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Technology Dependent Children

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Introduction:

Hi everyone! My name is Sara and I am a third-year medical student at the University of Ottawa. This podcast was developed with the support of Dr. Nathalie Major, a complex care pediatrician at the Children's Hospital of Eastern Ontario. Today we will be talking about children with medical complexity and focusing on a subset of these children who are technology dependent.

The objectives of this podcast are to:

1) Define children with medical complexity
2) Define technology dependence and list examples of the most commonly used technologies
3) Describe an approach to the assessment of a child with medical complexity and technology dependence
4) Describe the impact of caring for a child with medical complexity on the family

Case:

Let's begin with a case. You are a third-year medical student on your pediatrics rotation, and you are spending a few days rotating with the complex care team. On your first day with the team, your preceptor asks you to see Kate, a five-year-old girl with cerebral palsy with medical complexity and technology dependence, who is presenting to the clinic with her parents for a health surveillance visit. Trying to remember what these terms mean; you decide to quickly look over Kate's chart before going to see her.

While looking through her chart, you notice a document on file called a 'care plan'. You realize that this is a summary document created for Kate in collaboration with her parents and healthcare team which provides an up-to-date summary of her medical history and treatment plans. From her care plan, you learn that Kate has cerebral palsy as her primary diagnosis and several secondary diagnoses and associated conditions including epilepsy, obstructive sleep apnea, dysphagia as well as gastroesophageal reflux disease which has resulting in feeding issues, visual impairment, hearing loss,

intellectual disability and is non-communicative. She has over 10 different medications to manage her medical conditions.

Kate has limited mobility. She uses a wheelchair for the majority of the day; however, she occasionally will stand and walk for short distances using an assistance device like a walker with the assistance of a caregiver. She requires feeding through a gastrostomy tube (G-tube). Kate wears glasses for vision and has cochlear implants to help with hearing. She has difficulty with speech and communication and has recently began to work with a speech language pathologist to use an electronic communication board.

With this information, you head to the appointment. Where should you begin? How are you going to be able to cover everything in the allotted time of 30 minutes? What is your role and the team role in the care of Kate? We will return to this case at the end after reviewing our learning objectives.

Describing Children with Medical Complexity (CMC)

Children with medical complexity (CMC) share four defining characteristics:
  i)   one or more complex chronic conditions (lasting >6 months) that are often multisystem and severe;
  ii)   a functional limitation that is often significant and causes the child to be reliant on technology, such as feeding tubes and tracheostomies;
  iii)   a high index of healthcare utilization, requiring specialized care and services from different providers in multiple settings; and
  iv)   high healthcare services needs, such as care provision in the home and care coordination.[1]

Often, a caregiver, which is inclusive of a parent, frequently becomes the primary healthcare provider, which can lead to significant impacts to the family including both financial and emotional. It is important to recognize that there is high healthcare service need not just in the hospital but also in the community, including home and school supports – essentially wherever these children go, they will require support. Additionally, the experience of caring for a child with CMC can result in families feeling emotionally and socially isolated, exhausted, experiencing many stressors (for example, financial, the fear of losing their child, and post-traumatic stress disorder) and so caregivers and other family members may need support including healthcare services to help with coping.

Patterns and cost of health care use of children with medical complexity has shown that children with medical complexity account for a large proportion of healthcare spending. In Ontario, less than 1% of children fit the definition of children with medical complexity, and technology assisted of high intensity, yet this population accounts for ~32% of child healthcare costs.[2]

Challenges in providing care to CMC include fragmented care and caregiver burnout. Care models have focused on providing patients and their family, family centered care and care coordination, and really working with families to achieve their goals of care.

Defining what it means to be 'Technology Dependent'

There is a large variability of technologies on which these children rely, including support for respiration such as ventilation and oxygen, nutrition such as gastrostomy tube, and renal dialysis. Additionally technologies may be required to enhance mobility such as walkers , hearing through use of hearing aids, cochlear implants and communication for example electronic communication boards.[4] Put simply, a technology in this context is anything that the child uses to compensate for loss of function and to help them meet their activities of daily living[3]. This represents one of four criteria that defines this population along with chronicity, and medical complexity.

Technology dependent and/or users of high intensity care children are a subset of children with medical complexity who use technology intermittently, at least part of each day, or permanently, such as mechanical ventilators and/or prolonged intravenous administration of nutritional substances or drugs or other device-based support such as tracheostomy, oxygen support, tube feeding to compensate for vital bodily functions, and requires daily or near daily nursing care.[3] It is also important to consider children who are not necessarily technologically dependent but who have any chronic condition that requires as great a *level of care similar* to the above group, such as [2]:
- Children who, as a consequence of their illness, are completely physically dependent on others for activities of daily living at an age when they would not otherwise be so dependent
- Children who require constant medical or nursing (or delegate with competency) supervision or monitoring resulting from the complexity of their condition and/or the complexity of medication administration and/or the quantity of medication and therapy they receive

Commonly used Technologies

Two commonly used technologies are respiratory, and nutrition supports, each will be discussed in more detail. It is not possible to cover all the different types of technologies used by children and their indications in the scope of this podcast, each one could be a podcast in and of themselves! For those who are interested in more information, check out the Tracheostomy care Handbook from Cincinnati Children's Hospital Medical Centre[10] and Guidelines for the Administration of Enteral and Parenteral Nutrition in Paediatrics from The Hospital for Sick Children.[11] I've also included additional resources in the reference section.[12-14]

Respiratory support technologies are used to reverse or ameliorate the cause of respiratory failure. Home ventilation can be classified into three main categories: oxygen, non-invasive ventilation (i.e. CPAP, BiPAP) and invasive ventilation that is delivered through a tracheostomy. It should be noted that not all children with tracheostomies require ventilation; a tracheostomy may be required for airway patency. Conditions that warrant home ventilation include airway problems like obstructive sleep apnea, pulmonary parenchymal problems like chronic lung diseases, respiratory drive problems like congenital central hypoventilation syndrome and other respiratory problems such as neuromuscular weakness and chest wall deformities.[5] The choice of home ventilation depends on the underlying etiology of the child respiratory failure and each has its own guidelines for use.

Nutritional support in the form of enteral nutrition is initiated when children are not getting the appropriate nutrition for growth and maintenance from oral intake. Enteral nutrition can be provided in different forms, for example a gastrostomy tube (G-tube) or a gastrojejunal-tube.[5]

Approach to caring for a child with CMC

Learners, especially medical students on the wards for the first time, may feel overwhelmed when asked to see a child with medical complexity, especially if that child is also technology dependent. Learners may benefit from using a six-step approach to help them in assessing a child with medical complexity. [8] The 6 steps can be used for as a general approach but the specific actions for each step may need to change depending on the circumstances of the visit (for example, there is a difference between a brand new intake for a complex care child versus a surveillance visit or doing rounds during a new hospitalization).

1) Preparation
   ● Before going to see the patient, it is important to find out if the child has a medical care plan and to review this plan as well as their medical history in advance of the encounter
   ● If you are seeing this child for the first time, it can be helpful to read up on their conditions, especially if the conditions are rare and not something that has been covered within the curriculum. Two examples of resources to find good information are Rare chromosome.org (https://www.rarechromo.org/) and gene review (https://www.ncbi.nlm.nih.gov/books/NBK1116/)
   ● If the child is using technologies, it is helpful to read up on the technology prior to seeing the child so that you as the learner are familiar with indications for use.

2) History taking
   ● This all depends on the circumstances of the reason for the assessment
   ● It is important that you have access to old charts before the visit
   ● You should take a history like you would for any other patient – identify why the patient is coming to see you and their main concerns.

- When taking past medical history, whether for hospitalization as a new patient for the team, or for a new intake, **verify** the information rather than asking for all these details as if unknown. If you have prior access to charts, this demonstrates to the caregiver that you have taken time to get to know their child prior to the encounter. It can be very frustrating and difficult for caregivers to have to repeat their child's history over and over.
- Make sure to briefly review the child's PMH, FHx, Social Hx, Developmental Hx, Medications Hx and Vaccination status to determine if there are any changes from the care plan, and then do a ROS, using either a head to toe or a system by system approach. When doing the ROS, focus on the most concerning issues and look for any red flags
- There are also 'special items' that need to be considered during history taking, which will differ depending on the nature of the visit:
  - Technologies
    - For a new intake, you may want to discuss with caregivers what is meant by 'technologies' as well as potential technologies that their child may need
    - If the child is already using technology, it is important to ask if there are any issues with technologies, and re-evaluate the need for the technology if this is a child who you have previously seen. Verify current settings and schedules for these supports.
  - Support
    - Always make sure to assess the need for caregiver support and specifically for technology, assess their need for additional training on technology use or support with managing technology in the home
    - Financial support should also be discussed
  - School
    - It is also important to ask about school entry needs for the child, which becomes very important in terms of assistance with managing technologies at school
    - If the child is a new intake, then you should discuss with the family what school looks like for their child, the services they will be able to access while at school, and any concerns they may have
    - If a child is hospitalized, you should discuss with the caregivers who is responsible for calling the school to stop the in-school services

3) Comprehensive physical exam
- It is important to do a baseline physical exam with special focus on areas of concern
- Remember not to be shy to ask if you may take the child out of the wheelchair. You should consider comfort of the child (for example, does moving cause them distress or pain), and you should first find out if you will need two people assistance

- If hospitalized, always ask if they need special equipment for the bed
- It is a good idea to ask the caregiver the best way to examine the spine, hips, etc.

4) Identify needs and goal setting
- This is a very important step and it is important that goal setting is adapted to the circumstances of the visit
- For an acutely ill child, you will want to know goals of care if it is not clear in the chart
- If the child is hospitalized, you want to know what the criteria for discharge are from the caregiver perspective
- If it is a health surveillance visit, you will want to review the goals previously identified and any new ones as well and be sure to cover the next steps before the family leaves
- It is usually helpful to identify expectations; setting priorities ensures that the visit will be in line with the goals of care for the child
- Always time yourself and acknowledge that you might not be able to address everything at once and may need to break things into smaller chunks

5) Develop a care plan and roadmap
- In some cases, the care plan may already exist and you may wish to review it with the family and update as needed
- In other cases, you may identify that a care plan is needed and should work with the family to develop one
  - o Components of a care plan include: the child's name, address and contact information for the child's caregivers, advance directives, emergency management plan, growth data (weight, height, head circumference), the child's diagnosis, current issues, medications, allergies, a list of technology supports, diet, social history, developmental/functional status, immunizations, services and a list of all providers (including their contact information) who are involved in the child's care. An example of a "standard medical care plan" can be found here: http://www.pcmch.on.ca/wp-content/uploads/2017/07/PCMCH-CCKO-Medical-Care-Plan-Standard.pdf
- It is important to educate yourself on the services involved in the child's care, not just other sub-specialists but services in the community, home and school, so that you can work with caregivers in providing a smooth delivery of services to reduce their burden

6) Update medical summary and make any necessary changes to the care plan

Impact of caring for a child with CMC and technology dependence on families

Caring for a child with medical complexity can lead to a difficult experience for caregivers as often they are expected to take on the role of coordinating their child's

care in a system with many barriers, which makes the process difficult.[9] It is important to ask the caregivers how they are doing. Some questions to ask include:

- I know that there is a lot to think about in relation to your child's care. How are you doing?
- How are you coping with everything going on?
- How does your child's illness/condition impact you? And the rest of the family?
- Tell me what a day looks like for you and your family?
- When do you take time for yourself?
- Do you have a support system in place? If so, who? If not, let's discuss why not and see if we can work together to start building one.

Sometimes we won't always have the answer or a solution. However, acknowledging a family's concerns and allowing them to talk about their experiences goes a long way. Simply listening and being aware of the struggles these families go through can make a big difference.

It is important to note that we often see children with medical complexity and their families when their child is sick, which is a difficulty time. But it is important to remember that these children and families can have happy lives. This is where asking about goals of care can help with ensuring families have the best quality of life possible by helping them to achieve goals that are meaningful to them.

Back to the case

Let's return to our case. What, ultimately, is your role in caring for Kate and how should you go about approaching the appointment?

- Using the 6-step approach will help to keep the appointment focused and ensure that Kate's priority issues will be covered in this visit; you can use the 6 steps to guide you as outlined below:
  - o i) Before going to see Kate, you will have ideally read through her care plan and have familiarized yourself with her medical diagnoses, especially the rarer ones
  - o ii) and iii) Complete a thorough history and physical exam
  - o iv) Ensure that you set goals for the visit; ideally since Kate is dependent on technology, it is important to ask her parents if there are any concerns and discuss future plans for the use of technologies.
  - o v) Review Kate's care plan with her family and make sure that all the information is up to date
  - o vi) Make sure you update Kate's medical summary at the end and make any necessary changes
- You want to ensure you are treating Kate's care like you would any other child, ensuring that you are promoting normal growth and development and preventive services, including vaccinations, review of their medications, screening and anticipatory guidance.

- The closure of the interview is also very important
  - You should acknowledge the goals and at the end verify the information
    - A good way to say this is "These are the issues we have identified; the next steps are; is there anything else?" If there are, then we need to make a plan of how to next address

Review of key learning points

To wrap up, let's go back to our objectives and review a few of the key points discussed in this podcast:
- i) We reviewed the definition of children with medical complexity, recognizing that children with medical complexity share four defining characteristics: chronic conditions, functional limitations, increased healthcare use and increased needs such that parents are often caregivers and navigators.
- ii) Technology dependence (of high intensity) children can be defined as a subset of children with medical complexity who use technology temporarily or permanently to compensate for vital bodily function and need for support.
  - Common technologies include ventilation, gastrostomy tubes, renal dialysis; other technologies for the larger group to assist with activities of daily living include assistive device such as walker, glasses, hearing aids, and electronic communication boards
- iii) When approaching cases of CMC, it is helpful to use a 6-step approach that focuses on addressing one to two key issues per visit and providing care that is in line of the goals of care for the child and their family
- iv) Caring for a child with medical complexity can be a difficult experience for parents and caregivers. Read/know the child's history before meeting them. Acknowledge the caregiver's concern. Listen to them and their experiences. Simply listening and being aware of the struggles these families go through can help in building a trusting partnership with caregivers and ultimately will lead to a better experience for children and their families.

Thank you for listening to this podcast on children with medical complexity and technology dependence. We hope you enjoyed this episode!

References

1. Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, et al. Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. Pediatrics [Internet]. 2011 Mar 1 [cited 2016 Dec 7];127(3):529–38. Available from: http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.2010-0910

2. Cohen E, Berry J, Camacho X, Math M, Anderson G, Wodchis W, Guttmann A. Patterns and Costs of Health Care Use of Children with Medical Complexity. Pediatrics 2012;130: e1463-70

3. Glader LJ, Palfrey JS. Care of the child assisted by technology. Pediatrics in review. 2009 Nov 1;30(11):439.

4. Haffner JC, Schurman SJ. The technology-dependent child. *Pediatr Clin North Am.* 2001;48:751–762.

5. Gulla, K. M., Sahoo, T., & Sachdev, A. (2019). Technology Dependent Children. International Journal of Pediatrics and Adolescent Medicine.

6. Lawrason, A., & Kavanagh, K. (2013). Pediatric tracheotomy: are the indications changing?. *International Journal of Pediatric Otorhinolaryngology*, 77(6), 922-925.

7. Hayes Jr, D., Wilson, K. C., Krivchenia, K., Hawkins, S. M., Balfour-Lynn, I. M., Gozal, D., ... & Abman, S. H. (2019). Home oxygen therapy for children. An official American Thoracic Society clinical practice guideline. *American journal of respiratory and critical care medicine*, 199(3), e5-e23.

8. UP-to-Date: Children and youth with special health care needs. Dennis Z Kuo, MD, MHSRennee M Turchi, MD, MPHS Section editors: Teresa K Duryea, MDCarolyn Bridgemohan, MD Deputy Editor: Mary M Torchia MD. https://www.uptodate.com/contents/children-and-youth-with-special-health-care-needs/abstract/4

9. Dewan, T., & Cohen, E. (2013). Children with medical complexity in Canada. Paediatrics & child health, 18(10), 518-522.

10. Tracheostomy care Handbook: Cincinnati Children's Hospital Medical Center (updated: August 2015). Retrieved from http://www.cincinnatichildrens.org/assets/0/78/847/877/db29d0e9-5b1f-4af3-ae9c-7b1088a04f0c.pdf

11. Guidelines for the Administration of Enteral and Parenteral Nutrition in Paediatrics: The Hospital for Sick Children--SickKids, Toronto (June 2007). Retrieved

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from https://www.sickkids.ca/pdfs/Clinical-Dietitians/19499-Enteral_Parenteral_Nutrition.
pdf

12) Care of the Child with a Chronic Tracheostomy: American Thoracic Society Official
Statement(February 2013). Retrieved
from https://www.respiratoryupdate.com/members/login.cfm?hpage=ATS-Official-State
ment-Care-of-the-Child-with-Chronic-Tracheostomy.cfm

13) Soscia, J., & Friedman, J. N. (2011). A guide to the management of common
gastrostomy and gastrojejunostomy tube problems. Paediatr Child Health, 16(5),
281-287.

14) Sherman et al (2000). Care of the child with a chronic tracheostomy. This official
statement of the American Thoracic Society was adopted by the ATS Board of
Directors, July 1999. Am J Respir Crit Care Med, 161(1), 297-308.
doi:10.1164/ajrccm.161.1.ats1-00