Routine Preventive Care for Children with Medical Complexity

Dr. Tammie Dewan, MD, FRCPC
Dr. Esther Lee, MD, FRCPC
Dr. Nathalie Major, MD, FRCPC

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Speaker Name: Dr. Tammie Dewan, Dr. Esther Lee, Dr. Nathalie Major

Disclosure of Relevant Financial Relationships
I have no financial relationships to disclose.

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I will not discuss off label use and/or investigational use in my presentation
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• Canadian Pediatric Society Complex Care Special Interest Group (CPS Complex Care SiG)
  – Health Supervision Framework working group

Outline

• Context
  – Children with medical complexity
  – Preventive care
  – Challenges
• Approach to Routine Preventive Care for CMC
  1. Goal setting
  2. Health supervision
• Conclusion
  – Take home points
  – Questions for discussion
Two Components

1. **Family Goal Setting**
   - Short term
   - Long term
   - Acute/Resuscitative

2. **Health Supervision**
   - To facilitate appropriate preventive care and comprehensive review
   - Evidence-based and standardized
Defining Goals of Care

- Process of discussing the priorities/aims/understanding of care plans
- Extension of usual discussions about the treatment plan:
  - Short and long term goals, and advance care directives
  - Medical life sustaining treatment decision, advance care planning, advance directives, communicating prognosis in palliative care
  - Should include more personal, and focus on where they (the child/family) want to be, and how they want to live their lives.
- Allows clinicians to align the care provided with what is most important to the patient and his or her family.

A Child with Medical Complexity, Fragility

- Prematurity 24+5wks, CP GMFCS 5, mixed spasticity and dystonia
- Visually (severe ROP) & Hearing impaired-left sided cochlear implant
- BPD- recurrent aspiration pneumonia
- GERD, dysphagia (aspirate with liquid)
- OSA, Bipap, T&A
- PDA, Indomethacin-ARF, ligation
- Stage 3 VUR – STING procedure
- Meconium plug and microcolon/perforation & resection small bowel (17cm)
Process of Establishing Goals of Care

• **WHO?** Child/Family, Primary care provider, Specialty care provider, “provider”

• **WHY?** Good communication is a cornerstone of high-quality medical care

• **WHEN?** Longitudinal, every clinical encounters, pro-active vs acute care

• **Treatment Decisions Principles?** Rare disease, unique circumstances

Approach to Discussing Goals of Care

• **REMAP**
  - **Reframe:** current decision must be placed into the context of the clinical scenario
  - **Expect emotions:** naming and acknowledging emotions helps clinicians to explore them further; attend to affect, feelings of loss, fear, and guilt
  - **Map out the future:** must have a clear understanding of the goals prior discussing treatment options
  - **Align with Values:** verify what was understood
  - **Plan treatments that match values**
Examples: FTM, Care Plans and Medical Roadmap

Example: Care Plan
Example: FFTM

Example: Roadmap
Long term and Acute/Resuscitative Goal Setting:

**Family Team Meeting**

- **P** - Physical
- **E** - Emotional
- **S** - Social
- **S** - Spiritual
- **T** – Trajectory

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**Long Term Trajectory**

- **T** - Trajectory

http://ichef.bbci.co.uk/news/3736/wpa/prod/live/800/production/_87108582_voldemort_ap_976.jpg
The Mystery Child

- 9 year old boy with epileptic encephalopathy, central apnea, aspiration lung disease, GERD/G-tube feeds.
  - Underlying diagnosis unknown
- High inpatient utilization, moderate outpatient utilization...
- But ++outstanding issues
  - No recent hip/spine surveillance or follow-up
  - Feeding intolerance, low fluid intake
  - Lapsed immunizations
  - No dental care x years
  - No school attendance; no family support

Preventive Care

- An ounce of prevention is worth a pound of cure. — Benjamin Franklin
- Preventive care aims to protect, promote and maintain health and well-being and to prevent disease, disability and death

ACPM.org
Well-Child Tools and Guidelines

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Recommendations for Preventive Pediatric Health Care

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• Increased adherence 5 out of 8 universal recommendations

• High satisfaction amongst health care providers and parents

• Overall suboptimal adherence rates

• Desire for better integration
Health Supervision

The “Complex” version?

<table>
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<tr>
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**HEENT**

- **Eyes**
  - Regular eye exams?
  - Services for visual impairment
  - Corneal abrasion risk

- **Ears**
  - Hearing screened?
  - Sign language, adaptive technology?
  - Hearing impaired supports?

- **Mouth**
  - Dental hygiene
  - Dentist/Orthodontist care and cleaning
  - Dental insurance

**MSK**

- **Hips**
  - Clinical/radiographic Surveillance

- **Spine**
  - Clinical/radiographic Surveillance

**ENDO**

- **Bone Health**
  - Fracture history
  - Investigations – labs, imaging
  - Intervention: Ca, Vitamin D, bisphosphonates

**SYMPTOMS**

- Pain/Irritability
- Sleep disturbance
- Other

**MEDICATIONS**

- General review – still indicated? Dosing?
- Prescriptions, renewals, orders
- Routine monitoring
- Side effects, interactions
- CAM
- Special funding required
## Client Information

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## Medical History

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## Social History

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## Assessment

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## Plan of Care

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## Progress Notes

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## Discharge Plan

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## Follow-up

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## Documentation

- [Checklist Details]
Principles of Health Supervision

• Comprehensive
• Not prescriptive
• Evidence-based where possible
  – Intended to guide inquiry, not make specific recommendations
• Tailored
• Longitudinal

Summary: Routine Preventive Care

• When? How often?
  – Anytime
• Where?
  – Anywhere
• Why?
  – Addressing family goals and concerns
  – Promoting preventive/anticipatory rather than reactive care
• How?
  – Standardize/document
  – Engage families and share responsibility
Pearls

• Ask the family
  – Consider asking them to reflect/document in advance
• Be flexible and opportunistic
  – Seize opportunities AND book dedicated time
  – View health surveillance over longer time span
• Plan for longitudinal/recurrent conversations
  – Resuscitative and end-of-life care

Questions for Discussion

• What approaches/protocols have others developed?
• Feedback or suggestions for the approach we have presented?
• tdewan@cw.bc.ca (feedback, questions)
References