THE TRANSITION TO ADULT MEDICAL CARE FOR PEDIATRIC PATIENTS WITH COMPLEX MEDICAL CONDITIONS

Understanding the Barriers and Unique Needs

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The transition from pediatric to adult care for patients with chronic and complex medical issues is essential and yet fraught with gaps, both in terms of medical needs and community needs. While the topic has gained interest in the last 20 years, published literature has focused specifically on the pediatric population with chronic and complex needs rather than on methods of transition. Studies typically focus on one disease and/or population, which can make data or conclusions regarding this transition hard to generalize to all complex pediatric patients.

Transition remains a novel concept to many practitioners, and there are as yet no systematic or accepted transition methodology used and understood by pediatric and adult health care providers.[1] This article seeks to summarize the current literature and our initiatives at LGHP Roseville Pediatrics.

“Transition” is very different from a “transfer” of care.[2] While a transfer simply refers to a suggestion or referral to an adult-care physician following medical emancipation from their pediatric-care provider, *transitioning* involves an educational process that should start early in adolescence and continue until after the care has been initiated with an adult-care provider.[2]

The American Academy of Pediatrics historically has defined this transition as “the deliberate, coordinated process of moving a patient from pediatric-oriented health care to adult-oriented health care with the goal of optimizing the young adult’s ability to assume adult roles and function.”[3] The goal of health care transition is the maximization of “lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.”[3]

BARRIERS IN ACHIEVING A SMOOTH TRANSITION

Each pediatric patient with chronic disease is unique, and the transition process for children with disabilities can be challenging. A study examining patients with chronic conditions that had aged out of a pediatric special needs program demonstrated that 65% had had a poor transition experience as defined by occurrence of at least one of the following: loss of a consistent source of care, a missed or postponed appointment within the preceding six months, and/or loss of or a gap in insurance coverage.[4]

Pediatric-Specific Diseases

Lack of familiarity with pediatric-specific diseases, as well as a paucity of providers with the training to care for pediatric-specific diseases, challenges the medical transition of these patients. Adult physicians are not always up to date on the current treatments for the pediatric diseases with which their transitioned patients present, creating a potentially less-than-ideal situation for these patients.[1]

Adult-care providers have indicated feeling uneasy with the possibility that patients may be in the end stages of their disease and require a level of care outside of their scope. Concurrent psychosocial issues may also cause apprehension for physicians who are accepting these new patients.[5]

In a study of 112 eligible internists, participants ranked concerns associated with the care of transitioning complex patients (see Table 1 on page 37). The listed fears broke down into six main categories: psychosocial care, patient maturity level, dealing with family, being medically competent to treat the pediatric disease, orchestrating the transition with the pediatric team, and dealing with the health care system.[6]

When the relative frequency of each category was tallied, the fear of being incompetent to treat foreign childhood-specific diseases was at the top, along with the fear of waning family involvement in care, inability to understand and address the psychosocial needs of the patients, how to find a superspecialist, not having experience with adolescent medicine or needs, having to mediate end-of-life care with a patient they barely know, and mediating the expectations of the families, all while facing the financial burden of the extra time required for this unique care.

The conclusion of the paper was that internists require training that affords them increased understanding and familiarity with pediatric onset conditions.[6] Contrary to what some may assume, the article demonstrated that the adult-care physicians appreciate having family support. This suggests that the role of the family should not be phased out upon completion of the transition.

Lack of Communication

Even when there are willing internists to receive transitioning patients, a lack of communication and/or trust between pediatric- and adult-care providers can often be an additional challenge. Communication between pediatric- and adult-care providers was noted as a key factor in the success of a transition; adult-care doctors need to know specifics about their own patient's condition and the history of that condition.[7]

A related study revealed that adult-care physicians appreciate having those patients who are entering their practice arrive with a medical summary or accompanied by a phone conference with the patient's previous pediatrician.[8]

Conversely, a lack of communication between pediatric- and adult-care providers can cause a downstream ripple effect in which the parents and/or the patient are challenged to connect with an unprepared adult-care physician.[1]

Loss to Follow-Up

Loss to follow-up is often a consequence of a rocky transition experience. In one published study, adolescents and young adults with congenital heart disease were frequently lost to follow-up for a variety of reasons, including being uninformed or misinformed about the need for ongoing care.

Some felt that a lack of symptoms equated to being cured; many experienced insurance barriers.[2] In a study of 158 adult congenital heart disease patients, 63% had had at least a two-year lapse in care, the average lapse being closer to 10 years. Even more concerning is the fact that these patients later followed up when manifesting dangerous sequelae that could have been prevented.[9]

Young diabetic patients who opted out of care once they left their pediatric practice reengaged with the health care system when they experienced complications that could have been avoided.[10] Inadequate transition is a major factor in over-reliance on emergency health services.[11]

Medication Compliance

Medication compliance is also a critical issue. Enlisting parents during the adolescent years may improve compliance in studies, but if a transition plan does not enforce medication adherence, there are higher rates of non-adherence and serious medical complications.[12]

In a study of patients who had undergone organ transplant as children, medication adherence to tacrolimus dropped after they left pediatric care.[13] Responsibility and self-care is especially difficult for teenagers who must assume ownership of their own health care,[7] which speaks to the need for a transition process founded on education and personal care skills.

SPECIFIC MODELS AND REQUIREMENTS OF IDEAL TRANSITIONS

The variability in the disease processes and care needs of the medically complicated pediatric population makes creating a standardized transition process impossible, yet studies have validated specific tools and methods for successfully transitioning complex pediatric patients. Success requires attention be given not only to the patient but also to the families and caregivers, as well as pediatric- and adult-care providers.[14]

Focus on the Patient

Although physician focus is largely upon the specifics of diagnoses and management, ideal transition considers the many aspects of a patient's identity. The transition must include concern for psychosocial well-being, education, interests, social groups, and career pursuits, including a patient's goals for independence.

Good transitioning must include collaborations between specialists, primary providers, and medical care centers. It may be important to connect with the patient's school programs, social and employment entities, case management, and other service organizations. This may require knowledge of other professionals within the community and each patient's environmental and social circles.[14]

Intentional Programming

Ideal transition of a medically complex pediatric patient to adult care requires intentional programming to connect patients and families to resources for success in their adult life.

In a study of patients with cerebral palsy, patients needed help with medical decision-making, utilizing vocation-related resources, and overcoming other barriers.[15] Pediatricians often need to enlist care coordinators and social workers to connect patients with community programs, a practice that is widely considered efficacious,[16] but one that requires institutional recognition and financial support.

Identifying Goals

Identifying the many goals and hopes for the future, as well as the needed skills to achieve them, is a difficult yet vitally important task. It therefore makes sense to keep track of necessary skills.

Helping patients create a list of goals will elucidate what is needed. Non-medical goals can include vocation training, college education, or achieving a specific level of independence. Establishing goals early can help determine what education and resources patients may need.[17] Affixing a checklist of discussion points and skills to the medical record was found to be helpful in a study of primary care physicians involved in transitioning complex patients. This way, every medical professional who sees the patient will know where the patient is in the transition process.[7]

Medical Workbooks

Medical workbooks that the patient, physicians, parents, and other care team members fill out are another tool for transition. Workbooks can include worksheets that teach and help patients organize information about their disease and disease process, medications, health care plans, and what they understood from their appointments.

Workbooks also help patients plot progress that they have made and demonstrate to providers a record of their patients' progress. Finally, workbooks can double as a record of medical decisions and information that may be valuable to future providers.[7]

Transition Plan

Be it a checklist or other template, a written transition plan should be prepared by the time the patient is 14 years old.[2] Transition plans clarify what will help with education, independent living, and employment opportunities.

By listing these desires, adolescents learn the importance of continued care for their condition; increased responsibility in their care management may improve compliance.[2] The importance of a known and documented plan was demonstrated in a study of 4,000 adolescents with chronic health conditions; fewer than 20% of surveyed patients had developed any semblance of a plan with their pediatric doctors.[18]

Table 1. Top Concerns of Adult-Care Providers When Transitioning Patients to Their Care

(study categories in parentheses)

1. Internists may not have the training in congenital and childhood chronic illnesses to prepare them for management. (Medical Competency)
2. It is difficult to care for patients with cerebral palsy or mental retardation if the family does not stay involved. (Family Involvement)
3. It can be difficult to meet psychosocial needs of young adults, especially those living with chronic illness. (Psychological Needs)
4. Some patients may need a superspecialist to manage complex problems (e.g., complex congenital heart disease). (Medical Competency)
5. Internists often lack training in adolescent medicine, adolescent development, and adolescent behavior. (Medical Competency)
6. It is often difficult to face disability and end-of-life issues at an early age and early in the doctor-patient relationship. (Medical Competency, Psychological Issues)
7. Managed care/financial considerations limit the time an internist is able to spend with transitioning young patients. (System Issues)
8. The families of transitioning patients have high expectations of the amount of time/attention needed for proper care. (Family Involvement)

Adapted from Peter et al.[6]

Transition Coordinator

A transition coordinator can be an important part of a successful transition. This is a person who serves as a primary contact for the patient and family. As such, this individual needs to have time dedicated to this type of care. It follows that this individual must be a health care professional trained as an educator and an expert in the disease of the patient.[2] Institutional support in the form of dedicated time and commensurate salary for such coordinators will help prepare complex patients for success.

Support

Transition programs benefit tremendously from the support of a larger medical institution, because these processes require advanced planning and additional time. These programs further require paid personnel, office space, supplies, and time. The support of a larger institution therefore becomes necessary in many cases.[2]

COMPLEX CARE CLINIC AT ROSEVILLE PEDIATRICS

The Complex Care Clinic at Roseville Pediatrics was created four years ago with the aim of providing comprehensive primary care and care coordination to close gaps that would otherwise thwart health outcomes. The time required to coordinate subspecialty appointments, transportation, medical equipment, insurance coverage, home nursing services, and medical literacy requires decreased personnel.

In our clinic, a nurse care coordinator partners with the primary physician for management of the logistics and big picture in addition to the diagnoses. Our current program services almost 100 patients, and one of the biggest challenges we and our patients face is the transition from pediatric to adult care.

Our patients negotiate all the challenges described in this article, including gaps in insurance coverage as well as lack of access to medical subspecialty care, specific financial programs, home nursing agency coverage, and finding medical equipment. In addition, some encounter legal battles over medical decision-making.

As our current cohort of patients ages into adult care, our initiatives include creating workbooks to help parents coordinate and organize the myriad forms and lists they need to ensure fluid transitions regarding care needs. We are also developing a phone application — or “app” — to help patients organize care needs. The workbook and app will be used in coordination with attendance at a transition care clinic — separate from and in addition to other clinic visits — which we ask patients to start attending as early as age 12 years. We plan to use prospective surveys of this first cohort to examine and improve the effect of our interventions.

While developing this program, we have discovered that, in addition to the physician and nurse team who can lead medical coordination, we also need a social worker who can bring a unique skill set and knowledge of community services and how to access those services. We plan to continue building this comprehensive care model and anticipate that this transition care initiative could be expanded to help other medically complex patients who need assistance across the Lancaster General Health system.

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