



Health care transition for children with medical complexity: Challenges and lessons learned

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ABSTRACT

Background: Transition from pediatric to adult health care is a pivotal process for young adults, especially those with complex medical needs. Despite advancements in the medical care provided to children with medical complexity (CMC), there is a lack of systematic approaches and guidance for patients and families transitioning from pediatric to adult health care.

Methods: Health care providers and nurse case managers in the Complex Care Program (CCP) evaluated health care transition practices prior to 2019, and initiated quality improvement efforts to standardize transition guidance, planning, and documentation from 2019 to 2020 within the CCP.

Findings: Challenges identified with transitioning CMC include: 1) Varied approaches and timelines for health care providers, 2) Documentation in the EMR, and 3) Connecting to adult health care systems. Throughout this work, CCP staff have learned lessons to effectively transition CMC. Themes included: 1) Transition from a pediatric to an adult primary care provider first, 2) Start transition conversations early, 3) Identify a universal location to document transition planning, and 4) Importance of family involvement.

Implications for practice: To effectively transition CMC, health care staff must start conversations early, engaging all primary and specialty providers, patients, and families to create safe transition plans.

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Transition from pediatric to adult health care is a pivotal process for young adults, especially those with complex medical needs. Due to advances in medical care and technology, life expectancies for many chronic conditions have increased over the years (Berens et al., 2020). Despite these advancements, there is a lack of systematic approaches and guidance for patients and families transitioning from pediatric to adult health care. Due to the intricacy involved in health care transition (HCT), current guidance is for transition planning to begin at age 12 (Got Transition, 2021).

While HCT for patients with a single chronic condition has challenges (Berens et al., 2020; Kim & Ye, 2019; Smith et al., 2019), children with medical complexity (CMC) have increased risks of fragmented care, sentinel events, and difficulties accessing appropriate adult health care resources due to the number of different medical specialists involved (Cohen et al., 2011; Jolly, 2015; Kuo et al., 2018). The aim of this article is to share challenges identified and lessons learned transitioning CMC to adult health care.

History of complex care program and transition

Children's Wisconsin is an urban Midwestern free standing 306 bed facility that also has urgent care, primary care, and tertiary care with over 40 specialties. The Complex Care Program (CCP) at Children's Wisconsin historically known as the Special Needs Program, was developed in 2002 (Gordon et al., 2007). The CCP is comprised of an interdisciplinary team that provides care coordination and medical co-management services to CMC (Corden & Bartelt, 2020). Each patient has an interdisciplinary team consisting of a health care provider (Physician or Nurse Practitioner), Nurse Case Manager, and a Care Coordination Assistant (for additional information on the CCP, please see Corden & Bartelt, 2020). To qualify for enrollment in the CCP, patients must have three or more chronic conditions involving at least three organ systems and requiring three or more medical specialists, have one or more unplanned hospital stays lasting longer than five days, or have at least ten specialty clinic visits during the last year. Currently the program has approximately 700 patients; 20% are twelve years old and older.

In 2014 Children's Wisconsin developed resources for transitioning children and youth with special health care needs (CYSHCN) to adult care, including a policy and procedure, teaching sheets, and transition flowsheet within the EMR. In 2019 a health care transition (HCT) team within the CCP was created after being awarded a quality

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improvement (QI) grant focusing on health care transition utilizing a shared plan of care (SPoC) through Children's Health Alliance of Wisconsin's Medical Home Initiative. This QI grant was awarded again for the 2020 year. The HCT team was comprised of three nurse case managers, a nurse practitioner, a social worker, a parent representative, and members from the local regional center for CYSHCN (Wisconsin Department of Health Services has five regional centers dedicated to supporting families with CYSHCN and those involved in their care). This team met monthly to identify best practices based on review of the literature, family input, and professional experiences. We conducted Plan, Do, Study, Act (PDSA) cycles to guide the creation and implementation of transition tools that were later shared with the entire CCP. Three nurse case managers and a nurse practitioner continue to meet on a monthly basis with periodic collaboration with former HCT team members.

Challenges transitioning CMC

Varied approaches and timelines for health care providers

Transition conversations and planning within the CCP varied significantly prior to Fall 2019 and was dependent on the knowledge and background of the patient's CCP team. Most providers and nurse case managers discussed transition around the age of 17–18 most commonly due to the urgent need of guardianship or shared decision making. Occasionally during a hospital admission, it was found that patients at the age of 18 did not have guardianship. This forced the CCP, including social work, to urgently fill out required paperwork and navigate the legal system. Once the legal needs were addressed, members of the CCP would start or continue the logistics of creating a safe transition plan from pediatric to adult care.

When discussing patients in the CCP with primary and specialty providers, we realized the differences in approaches between each specialty, specific diagnoses, and providers within a given specialty. In January of 2019 we reached out to the manager of each specialty clinic to learn about their transition practices. Some specialties had a strict age cut off of 18 years, while others had no transition guidelines. Within specialties, some programs for specific diagnoses had formalized processes for transfer of care, including cystic fibrosis and diabetes. Many pediatric primary care providers (PCPs) offered to keep patients into their 20s, while others offered to follow them indefinitely.

Varied approaches between providers of CMC leads to more fragmented care, causing parental confusion, anxiety, and safety concerns given partial transfer of care. Questions arise regarding who would serve as the medical home, what type of facility would CMC be admitted (pediatric or adult depending on reason for admission), and how communication would occur between different providers or institutions. Typically, a PCP serves as a patient's medical home. For CMC, if their specialists are at an adult facility, their pediatrician may not be able to facilitate admission. Without a medical home that has access to a patient's specialty care providers, there is a higher chance for issues regarding continuity of care (not having necessary medications, supplies or equipment, and ineffective management of multiple chronic conditions).

Documentation in the Electronic Medical Record

An electronic medical record (EMR) provides opportunity to document and share patient information with people within a health care system and external health care systems with the same EMR. While having an EMR provides opportunities to share critical information regarding HCT planning, there are numerous places and inconsistencies of where people can document this information. In 2014 a transition flowsheet was created at Children's Wisconsin that could be accessed in different areas of care to document what transition education was provided, when patients could verbalize understanding of their health

conditions and medications, and when other key aspects of transition had been completed. When we evaluated this flowsheet with patients enrolled in the CCP in 2019, we found that no specialties including the CCP had utilized this tool. If transition planning was documented, it was found in a clinic note, telephone encounter, or other locations outside of the EMR. Without a central location of documenting transition status in the EMR it is difficult for care teams to discern plans and next steps.

Connecting to the adult health care system

Some pediatric health care facilities have affiliations with adult health care facilities. At Children's Wisconsin, patients have multiple adult health care systems to choose from. While it is beneficial that patients have different options, this can cause challenges such as identifying providers and understanding workflows within different health care systems. For our patients who live far from Milwaukee, it is often best to have adult health care closer to home.

It has been difficult to connect with adult providers who are willing to care for CMC. Parents look to the CCP for recommendations for adult providers; however, we often do not have them. There is no CCP program in the adult world to help with the transition process. We were able to connect with a local Med/Peds provider who shared a list of local Med/Peds providers that might be willing to care for CMC, however many of these providers had limited to no availability for new patients.

Lessons learned transitioning CMC

Transition from a pediatric to an adult primary care provider first

Prior to starting the transfer of specialty care, we have found it beneficial to transition the PCP first. Some care that was provided by pediatric specialists may be able to be managed by adult PCPs, especially if it is a Med/Peds provider. This has included tube feedings, reactive airway disease, hypothyroidism, adrenal insufficiency, chronic pain, and mild obstructive sleep apnea. It is important for families to communicate with the adult PCP to determine what level of care they are comfortable providing and what would need to be managed by an adult specialist.

Adult PCPs have knowledge of and relationships with many adult health care specialists and can help to facilitate this transition easier than a pediatric PCP can. We have found this is especially true for patients who live in rural areas or are out of state. One example we experienced was transitioning a patient who lived in a different state to local adult health care providers. Family was able to identify a Med/Peds provider in their area. Members of his CCP team had multiple conversations with his Med/Peds provider throughout the transition process about what she would feel comfortable managing and what would require adult specialty care. She was able to facilitate referrals to adult specialists, talk with their local hospital, and ensure that there was appropriate management for all his chronic conditions. If we had not found this PCP we would not have been able to transition him in a safe and timely fashion, putting him at high risk for lapse of care.

Start transition conversations early

Transition from pediatric to adult healthcare is a major milestone. When providers start discussing HCT at age 12, family has time to mentally prepare for the transition and allows health care providers time to develop a clear transition plan. Some families have shared that their transition plan is to not transition to adult specialists but to stay with their pediatric providers indefinitely. Many parents feel that if they do not bring up transition, their chances of remaining in a pediatric health care system is higher. Health care providers need to take ownership of starting these conversations. Starting HCT conversations early provides

flexibility on how detailed the transition conversation needs to be at each visit. It often takes several conversations with specialists to develop a transition plan and to get buy in from the patient's entire care team. Since CMC are followed by multiple specialists, this process is more complicated and takes longer to create safe plans. There are many components related to transition that are outside the health care system that take time such as guardianship and developing a plan for what will take place after high school. It is imperative to allow time for transition planning to allow for a smooth and safe transition. Although other aspects of transition may not appear to directly impact HCT planning, it can impact the overall success of patients and families to adjust to adult care and in turn can impact their physical health and medical compliance.

Identify a universal location to document transition planning

To help others in the health care system identify transition age patients, CCP providers began adding ICD 10 code Z71.89 Counseling for Transition from Pediatric to Adult Care Provider to the problem list for patients ages 12 and older. This led to conversations between different specialties regarding planning for HCT. Audits have revealed that 57% of transition age CCP patients had this diagnosis in the problem list.

In Fall 2019 the CCP added transition to our shared plan of care (SPoC) after conducting PDSA cycles with three families (see Appendix A). This offered a central location to see each specialty's plan for transition. Inclusion of transition in the SPoC as of April 2021 was approximately 47%. Information in the SPoC regarding transition could include age at which transfer will happen, if the patient's adult PCP could manage or if an adult specialist was needed, and if there were recommendations for a specific provider to take over management. CCP SPoCs are updated every six months by the patient's primary team and are shared with medical providers involved in the patient's care in addition to the patient's family. While utilizing a SPoC can improve communication between multiple stakeholders, it requires CCP providers to reach out to specialists or chart review to be able to include updated information. The information in the EMR can only be accessed by looking at the most recent CCP note, or by a printed version for families every six months. This also does not address CMC who are not followed by the CCP.

A universal flowsheet within an EMR would be a helpful central location with access to all specialists involved in his or her care. While a flowsheet created by Children's Wisconsin in 2014 allowed for centralized documentation, it did not easily address the needs for CMC, especially those with neurologic impairments. Members of the CCP are currently evaluating this flowsheet to offer edits to address these populations.

Creation and utilization of dot phrases (predeveloped text that can be easily placed in a note or after visit summary) have been found helpful for documenting pre-anticipatory guidance for patients and families (see Appendix B). Dot phrases were developed by the CCP HCT team as one way to standardize the transition process. The dot phrases we created were based off timelines supported by Got Transition. Our dot phrases focus more on patients who will require guardianship or significant support from their families, whereas Got Transition addresses many patients who do not require this level of support. The CCP utilization of transition dot phrases since August 2019 has increased from 43% to 68%. These dot phrases have been shared with a transition committee within Children's Wisconsin and have been distributed to these members. There are ongoing discussions on if these dot phrases would be beneficial for other specialties to use and have access to.

Importance of family involvement

The thought of transitioning one's child's care from pediatric to adult care is often a very stressful and daunting process for families. Often

families have built strong, trusting relationships with their child's pediatric providers and the thought of starting over is not something most do eagerly. Due to needing family buy-in for this process, and the need to make the transition to adult health care as stress free as possible, family involvement is crucial. The CCP HCT group felt strongly that parents within the CCP need to give input on the process of transition and give honest opinions on how best to address the intimidating process.

The parent representative involved in our HCT team has a child who is in the process of HCT. This parent has been involved in all large group meetings and has given invaluable insight on the process of transition from a parent's point of view. This parent has given our group "lessons learned" in her own transition process to help us better understand how to help other families. For instance, this parent wished she would have looked for an adult PCP sooner in the transition process. In addition, this parent and her child had the opportunity to attend a joint visit between her current pediatric neurologist and their new adult neurologist. The parent found this experience extremely helpful in the transition process and felt that it was necessary for other families to know that this can be requested, although not always possible.

The CCP HCT team has included the CCP family advisory committee in our process to improve HCT. Once dot phrases were developed, they were brought to the family advisory committee to receive feedback. The family advisory committee gave input on how to best engage families in the transition process.

The Wisconsin Regional Centers for CYSHCN have facilitated presentations with families of CYSHCN regarding HCT in the past. Families of CMC shared that this presentation did not fully address their needs due to their child's medical complexity and neurologic impairments. In response to this feedback, families assisted in the development of new educational materials for families of CMC. A seminar given by Wisconsin Regional Centers for CYSHCN was constructed with the help of the CCP HCT and parents of CMC. The seminar titled "Dreaming Differently" was available for all families interested in attending and focused on preparing families with CMC with neurologic impairment for HCT.

Overall, the participation of families in developing a standardized process for HCT has been priceless. Having personal insight on how to ease stress in an important milestone of their child's life has driven the CCP HCT team in their efforts. Many families in the later transition age (17+) often expressed that they wished they would have started the conversation sooner. Knowing how important this is to families, the CCP now starts HCT conversations at the age of 12. Many families who are new to the transition process are often shocked when this topic of conversation is discussed so young but quickly learn that they needed this time to process this large undertaking.

Implications for practice

Practitioners in multiple practice areas can apply the lessons we learned from transitioning CMC to adult health care. For example, this can be used for condition specific programs such as cerebral palsy and cystic fibrosis. These approaches will also be helpful for primary care providers managing adolescents as they near adulthood. HCT is most successful when all members of the adolescent's care team work towards the united goal of safe transition to adult health care.

Conclusion

The process of transitioning CMC from pediatric to adult health care is a complex and daunting process, requiring early planning and collaboration between health care teams, patients, and families. Having a structured workflow in the CCP has aided in earlier conversations

and creation of safe transition plans for CMC. Although these efforts have improved transition practices within the CCP, it is not yet standard practice for the entirety of the program. Identification of remaining barriers to implementation will be necessary to optimize the transition of CCP patients. Ongoing work is needed to evaluate transition processes within different specialties and to identify best practices to create an organizational approach to safely transition CMC to adult health care.

Authorship statement

All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the manuscript. Furthermore, each author certifies that this material or similar material has not been and will not be submitted to or published in any other publication before its appearance in the *Journal of Pediatric Nursing*. All persons approved of the final submission.

Appendix A. Complex care program – shared plan of care by systems

SYSTEM/TOPIC	Problem/Issue	Plan/Suggestion	Provider Responsible	Pending	Transition (≥12 years old)
General	General Health	Follow up for general pediatric health care needs	David Smith, MD		Transition to Joseph Langdon MD (med/peds provider) before 17 years old
Patient and Family Goals	To avoid hospitalization To develop safe transition plan to adult health care				
ENT	Tracheostomy dependence	No changes with tracheostomy Follow up in 6 months	Amy Jones, MD	Follow up July 2021	Transition to adult ENT at 18 years old
GI	G-tube dependence Constipation	No changes made to feeding regimen. Increase miralax to 17 g daily and senna to 5 ml BID Follow up in 6 months	Tim Button, MD	Follow up May 2021	Discuss potential management by adult primary care provider
Orthopedics	Neuromuscular scoliosis s/p posterior spinal fusion	Follow up with repeat x-rays in 6 months	Amelia Femur, APNP	Follow up May 2021 with spine x-rays	Will stay with pediatric provider indefinitely
Physical Medicine & Rehabilitation	Spastic quadriplegic cerebral palsy Wheelchair dependence	Continue botox to lower extremities every 3 months New orders sent for wheelchair to DME	Jack Bacló, MD	Botox injections February 2021	Transition to Felicia Stander DO between 18 and 20 years old
Pulmonary	Chronic lung disease	Continue twice daily respiratory treatments when well, increase to every 4 h when sick. Follow up in 6 months	Juniper Inhaler, MD	Follow up July 2021	Transition to adult pulmonologist at 18 years old

Appendix B. Transition dot phrases by age

Age 12–14

Transition Planning.

- Start thinking about where you would want to transition health care to (closer to home, in the Milwaukee area, etc).
- Please contact or visit the regional center for Children and Youth with Special Health Care Needs to learn more about resources regarding transition to adulthood.

Southeast Regional Center

Family resource center – Children’s Wisconsin (Milwaukee Campus)
 Website: <https://www.southeastregionalcenter.org/Southeastregional>
 Email: serc@chw.org
 Phone: 800–234-KIDS(5437).

Age 14–16

Transition Planning

- Choose what location/health care system you would want to transition to.
- Ask your pediatrician how long they will continue to follow you and if they have recommendations for an adult primary care provider.
- Start talking with your specialists about transition.
- Ask school about transition coordinator and request transition plan. If home schooled, contact regional center for guidance.
- Please contact or visit the regional center for Children and Youth with Special Health Care Needs to learn more about resources regarding transition to adulthood.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Age 16–18

Transition Planning

- Identify what location/health care system you would want to transition to and get connected with an adult primary care provider.
- Ask current specialists for recommendations for adult specialty providers.
- Ask school about transition coordinator and request transition plan if not already in place. If home schooled, contact regional center for guidance.
- At **17 years and 6 months**, apply for guardianship or supported decision making. If you have questions, please contact the regional center or ask your child's social worker.
- At **17 years and 6 months**, consider connecting with your local aging and disability resource center (ADRC). You can receive more information at the regional center.
- Please contact or visit the regional center for Children and Youth with Special Health Care Needs to learn more about resources regarding transition to adulthood.

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Age 18 and older

Transition Planning

- Ask current specialists for recommendations for adult specialty providers if not already completed, and ask when the last visit will take place.
- Start attending appointments with adult primary care provider and specialists.
- Ask school about transition coordinator and request transition plan if not already in place. If home schooled, contact regional center for guidance.
- If guardianship or supported decision making has not been done, please contact the regional center or ask your child's social worker for help.
- Consider connecting with your local aging and disability resource center (ADRC). You can receive more information at the regional center.
- Please contact or visit the regional center for Children and Youth with Special Health Care Needs to learn more about resources regarding transition to adulthood.

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