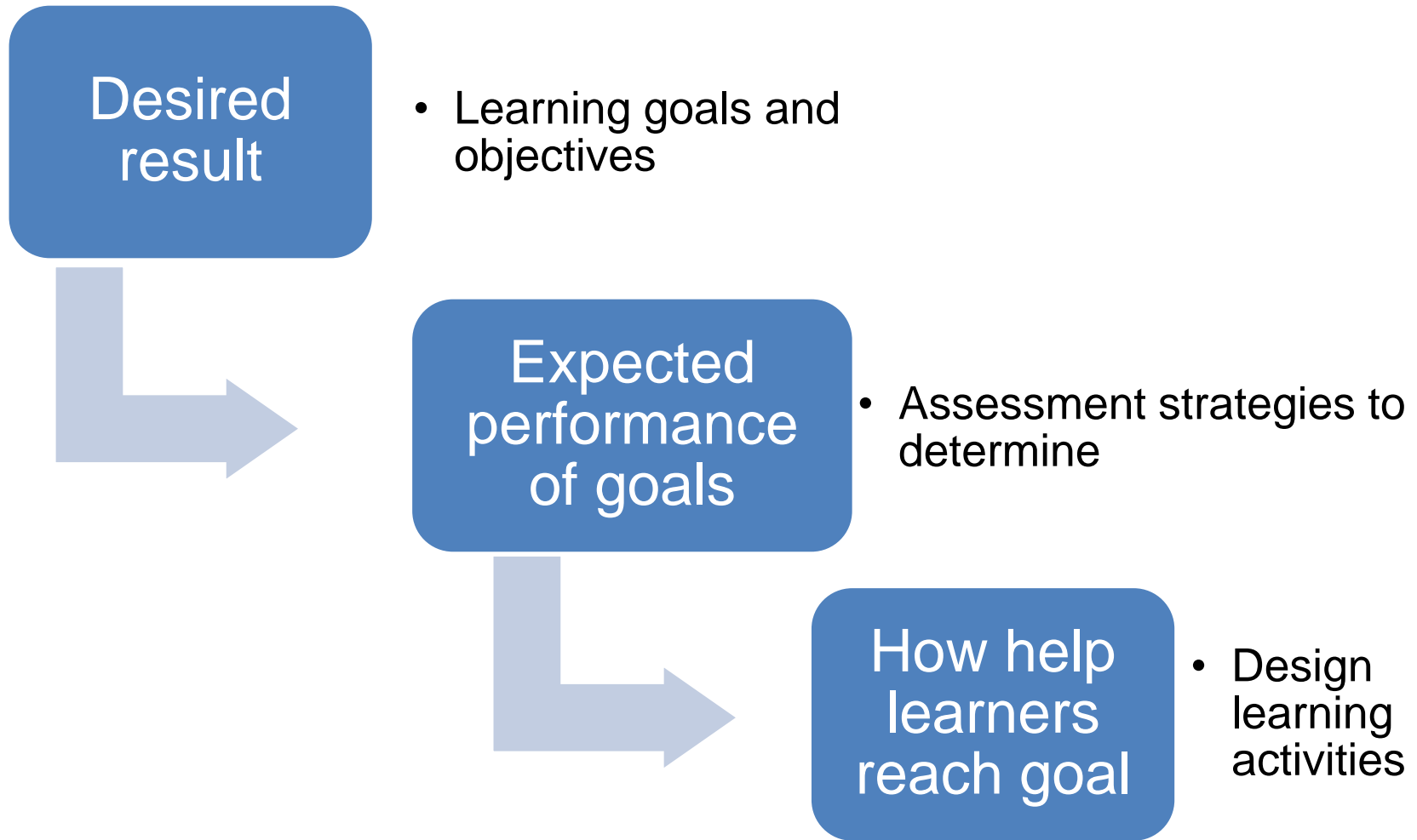
- Is transitional medicine/complex care in your curriculum?
 - How is it currently taught?
 - What is included?
 - How was it instituted?
 - Areas for improvement?
 - Resident response to curriculum?
- If not, is there interest?
 - Where could it be added?

Needs assessment and curriculum design

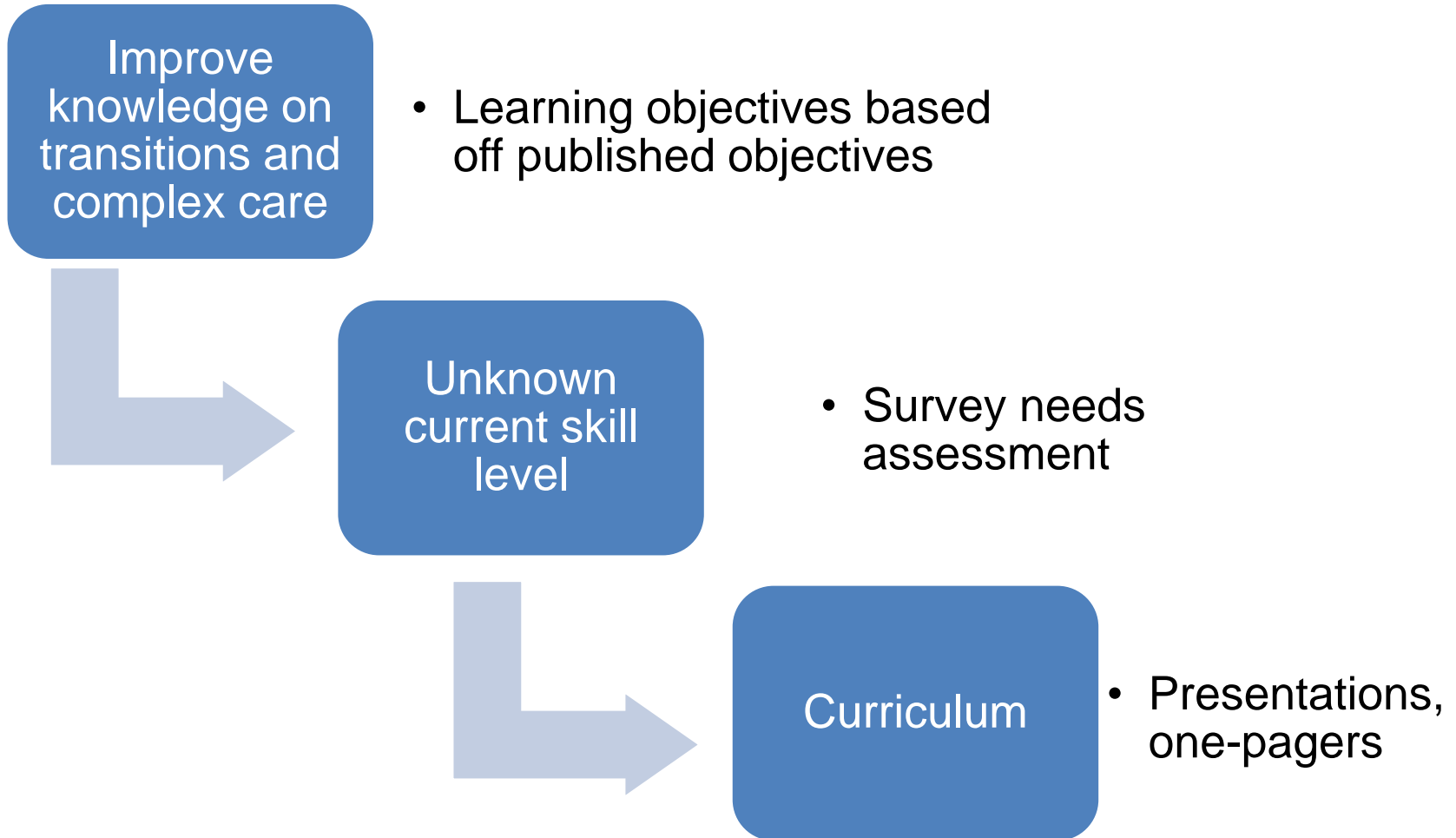
Basics of assessment

- **Assessment = performance of learners**
 - Needs: prior knowledge (baseline)
 - Formative: feedback throughout course
 - Summative: expected level of performance

Designing a course based on assessment



Transition medicine/ complex care curriculum



Methods for identifying knowledge gaps

- Survey
 - Quick tips
- Focus groups
- Clinical scenarios
- Outcomes data

Transition Medicine Needs Assessment survey

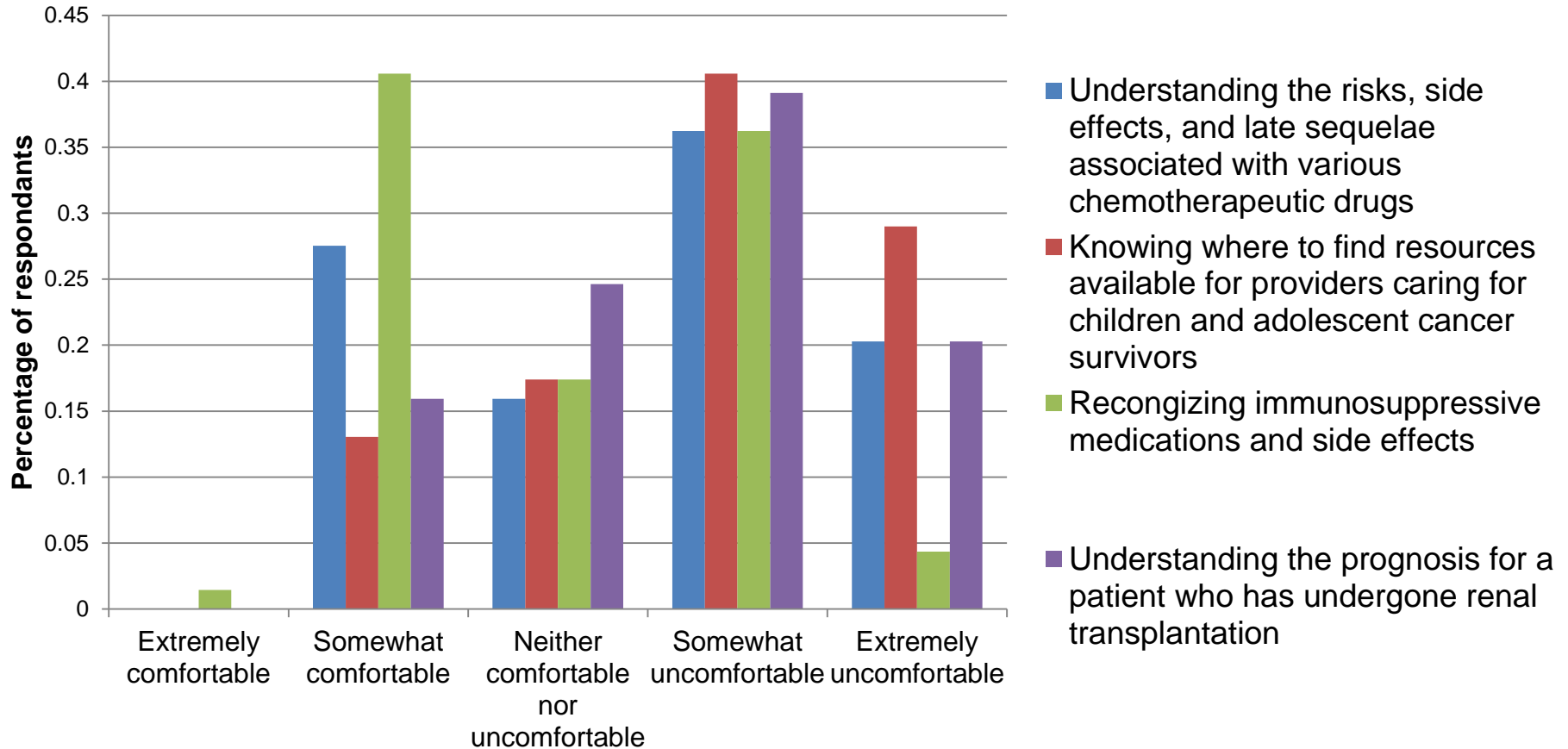
- Qualtrics survey sent to medicine and pediatric residents
 - Likert scale responses for comfort level
- Pre-intervention
- Length:
 - IM: 17 components
 - Pediatrics: 22 components

Examples of questions for pediatric trainees

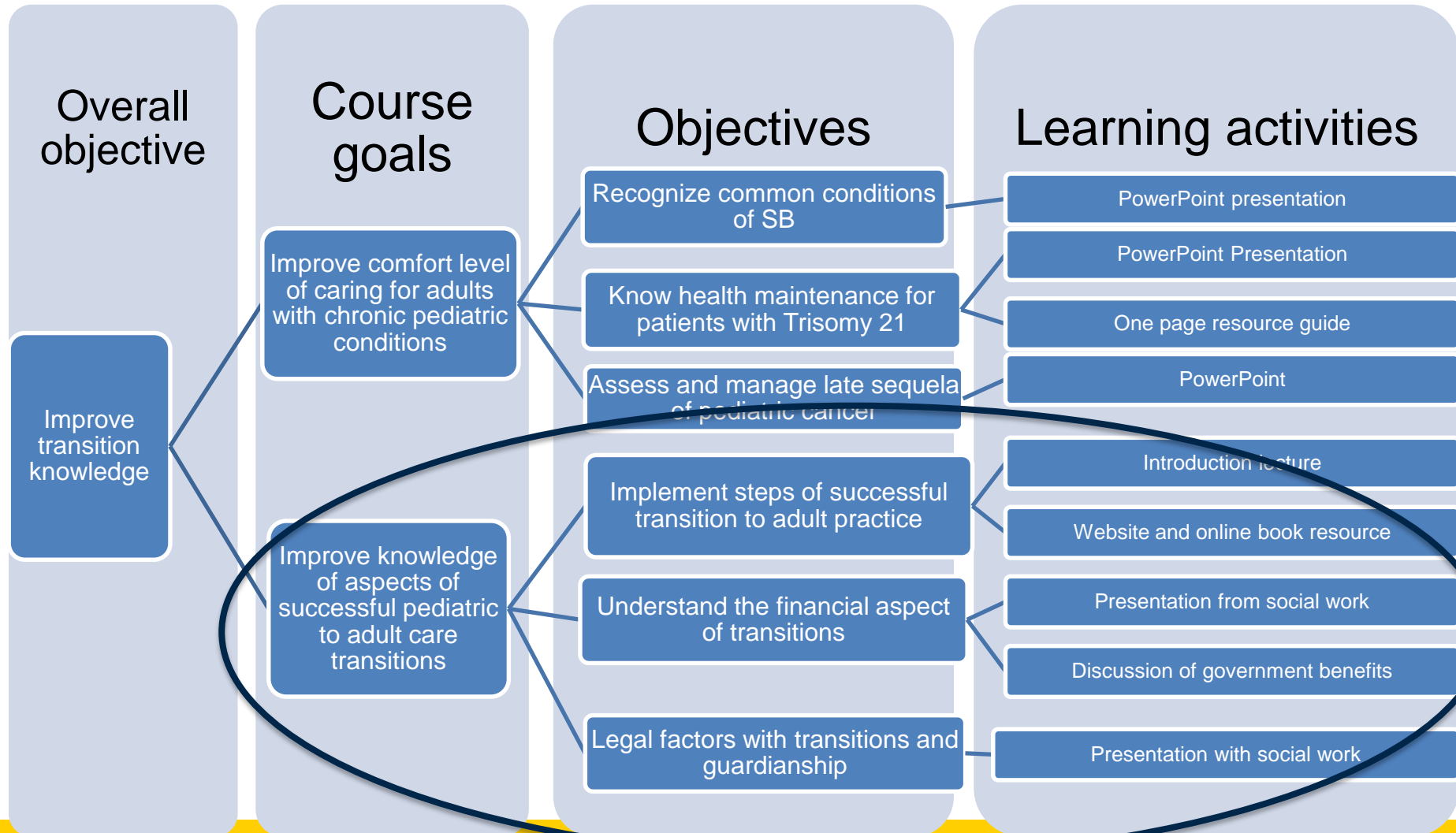
- Please identify your level of comfort with the following competencies related to health care transitions for healthy children and those with special health care needs
 - Providing appropriate guidance to help transition adolescents from pediatric to adult healthcare
 - Knowing the key steps in a planned healthcare transition
 - Identifying the financial and legal factors associated with transitioning an adolescent with special healthcare needs
 - Distinguishing between government benefits (ie SSI, SSDI)
 - Discussing decision-making and guardianship with a patient and family

Example of pediatric needs data

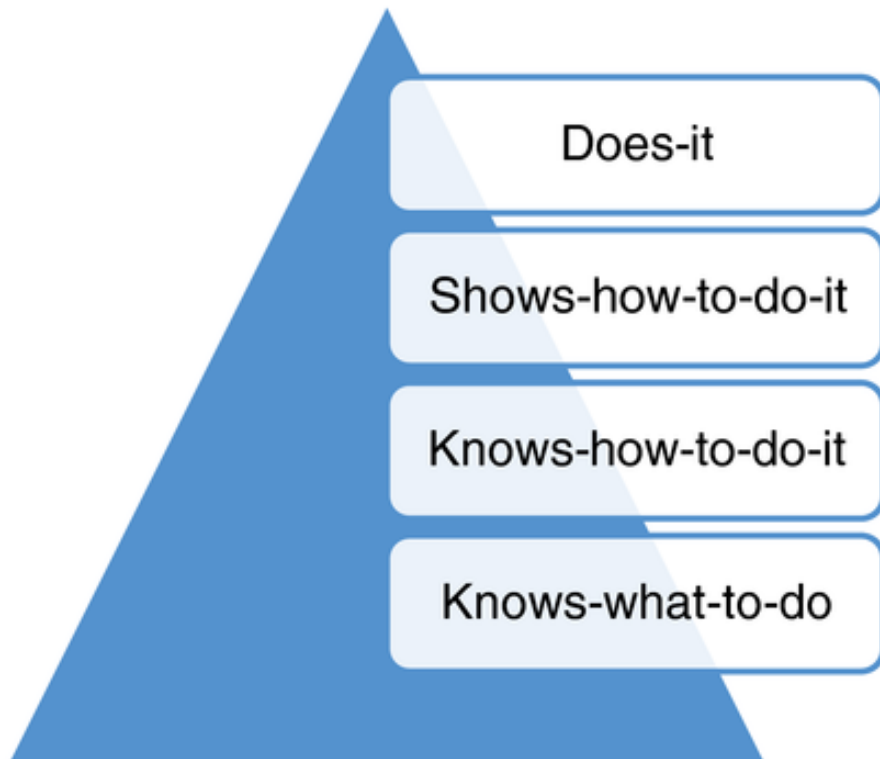
Resident comfort level caring for cancer survivors and transplant recipients



Course Blueprint Example – Transitions of care for the internist



Summative Assessment



- Miller's Framework

- Outcomes data

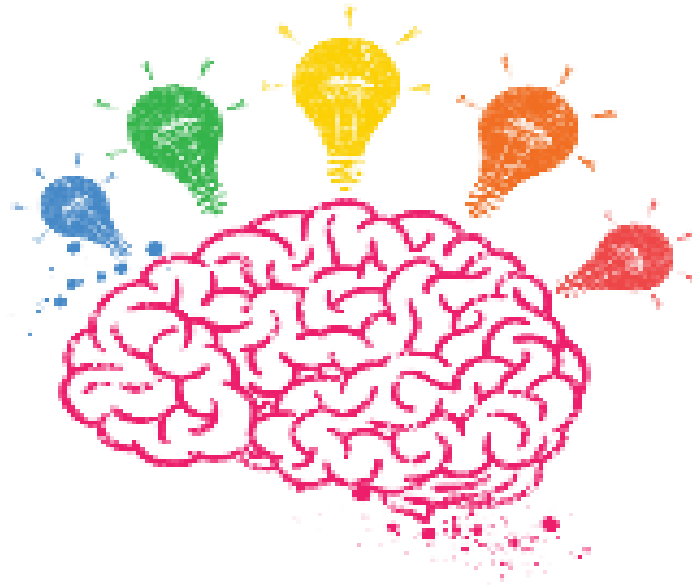
- Fill in the blank response
- Teach to others

- Objective – Multiple choice pre/post testing
- Subjective – personal knowledge gain

Brainstorming: Starting this at YOUR institution!

FREQUENCY

VENUE



AUDIENCE

PRESENTERS

TOPICS

Michigan Medicine Lecture Series

- Lecture Topics
- Presenter(s)
- Audience
- Venue
- Frequency

Lecture Topics

- Healthcare Transitions
 - Introduction
 - Financial and Legal Concerns
- Caring for Children with Special Healthcare Needs
 - Spina Bifida
 - Down Syndrome
 - Intellectual Disabilities
 - Long Term Survivorship
 - Solid Organ Transplant
 - Technology Dependent

Presenters

- Lectures created and presented by Medicine-Pediatric residents with guidance from a faculty mentor

Audience

- Pediatric Residents
- Medicine-Pediatric Resident
- Medicine Residents

Venue

- Pediatric morning and noon conferences
- Internal Medicine ambulatory morning report

Frequency

- Goal: Each lecture to be given once a year

Pediatric Lecture Series

- ① [Transitional Medicine: A Pediatric Perspective](#)
- ② Caring for Children with Special Health Care Needs: Spina Bifida
- ③ Caring for Children with Special Health Care Needs: Intellectual Disabilities
- ④ Long-Term Survivorship: Life after Childhood Cancer
- ⑤ Caring for Children with Special Health Care Needs: Solid Organ Transplant
- ⑥ Children with Special Needs: Technology, Mobility, and More
- ⑦ Financial and Legal Issues with Healthcare Transitions
- ⑧ Parental Experiences: Life with a Child with Chronic Illness

Internal Medicine Lecture Series

- ① [Transitional Medicine: An Internist Perspective](#)
- ② Caring for Adults with Childhood Illnesses: Cerebral Palsy, Mobility Impairment, Nutritional Support, and Technology Dependence of the Nervous System
- ③ Long Term Survivorship: Life after Childhood Cancer
- ④ Caring for Adults with Childhood Illnesses: Spina Bifida and Down Syndrome
- ⑤ Social-Legal Issues for Adults with Childhood Illnesses (Access to health insurance, guardianship, and more)
- ⑥ Caring for Adults with Childhood Illnesses: Intellectual Disabilities

Michigan Medicine Healthcare Transitions and Complex Medical Conditions Arising out of Childhood Lecture Series



**Pre-Assessment
September 2017**

**Post-Assessment
June 2019**

Bringing the Lectures to Life!

Going Beyond a Lecture Series

1.) Resident Resources

- One-pagers
- Addition to House Officer Survival Guide

2.) Cross-Over Lectures

Creating “one-pagers”

- Summary of what was discussed in the lecture
- Highlights take away points for that topic
- Can easily be saved as reference for use when needed

Creating “one-pagers”

Intellectual Disability

Definition: Disability acquired prior to the age of 18 years and characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills.

- **Conceptual:** receptive and expressive language, reading, writing, math, reasoning, knowledge, and memory
- **Social:** interpersonal communication skills, friendship, empathy, social judgment skills including gullibility, naivete, following rules, observing limits, avoiding victimization
- **Practical:** personal care activities – eating, dressing, bathing, meal prep, telephone communication, transportation; occupational skills – organizing school/work activities, money, job duties

Causes: 1/3 cases have unknown etiology, separated into genetic and non-genetic causes

- **Genetic:** Down syndrome (most common), Fragile X, Rett syndrome, Williams syndrome, Prader-Willi, Phenylketonuria, Angelman syndrome, other genetic causes
- **Non-genetic:** fetal alcohol syndrome, cerebral palsy, infections (measles, rubella, etc.), teratogenic causes, traumatic brain injury, autism (also has genetic component), seizure disorder

Severity:

Severity Level	IQ range (+/- 5)	Adaptive functioning	Intensity of supports needed in daily living activities
Mild	55-70	<ul style="list-style-type: none"> - Unskilled job capacity - Income support - Stable relationships - Poor parenting skills - Able to communicate by phone and in writing - Decision making: able to make some medical, financial and personal decisions 	Intervallent: Support needed on an as-needed basis; episodic or short term
Moderate	40-55	<ul style="list-style-type: none"> - Supported employment - Income support - Residential supervision - Help with shopping - Vocational/adequate for daily functioning - Decision making: need help in all areas 	Limited: Constant over time, but time limited
Severe	25-35	<ul style="list-style-type: none"> - Supervision in residential and day programs - Decision making: unable to make most medical decisions, not capable of making financial decisions 	Extensive: regular, consistent lifetime support. Regular support in at least 1 aspect such as work, home
Profound	Less than 20-25	<ul style="list-style-type: none"> - 24 hour support and supervision - Nonverbal - Dependent for self-care/hygiene - Does not have decision making capacity 	Persevere: High intensity, across all environments, lifetime, and potentially life-sustaining

Office visit considerations:
 Living situation (including guardianship for >18 y/o), communication challenges, physical challenges (need for additional therapies), behavioral issues, assess for polypharmacy, caregiver stress, need for additional services (social services, musculoskeletal issues, seizures, behavior, etc)

Medical considerations: often disease specific (see specific diseases)

Screening include: hypothyroidism in Down syndrome, mobility issues, urinary tract infections and dysphagia in CP

Evaluation of Agitation/behavioral changes with ID:

Physical	Environmental	Emotional
<ul style="list-style-type: none"> - Medical conditions leading to pain: peptic ulcer disease, dental pain, MSK issues, - Infections: PNA, UTI - Medication adverse effects - Constipation - Sensory discomfort: new clothes/shoes 	<ul style="list-style-type: none"> - Reduced supports; loss of staffing - Change in residence - Change in routine - Lack of adequate communication with family, friends, 	<ul style="list-style-type: none"> - Depression or anxiety due to - Addition of a new roommate or sibling - Loss of a parent/caregiver - Social isolation

Solid Organ Transplant Fact Sheet

Definition	The replacement of a nonfunctioning solid organ such as kidney, liver, or heart with an organ obtained from a cadaver or living donor.
Epidemiology	Individual remains on immunosuppressive medications indefinitely in order to avoid organ rejection. The number of pediatric patients living with a kidney transplant has more than doubled since 1988. The majority of children with solid organ transplants now survive into adulthood.
Immunosuppressive Medications	Calcineurin inhibitors (tacrolimus, cyclosporine) <ul style="list-style-type: none"> - HTN, HL, DM, nephrotoxic mTOR inhibitors (sirolimus, everolimus) <ul style="list-style-type: none"> - ↑ triglycerides, cytopenias, nephrotoxic Anti-metabolites (mycophenolate, azathioprine) <ul style="list-style-type: none"> - Mycophenolate: GI sx, teratogenic - Azathioprine: liver dysfunction, pancreatitis Steroids <ul style="list-style-type: none"> - HTN, DM, obesity, osteoporosis, psychosis
Sequelae of Disease/Transplant	Infection Atherosclerotic cardiovascular disease Hypertension New-onset diabetes Osteoporosis Chronic kidney disease Malignancy (skin, PTL, anogenital) Neurocognitive issues Anxiety/depression Decreased quality of life
Health Maintenance	Annual Dermatology visit Annual Ophthalmology visit (if on prednisone) Dentist every 6 months (starting 6 months after transplant) Annual pap smear Yearly lipid profile Immunizations up to date (Pneumovax, no live vaccines) Consider yearly DEXA scan 30 minutes of aerobic exercise daily Sunscreen with minimum SPF > 45 Frequent PHQ9 screening Avoid nephrotoxic medications, renally dose medications

Healthcare Transitions and Complex Medical Conditions Arising Out of Childhood
 Created by Emily Hanman, MD
 Updated March 2019

Trisomy 21 Highlights

Newborn (Birth to 1 Month):

- Echocardiogram: 50% risk of heart defects
- Congenital Hypothyroidism (1% risk): TSH
 - o On most newborn screens (including Michigan), though some use T4.
- CBC for transient myeloproliferative disorder, polycythemia
- Screen for feeding problems and hypotonia, discuss risk of respiratory infections
- Red reflex for cataracts
- Hx and PE for duodenal/anorectal atresia

Infancy:

- Within first six months: ophthalmological evaluation
- Discuss symptoms of sleep apnea, refer if necessary
- Discuss cervical spine neutral positioning
- 6 months and 1 year: Repeat TSH

Childhood:

- TSH and CBC annually
- Audiological exam annually; ophthalmologic exam every 2 years
- Sleep study once by age 4 years
- Discuss atlantoaxial instability
 - o Warn about new onset symptoms of gait changes, bowel/bladder function changes, neck pain, torticollis, or weakness
 - o Cannot evaluation on x-ray until 3 years old and routine evaluation of asymptomatic children with radiographs not recommended
 - o Special Olympics requires neck x-rays for some sports
- Consider celiac evaluation if failing to thrive
- Early intervention: PT, OT, speech; establishing IEP

Adolescence into Adulthood

- TSH, CBC, and hearing screen annually
- Ophthalmological every 3 years
- Discuss puberty, need for gynecological care in pubescent female
 - o Only case reports of male fertility
 - o Females with trisomy 21 can conceive – 50% chance of offspring having trisomy 21.
- Facilitate transition: guardianship, financial planning, behavioral problems, school placement, vocational training, independence, group homes, etc.

Addition to RAWRZ guide

- RAWRZ House Officer Survival Guide
 - updated each year
- Last year added “ Transition to Adult Care” and “Children with Special Healthcare Needs” section

Cross-over lectures

- Reviewing a case relevant to both internal medicine and pediatrics
 - Example: 20 year old with chest pain
 - Having adult subspecialist attend presentation for discussion and answering questions
- Collaborative Grand Rounds

Future Directions

- Expanding audience to include other residents (ie. family medicine) and medical students
- Residency Interest Group
- Website combining national resources and one-pagers fact sheets to help providers care for youth with special healthcare needs and adults with childhood illnesses
- Structured pediatric and IM electives
 - Healthcare Transitions
 - Complex Medical Conditions Arising out of Childhood

What are other institutions doing?

- Internal Medicine, Pediatric, and Med-Peds residents rotate through transitions clinic during ambulatory block at Duke University Medical Center
- Harvard Crossover Curriculum: Guest faculty from opposite discipline at resident conferences
- Continuity clinic curriculum includes transitions cases at many institutions

Resources

Websites



American College of Physicians - Pediatric to Adult Care Transitions Initiative “Toolkit”: <https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative>

Websites



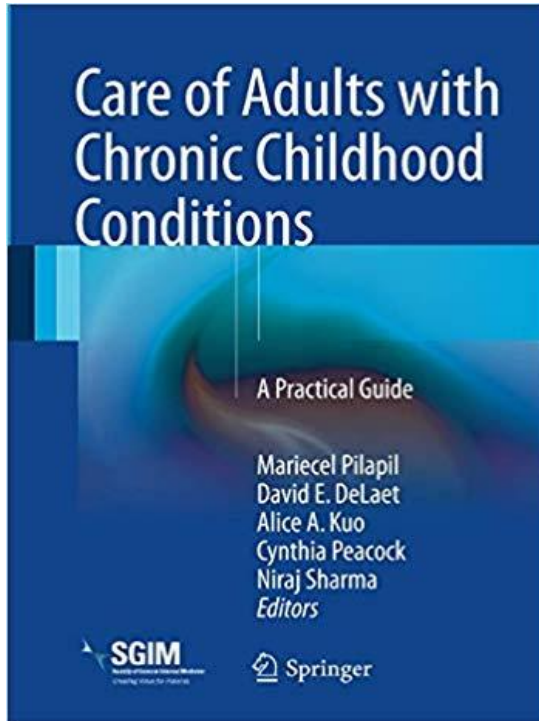
Got Transition:

<https://www.gottransition.org/>

Got Transition

- Tools for providers such as handouts and webinars to help with planning a patient's transition of care
- Resources on other important aspects of care transitions (health insurance, guardianship, educational support)
- FAQs and quizzes for patients

Books



Pilapil, Maricel, David E. DeLaet, Alice A. Kuo, Cynthia Peacock, and Niraj Sharma. *Care of Adults with Chronic Childhood Conditions: A Practical Guide*. Cham: Springer, 2016.

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- Dr. Peacock and the Baylor COM Transition Clinic

USB Flash Drive



- Workshop PowerPoint and Handout
- The following lectures from Michigan Medicine's Lecture Series:
 - Transitional Medicine: A Pediatric Perspective
 - Transitional Medicine: An Internist Perspective
 - Long Term Survivorship: Life after Childhood Cancer
 - Pediatric
 - Internal Medicine
- Examples of One-Pagers

Sources

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