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The next layer is the *individual provider-patient system*. This is the layer we usually focus on when teaching medical or clinical skills. This is the level where the diagnosis and treatment plan is determined. The fee-for-service payment structure focuses on this layer paying the provider for the services delivered by this subsystem.



The third layer is the *clinical microsystem*, which will be the focus of this workshop. This element is the combined front-line staff, patient, provider, information technology, and processes of care that actually deliver the care to patients. This is the part of the system that provides patient satisfaction and quality of care.

The fourth layer is the *Institutional macro-system*, which is the institution housing multiple clinical microsystems. The institution links microsystems through common policies, agreements, and information systems. The fate of one clinical microsystem in large part depends on the cooperation and smooth transition of care across multiple microsystems. The quality of care and the overall patient experience also depend on the smooth transitions across a macro-physicians offices, laboratory, pharmacy, radiology, cardiology, hospital, emergency department, and so on.

The outer layer of the health care system is the *community, market, and social policy systems* which govern and regulate health care and drive the behavior of every player in the whole health care system. Large scale system reform occurs at this level; consider the *Patient Protection and Affordable Care Act* (ACA) of 2010 (Obamacare) is the biggest example of power to reform the system of care. monitoring, planning, behavioral change, etc.). One key element of the Patient Centered Medical Home (PCMH) model of care is providing patients with a summary of the encounter to guide them in participating in their care.

Support processes uphold each microsystem.

Measurement and Improvement Processes provide information to the microsystem about how it is working to achieve its goals. This support function is currently undergoing the most radical changes at the microsystem level.

The second important support process is *Teamwork and Care Management*. The PCMH models of care have highlighted the critical importance of this process. Guided by a set of policies and procedures, all of the providers and staff have assigned roles to manage and coordinate the care the microsystem delivers. The principle underlying these supporting processes is that each member of the microsystem (including the patient) works

competency and of next generation patient care.

TEAMWORK - A team is two or more individuals with specialized knowledge and skills and specific roles to make decisions and perform interdependent tasks,

In 2011, the Patient Centered Primary Care Consortium summarized the elements of the PCMH as providing superb 24/7 access to care, patient engagement in care, clinical information systems, care coordination, team care, patient feedback and input to c

access and continuity of care through electronic communication between patients and the practice and provide appointments or visits that meet the needs of patients.

When OUP-T rolled out its PCMH project Dr. Duffy developed the slide below to compare current primary care practice with the PCMH model of practice. The slide illustrates this difference and helps us to understand how dramatically the transformation in primary care systems is becoming. For this audience and the case that we'll be studying, the Hematology practice actually acts as the medical home. Are we prepared to teach and practice in this way?

Systems-Based Practice ASH PDW

Likewise, the *non-primary care microsystems* connect to myriad PCMH microsystems and to each other through the *Health Access Network* and *Health Information Exchange* each microsystem organizes its work according to the policies and procedures contained in the agreements of the *alignment plan*.

for the PCMH Neighborhood. This policy provides guidance and formats for agreements across microsystems for co-management, referral, and coordinat specialty microsystems.

The ACP position paper on Patient-Centered Medical Home Neighbors is helpful. We quote liberally from this document below. It maintains the primary care practice as a patient home but specifies specialty practices as neighbors in a neighborhood of care. In general, there are various relationships and exchanges possible between pediatric or adult primary practices and their specialty colleagues:

1) Pre-consultation exchange -

sees the patient at least monthly for 2 years of active therapy. The hematology practice assumes all responsibilities for care and is first call/first responder to any health issue."

For what type of patient should a hematology practice assume complete or near-complete care?

acute leukemia/BMT sickle cell anemia Today we'll have a case management conference to arrange the transfer of Jonathan from pediatric to adult hematology. Each table will be divided into seven roles - - each with unique insight and capability concerning Jonathan. Here are the roles:

Jonathan - - 17 1/2 years old, patient with severe hemophilia A Pediatric hematology fellow - - has worked with Jonathan for the last 2 years Adult hematology fellow - - will work with Jonathan for the next 2 years Pediatric RN/Case Manager - - has worked with Jonathan & parents for the last 10 years Adult RN/Case Manager - - will work with Jonathan for the next 10 years Pediatric Social Worker - - has worked with Jonathan & parents for the last 10 years Adult Social Worker - - will work with Jonathan for the next 10 years

Each participant will receive a shared history and unique information appropriate to the role they are playing in the conference. The task of the group is to accomplish a high quality transfer of care as Jonathan moves from one microsystem to the next. What will guide the group? That's part of the challenge. We've included the transitions document from the consortium of hemophilia treatment centers that addresses patients aged 16-18 and mentions the transition to adult practice. It is correct to recognize this as an issue, but could this group come up with some useful tools and practices to share? We think so. You will craft the transition of care document for Jonathan and patients like him. Acknowledge Jonathan's needs and the capabilities and perspectives that each team member brings. An aspirational goal: could one of your teams come up with a tool that could be used and disseminated?

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Shared History Jonathan is a 17 1/2 year old young man with severe hemophilia A. He was diagnosed at circumcision. Jonathan experienced his first spontaneous bleed at the age of 4 and began prophylactic factor VIII infusion thereafter. Since childhood he has been cared for in a pediatric hematology practice in an academic medical center (AMC) less than one hour from his home. He visits a pediatric Hemophilia Treatment Center (HTC) that is 2 hours away annually. Jonathan has signs of early arthropathy in his right knee but does not have other target joints. This meeting involves the transfer of care from pediatric to adult hematology in the same AMC. Jonathan will attend college on the undergraduate campus in less than a year.

Information Specific to each Role:

Jonathan - - I'm excited about going to college and living in the dorms, but a little nervous as well. I received a scholarship that will cover tuition, room & board. That's needed, because my Dad just lost his job and things are tight on only Mom's income. I've been self-infusing factors sinc4(Cen)5(o)-61 0 0 1 349.9 4f/ early

anyway. He came in with a huge hematoma. He settled down and came to enjoy swimming. For the most part Jonathan is compliant and is becoming more and more self-reliant. But - - he's still 17.

Adult RN/Case Manager - - I find adolescent/young adult transitions to be challenging. In fact, we've

- 1) Draft of ABIM Milestones concerning SBP - we'll be using one of these for our evaluations
- 2) Hemophilia Treatment Centers transition guidelines for patients 16-18 as reference

Name:

DOB:

DOB:

TRANSITION GUIDELINES 16-18 Years Old

Self Advocacy & Self Esteem				
Goals & Objectives	Strategies	16	17	18
Young adult expresses medical, physical and social needs to others.	Discuss bleeding disorder/impact on daily living and plans for future.			
	Young adult should demonstrate knowledge of physical abilities.			
	Self-infusion, documentation and interaction with staff expected.			
Young adult will be able to advocate and negotiate for health care.	Ensure young adult has <u>skills</u> to negotiate needs (travel letter, E.R. care, P.T. referral).	care.		•

DOB: TRANSITION GUIDELINES 16-18 Years Old

Independent Health Care Behaviors					
Goals & Objectives	Strategies	16	17	18	
Young adult demonstrates understanding of healthcare needs by participating in treatment/decision- making.	Assess/reinforce young adults understanding of treatment regimen/comprehensive care. Assess adherence.				
	Assess/reinforce young adult's understanding of benefits/adherence with home exercise/PT program and RICE.				
	Reinforce need to contact medical providers if home exercise program causes problems /concerns.				
Young adult participates in health care management by keeping records and communicating with healthcare providers.	Ensure young adult communicates with HTC providers (appointments, prescriptions).				
	Ensure young adult tracks home therapy/medical supplies/medications.				
	Stress reporting complications/problems to HTC.				
	Increase young adults personal time with HTC staff during clinic visits. Encourage young adult to list questions.				
	Ensure females record menstrual bleeding (duration, amount and discomfort) for review at clinic.				
	Discuss who to call for what.				
Young adult, family and healthcare providers negotiate decisions, roles and responsibilities for healthcare.	Ensure young adult completes personal care record/emergency care plan for school /home.				
	Ensure young adult knows address/phone number of treatment center.				
	Continue CVAD/venipuncture transition (if applicable).				
	Continue discussion of developmental tasks re: young adult/disclosure.				
	Discuss changing roles as young adult accepts responsibility for care.				
Family and young adult utilizes preventative and supportive care services in their community.	Encourage youth to consult PT re: bleeds/joint protection or joint protection and fitness.				
	Discuss access to community resources (local fitness center, walking trails, parks, etc.) to promote a health lifestyle.				
Young adult understands genetic implications of his/her bleeding disorders.	Ensure young adult understands genetic variables/implications of his/her diagnosis.				
	Provide written materials (family tree).				
	Offer genetic referral as needed.				
Young adult understands implications of carrier status.	Ensure young adult understands carrier status and its implications . Provide written materials.				
	Educate at risk family members re: carrier testing.				
Young adult understands implications of symptomatic carrier status.	Ensure symptomatic carrier understands the diagnosis, when and where to seek hematological care, refer to GYN care if necessary, etc.				

Comments/Literature Provided: