

Improving outcomes for children with complex chronic conditions through explicit co-management

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Why the word complex in our title?

- Problems are simple, complicated, or complex
- We often treat complex problems as though they are merely complicated
- And wonder why we don't get better outcomes

Simple problems

- Solve by following a recipe
- Good recipes give good results
- No special expertise is required

Complicated problems

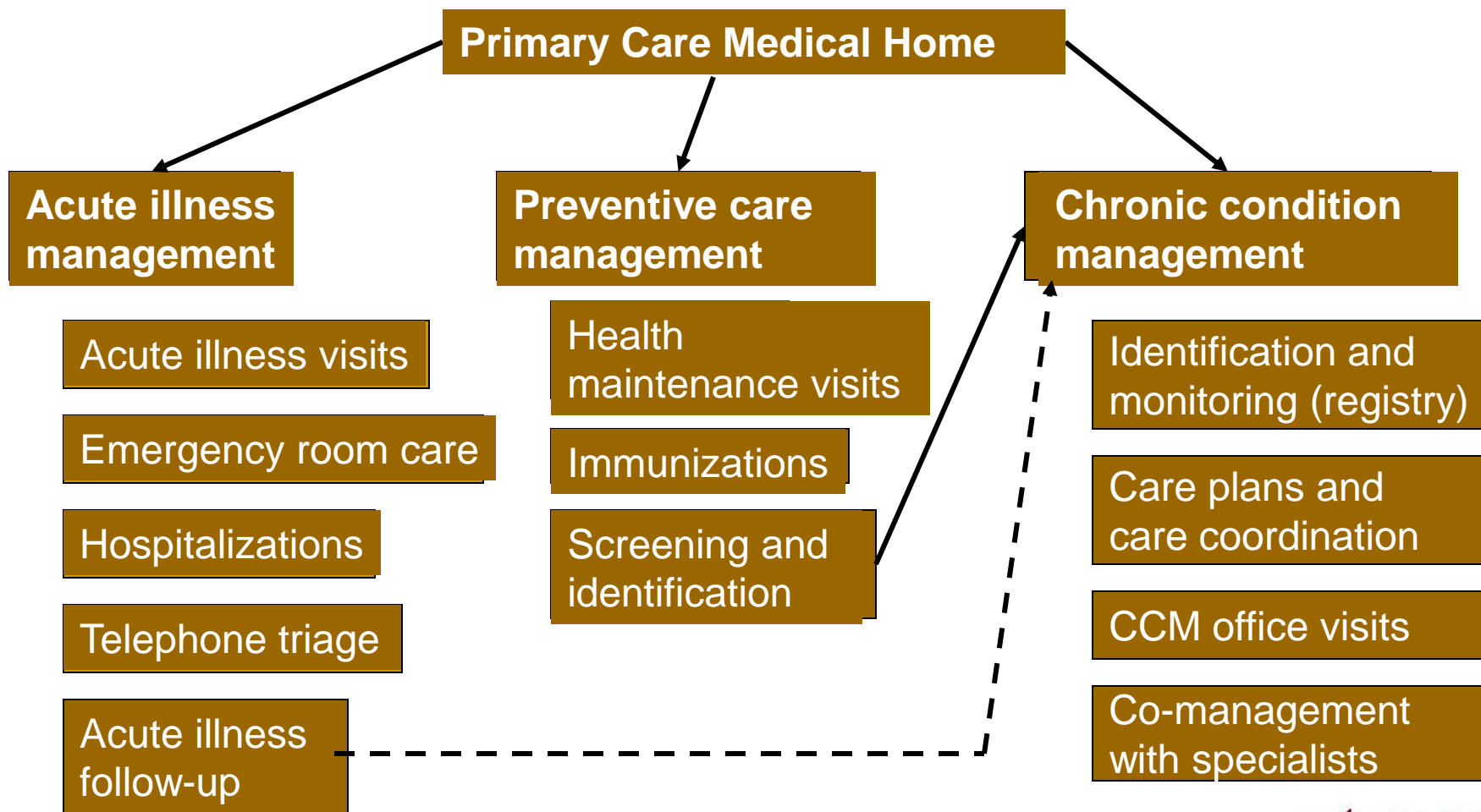
- Sequential, linear process
- Single system
- High level of expertise in a variety of fields needed
- Replication of success is expected
- High degree of certainty of outcome
- Checklists improve outcomes – Gawande
 - Introduce the team

Complex problems

- Processes may be simultaneous, non-linear
- Multiple systems involved
- Expertise necessary, but not sufficient
- Communication and coordination critical

- Treating complex problems as merely complicated is risky
- Complex condition care is really about human care within complex systems

The Medical Home Model



Co-management means...

- There is a role for families, for primary care, and for specialists
- These roles are explicitly defined – everyone on the same page
- There is a process or system to define, communicate, & document roles
- Roles may change or fluctuate (and need re-definition) over time
- Primary care role may be more generic for children with rare, complex conditions rather than specific to the chronic condition
 - ❑ Assuring appropriate preventive care and routine acute illness care
 - ❑ Sounding board for families/patients about worries and concerns
 - ❑ School or developmental issues
 - ❑ Coordinating community or family support resources
- Or, it may be specific to the chronic condition
 - ❑ Alternating chronic condition follow-up visits with specialists
 - ❑ Performing routine monitoring (weights, lab tests, etc) as part of care plan
 - ❑ Providing initial triage of exacerbations or complications

Locus of co-management control

- Can rest with the primary care medical home
 - Asthma
 - ADHD
 - Developmental delay
- Can rest within in a specialty clinic
 - Cystic Fibrosis
 - Sickle Cell Disease
- Can change over time or fluctuate with patient status and family preference
 - Children with rare, complex conditions
 - Metabolic disorders diagnosed through newborn screening
 - Hypoplastic left heart syndrome

Locus of co-management control decisions should

- Always include families/patient in the process and respect their preferences
- Always be explicit and effectively communicated among the stakeholders
- Always take non-medical circumstances into consideration
 - Geography
 - Local resources
 - Family support network
- Always be documented in some way

Failure to define co-management roles may lead to

- Less certainty
 - Greater stress
 - Inefficient use of resources
 - Unwanted outcomes
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- That is, lower quality of care, higher costs, reduced patient safety