

COMMENTARY

The Complex Care Review of Systems: An Aid to the Initial Evaluation of Severely Neurologically Impaired Children and Adolescents

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INTRODUCTION

Whenever a new complex, neurologically impaired patient is first encountered in the hospital or clinic, obtaining a complete history and creating a problem list can be overwhelming. Even if one has the time to obtain the history chronologically, families may leave out important details.

We have successfully used the following adaptation of a review of systems (Table 1) during the initial encounter in our Program for Children with Medically Complex Needs at Vanderbilt. This review of systems, when combined with initial open-ended questions

about the family's concerns, will capture the most important elements needed to create a summary of the patient's problems. The review of systems can easily be added as a template in the computerized medical record. In the Epic medical system, for example, it can be incorporated into a dot phrase.

Each section in the review of systems can be expanded or condensed as needed. For example, one may or may not want to list things such as tracheostomy size or ventilator settings, depending on the provider's level of management of the problems in this area.

Table 1: Pediatric and Adolescent Complex Care Review of Systems

Medications: ENT: History of T and A or airway surgery? Snoring? Tracheostomy? Source of dental care? Resp history: Pneumonias? Respiratory illness? Allergies: Allergic rhinitis, asthma? Immunizations: Flu shot? Vaccines? Issues with secretions? How often does he/she need suctioning? Cardiac: GI/Feeding: Feeding issues? Feed po? GERD, retching or vomiting? Feeding schedule/diet. Constipation: G tube, GJ tube, or other indwelling catheters? Hx pancreatitis? Nissen fundoplication? GU: History of UTI's, kidney stones, urinary retention. GYN: Menses? Problems with menses? Contraceptives? Neuro: Seizures? Unexplained irritability? Meds for spasticity? Autonomic function: ability to run fevers? Usual temp? Heart rate issues? Sleep: Problems with sleep? Snoring? Obstructive sleep apnea? Blood: Any blood disorders? Endocrine: Thyroid, adrenal or other endocrine issues. Surgery: Current developmental skills: verbal ability, ability to walk, communication. Therapies: Physical, occupational, speech or feeding therapy? Skin: Decubiti? Other skin issues? DME: Wheelchair, shower chair, stander, hospital bed, gait trainer, car seat? pulmonary chair? Lift? Feeding pump, vent, bipap machine, suction machine, home oxygen? DME companies: Respiratory, feeding, other (sometimes different companies provide different things) Ortho: dislocated hips, scoliosis, fractures? Hearing: Vision: Social: Where do parents live? Who is at home with him/her? How far away from hospital/clinic? Home nursing? Hours? School? Things he/she enjoys: Goals of care: What are your worries about your child, what are your hopes? <i>On the advice of our palliative care colleagues, we've found that asking the latter two questions is often more helpful than asking about goals initially.</i>

Once this review of systems is completed, a problem list can be created and used for ongoing management.

EXAMPLE INITIAL ENCOUNTER

**Case presented is a composite patient to highlight all components of the review of systems.*

BL is a 6-year-old boy who was seen in the complex care clinic for an initial evaluation. He suffered a severe brain injury in an automobile accident at age 6 months. His mother reports feeling overwhelmed with his care and has difficulty coordinating care with his specialists. He eats very slowly and has not gained weight well. He has a seizure disorder and is followed by neurology

After the initial history and physical exam, the following review of systems was obtained:

Medications: *clobazam bid, rufinamide bid, levetiracetam tid, valproic acid tid, prn rectal diazepam (doses were listed in the medication section of the chart).*

ENT: History of T and A or airway surgery? Snoring? *None.*

Tracheostomy? *No.*

Source of dental care? *Has not seen a dentist yet.*

Resp history: Pneumonias? Respiratory illness? *Admitted twice with pneumonia, once for a week and once for two days, most recently 4 months ago. Not on oxygen at home. He coughs frequently.*

Allergies: Allergic rhinitis, asthma? *No hx of allergies or asthma.*

Immunizations: Flu shot? Vaccines? *Vaccines up to date including influenza vaccines.*

Issues with secretions? *He does drool at times. Mom does not have a suction machine but does think it would be helpful. She frequently has to wipe his face.*

Cardiac: *No known heart problems.*

GI/feeding. Feed po? *He does eat by mouth, but it takes 45 minutes or more to feed him. Mom met with dietitian during visit to discuss feeding schedule. Eats pureed food. GERD, retching or vomiting? He does not vomit but sometimes spits up. He is not gaining weight as expected based on the growth chart and appearance. (weight is at the 10th percentile and has been relatively flat). He is fed pureed table food and 24 ounces of commercial formula. (30cal/oz)/day. He has not had a swallow study. Mom was told by her pediatrician that he might need a G tube and we spent considerable time talking about the pros and cons of this.*

Constipation: *Sometimes strains with bowel movements. Does not go every day.*

G tube, GJ tube, or other indwelling catheters? Hx pancreatitis? Nissen? *No history of G tube, Nissen, pancreatitis.*

GU: History of UTI's, kidney stones, urinary retention. Menses? Contraceptives? *None.*

Neuro: Seizures? *Seizures have been difficult to control. He is followed by neurology but missed his last appointment. He will stare into space at least 4 times a day. These episodes last less than a*

minute. Mom thinks they probably occur more often, but they may not notice them. He also has generalized tonic clonic seizures lasting 1-2 minutes perhaps once a month. Had a history of subdural bleed with initial auto accident. Unexplained irritability? No.

Meds for spasticity? None but does have diffuse spasticity.

Autonomic function: ability to run fevers? Usual temp? Heart rate issues? No issues.

Sleep: Problems with sleep? Snoring? Obstructive sleep apnea? No.

Blood: Any blood disorders? None. Did have a brain bleed with initial automobile accident.

Endocrine: Thyroid, adrenal or other endocrine issues. No known problems.

Surgery: 1. Underwent decompression craniectomy with accident age 6 months. Some of the cranial bone was removed. 2. Extensive cranioplasty with bone graft age performed at age one year.

Current developmental skills- verbal ability, ability to walk, communication: Seems happy to see parents, laughs at times. Nonverbal. Will pull socks off and put them in his mouth. Mom said that his

developmental level is between 3 and 5 months by developmental medicine. Cannot walk. Unable to sit without support. Visually impaired due to cortical defects per ophthalmology.

Therapies: Physical, occupational, speech or feeding therapy? No feeding therapy. Gets physical therapy through a school program three times a week.

Skin: Decubiti? Other skin issues? Some redness on buttocks, no skin breakdown.

DME: Wheelchair, shower chair, stander, hospital bed, gait trainer, car seat? pulmonary chair? Lift? Feeding pump, vent, bipap machine, suction machine, home oxygen? Has wheelchair, stander, bath chair, ankle-foot orthotics, no suction machine.

DME companies: Respiratory, feeding, other (sometimes different companies provide different things) Gets wheelchair, stander from hospital wheelchair clinic company. Formula supplied by separate DME company.

Ortho: dislocated hips, scoliosis, fractures? No history of fractures with initial accident except for cranial fracture. Had hip x rays and hips not dislocated.

Hearing: *seems to hear well. Has upcoming audiology appt.*

Vision: *Saw ophthalmology. Mom was told he had cortical visual impairment.*

Social: Where do parents live? Who is at home with him/her? How far away from hospital/clinic? *Parents live 3 hours from the clinic. Dad is an accountant. Mom stays home.*

Home nursing? Hours? *None.*

School? *Is enrolled in school and gets PT as above.*

Things he/she enjoys: *Loves music.*

Goals of care: What are your worries about your child, what are your hopes? *Mom became tearful when asked about her hopes. When asked about worries, she was worried that he might have another severe episode of pneumonia. This led to a conversation about the family's thoughts about aggressiveness of intervention. Mom said she would like him intubated if necessary and resuscitated fully if he required in the future. Mom feels that he has a good quality of life and smiles frequently. Mom admitted to being overwhelmed at times with his care.*

After obtaining a family history and social history, as well as performing a physical exam, the following problem list was created:

EXAMPLE PROBLEM LIST

Synopsis:

BL is 6 year-old boy with profound developmental delay due to a previous CNS bleed, diffuse spasticity, poor weight gain due to dysphagia, seizure disorder, and history of pneumonia requiring hospitalization on two previous occasions.

Problems:

Inadequate weight gain. Weight is within normal range but weight gain has been flat and therefore crossing percentiles downward on the growth chart. Met with nutrition today and intake determined to be lower than ideal. Well hydrated on exam. Mom resistant to gastrostomy tube at this point.

Plan: Dietitian advised mom on methods to increase caloric density of intake for now but will schedule video swallow study with the feeding/speech team and discuss further interventions with mother.

Return in 1 month.

Dysphagia

Plan: video swallow study scheduled.

Will review results with parent when available.

Constipation

Plan: will start polyethylene glycol 3350, 8.5 gms /day (1.2 capful) with goal of at least one BM/day.

Sialorrhea.

Plan: will follow for now but may consider glycopyrrolate at future visit.

Ordered suction machine for home use.

Hx of pneumonia x 2. This may be related to aspiration of oral feedings and aspiration of secretions, in addition to underlying CP.

Plan: will schedule video swallow study with feeding/speech therapist as noted above.

After this, will have further discussion about G tube and oral feedings.

Seizure disorder. Approximately 4 staring spells and 2 generalized tonic clonic seizures per month. Overdue for appt with neurology.

Plan: Message sent to complex care scheduler to assist with arranging follow up appointment with neurology.

History of subdural CNS bleed . Occurred after auto accident age 6 months.

Profound developmental delay

Plan: continue to be followed by developmental medicine and receive special help at school.

Spastic quadriplegia

Plan: monitor hip x-rays, follow for scoliosis as well per protocol. Due next year.

Refer to Cerebral palsy clinic for discussion of baclofen, botox injections if needed.

Contractures: has heel cord contractures, also elbow and knee contractures.

Plan: Continue with physical therapy.

Continued routine follow up with orthopedics.

At risk for hearing deficit

Plan: has audiology appt scheduled.

Hx of cortical visual impairment

Plan: followed by ophthalmology.

Dental:

Plan: Refer to special needs dentist.

Decubitus: stage 1 decubitus on ischial tuberosities.

Plan: Refer to wheelchair clinic to check padding and fit.

Mom to monitor closely for skin breakdown.

Reduce time in wheelchair when possible.

Mepilex® pads to affected area to provide additional cushioning.

Paged wound care nurse to talk with mother today in clinic.

Social: Mom not interested in home nursing at this point but is exhausted at times. Some of this is due to excessive time required for feeding.

Plan: will continue to provide support. Does not qualify for home nursing currently. No respite services available.

DISCLOSURES/CONFLICTS OF INTEREST: Nothing disclosed.

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TABLES

Table 1: Pediatric and Adolescent Complex Care Review of Systems

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Tracheostomy?

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Allergies: Allergic rhinitis, asthma?

Immunizations: Flu shot? Vaccines?

Issues with secretions? How often does he/she need suctioning?

Cardiac:

GI/Feeding: Feeding issues? Feed po? GERD, retching or vomiting? Feeding schedule/diet.

Constipation: G tube, GJ tube, or other indwelling catheters? Hx pancreatitis? Nissen fundoplication?

GU: History of UTI's, kidney stones, urinary retention.

GYN: Menses? Problems with menses? Contraceptives?

Neuro: Seizures? Unexplained irritability?

Meds for spasticity?

Autonomic function: ability to run fevers? Usual temp? Heart rate issues?

Sleep: Problems with sleep? Snoring? Obstructive sleep apnea?

Blood: Any blood disorders?

Endocrine: Thyroid, adrenal or other endocrine issues.

Surgery:

Current developmental skills: verbal ability, ability to walk, communication.

Therapies: Physical, occupational, speech or feeding therapy?

Skin: Decubiti? Other skin issues?

DME: Wheelchair, shower chair, stander, hospital bed, gait trainer, car seat? pulmonary chair? Lift? Feeding pump, vent, bipap machine, suction machine, home oxygen?

DME companies: Respiratory, feeding, other (sometimes different companies provide different things)

Ortho: dislocated hips, scoliosis, fractures?

Hearing:

Vision:

Social: Where do parents live? Who is at home with him/her? How far away from hospital/clinic?

Home nursing? Hours?

School?

Things he/she enjoys:

Goals of care: What are your worries about your child, what are your hopes?

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