

Transition From Pediatric to Adult Renal Care: Education, Preparation, and Collaboration for Successful Patient Outcomes

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The transition of patients from pediatric to adult renal care is a complex process that requires careful planning and thorough execution. While the topic is popular and yields much discussion, the recommendations for best practice methods are not well defined. It is clear, however, that the published literature recognizes the importance of a successful transition program leading up to the transfer of care for adolescent/young adult patients. In response to the need for a defined transition program, the dialysis and kidney transplant program at Children's Mercy Hospital developed a transition program designed to meet the educational and developmental needs of this patient population. The program is enhanced by a city-wide collaborative group which consists of pediatric and adult renal care providers. This group meets annually to strategize ways to improve the transition program and transfer of care process in general. Ongoing evaluation will include seeking patients' input with regard to the effectiveness of the program from their perspectives. The goal of the transition program and collaborative effort is to achieve positive outcomes for this patient population.

INTRODUCTION

Kennedy and Sawyer (2008) define "transition" as the period of preparation prior to and after the event of transfer. Transfer is the actual shift of patients' care from pediatric to adult health care providers. This has been discussed extensively throughout the past two decades; however, best practice methods are not well defined as a part of pediatric subspecialty care, including nephrology. The research available is limited largely due to a lack of a substantial history of the long-term survival of pediatric patients with a variety of chronic diseases. As positive outcomes for pediatric patients with chronic diseases increase in frequency and duration, it is important to have care of these patients provided in the most appropriate medical facilities. This strategy is recommended by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine (2002) as well as the Society for Adolescent Medicine (2003) to address the developmental process of adolescents emerging into adulthood. The Society for Adolescent Medicine (2003) bases its definition of an appropriate medical facility on chronological age and developmental attainment.

The goal of transitional care is to maximize lifelong functioning through high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood (Chaturvedi, Jones, Walker, & Sawyer, 2009, p. 1055). The population requiring transitional services is increasing. The literature has recently indicated a significant improvement in success rates and as many as 90% of dialysis and transplant patients are living past 21 years old (La Rosa, Glah, Bluarte, & Myers, 2011). With increasing survival rates, combined with the goal of excellent care, the issue of transition is attracting attention because of the need for adolescents and young adults to develop the skills and capacities for long-term self-management of their health care.

The literature has identified lack of planning as one of the most common reasons for the failure of patients to move

successfully from pediatric systems into adult-oriented systems, while maturity was identified as the key factor necessary for successful transfer (Watson, 2005). Overprotectiveness by parents and other caregivers has been identified as another barrier to transfer (La Rosa, et al., 2011). Recognizing that general education alone was not effectively preparing patients for the transition to adult care, it has been recommended that the transition process include both general education about the patients' diagnosis and treatment, and teaching skills that address the areas of independence and self-management of health care (Lugasi, Achille, & Stevenson, 2011). Education on managing simple health tasks such as calling in for prescription refills or scheduling appointments has contributed to more a successful transfer (Bell, 2007).

Another important aspect of the transition process is for the medical team to look beyond the "check list" of transition tasks for the patient and the inherent risks of non-adherence and, instead, emphasize the need for regular communication and understanding between the patient and medical team. This skill will likely serve them well in the new health care setting (Watson, 2005). Regular communication with adolescents/young adults throughout the transition process should ideally make them feel a sense of achievement in reaching such an important developmental milestone. The goal is to motivate them or gain their "buy-in" regarding the upcoming transfer of care and their important role in making it successful.

Improved communication between the pediatric and adult medical teams regarding barriers to a successful transfer of care has also improved the process (Watson, 2005). Both pediatric and adult care providers must be invested in a successful transfer process if it is to be accomplished optimally. Recent literature recommends joint visits between pediatric and adult providers, as well as pre-transfer visits of the adolescents/young adults to their potential adult provider systems (Lugasi, Achille, & Stevenson, 2011).

Research suggests that pediatric nephrologists and their medical teams have training in adolescent issues to be able to assist patients in becoming engaged in their complex medical regimens and promoting resilience in the face of chronic illness (Watson, 2005).

The literature also suggests that the pediatric providers have a vested interest in their patients. However, it is also recognized that pediatric facilities often have more supportive resources for patients and families than adult facilities (La Rosa et al., 2011). Pediatric providers are often accused of “spoiling” their patients and have difficulty with trusting a new provider with meeting the needs of their patients in an adult facility (Watson & Warady, 2011, p. 156). Adult providers have been found to be unprepared and lack knowledge about pediatric renal disorders and the developmental needs of adolescents and young adults transferring to their care (Watson & Warady, 2011). Because of their vested interest and resources available, pediatric teams must be knowledgeable about transitions and should ideally take the lead in the process. The Children’s Mercy Hospital program in Kansas City, MO, follows this design.

PATIENT EDUCATION AND PREPARATION

Based upon the published information regarding the transition process and the clear need for transition preparedness for patients with chronic health care needs as well as their parents, a transition education program was developed and implemented by the dialysis and kidney transplant program at Children’s Mercy Hospital. The program, entitled “Kidney Education for Your Success (K.E.Y.S.),” is designed to be initiated when the patient reaches age 12 (or at diagnosis of chronic kidney disease if it occurs later) and to continue until the patient is transferred to adult care. This generally occurs prior to the patient’s 22nd birthday. The education is provided as part of standard care to all dialysis and kidney transplant patients at Children’s Mercy Hospital. The curriculum is presented in four phases (see Table 1.1) to the patients during routine clinic visits in the Kidney Center and/or Dialysis Unit at Children’s Mercy Hospital during time that is specifically allocated for transition education. There are currently 13 dialysis and 60 transplant patients participating in the program.

Phase One of the program focuses on “Finding Your K.E.Y.S.” This phase is directed toward patients who are 12 to 14 years of age. The goal of this phase is for patients to begin learning the basics about their health and its effects on their everyday life. As they learn about these issues from the K.E.Y.S. program, they are encouraged to start thinking about ways to take a more active role in their medical care. In this phase, education is provided by a member of the medical team and patients participate by completing learning activities to reinforce the teaching. The medical team member makes sure patients accurately grasp essential concepts prior to proceeding to the next phase.

Phase Two focuses on “Sharing Your K.E.Y.S.” This phase occurs when patients are between 15 and 17 years of age. In this phase, the patients have opportunities to show the medical team the skills and knowledge gained thus far in the program through the teach-back method (asking patients to explain or demonstrate what they have been told). This is a time for patients to work with the medical team to develop new skills and improve on existing ones (knowing their lab values, knowing each of their medications and why they are taking them, identifying employment/education goals for their future), all designed to help the patients become expert in their own medical care.

Phase Three focuses on “Turning Your K.E.Y.S.” This phase occurs between 18 to 20 years of age and is designed to encourage patients to gain real-life experience and to build on their involvement in their medical care. This occurs by incorporating information from the classes into their everyday lives, such as ordering medication refills, scheduling medical appointments, and participating in direct communication with their medical team. The incorporation of these concepts allows patients to practice self-reflection (looking inward) and self-care techniques. This phase gives patients opportunities to identify how their disease impacts their lives and emphasizes the importance of effective coping and management skills. By this time, patients will be able to demonstrate knowledge of their kidney disease and begin taking more responsibility for their future medical care.

Phase Four of K.E.Y.S. focuses on “Unlocking the Door.” This phase begins at the completion of Phase Three and should conclude by age 22. This final phase incorporates the actual transfer of care to an adult provider. The team works with patients to facilitate the completion of a transfer checklist, which includes scheduling a tour of the adult facility and meeting the adult care staff; identifying plans to get labs and medications; and addressing any insurance, pharmacy or medication issues that may arise during the transfer.

COLLABORATION

In addition to the collaborative, educational approach developed for patients through the K.E.Y.S. program, the Children’s Mercy Hospital team recognized the importance of partnering with adult renal providers in the Kansas City community with the goal of identifying barriers and solutions for a successful transfer of patients. In a freestanding children’s hospital such as ours, pediatric care providers frequently do not have regular interaction with adult providers who will ultimately care for the transitioned patients. To bridge this gap and provide an avenue by which this communication could occur, a city-wide dialysis and kidney transplant collaboration was developed in 2010 to improve the transition education and transfer of care processes.

Table 1.1 *The K.E.Y.S. Program*

Phase	Age of Patient	Education Goal	Education Curriculum
<i>Phase 1</i>	12–14	Didactic and interactive education to teach concepts and skills	Diagrams, crossword puzzles, matching exercises, hands-on demonstrations, and word-find activities that all pertain to learning the patient’s diagnosis and how to be involved in medical self-care
<i>Phase 2</i>	15–17	Reinforcement of concepts and skills by utilizing the “teach-back” method, where the patient tells the provider what has been learned	Fill-in-the-blank and true/false worksheets designed to assess knowledge of the skills and concepts presented
<i>Phase 3</i>	18–20	Incorporation of concepts and skills into real-life situations. The patient is able to express how each concept and/or skill impacts his/her life.	Worksheets with open-ended questions that allow each patient to express how previously learned concepts and skills are applied/incorporated into daily living
<i>Phase 4</i>	21 through transfer to adult care	Successful completion of the transfer of care to an adult facility	Checklist of steps to be completed to lead up to and include the actual transfer of care between providers

The initial collaborative conference was entitled “Transition: Navigating the Journey from Pediatric to Adult Care.” A multidisciplinary group of pediatric providers from Children’s Mercy Hospital and adult renal providers in the Kansas City area attended the meeting. The group consisted of adult and pediatric nephrologists, an adolescent medicine physician, dialysis nurses, transplant coordinators, dietitians, social workers, financial counselors, and importantly, several patients who had transitioned to adult care themselves.

The objectives for this day were to: 1) review the stages of young adult development, including the impact of chronic illness on development; 2) describe transition strategies based on published research; 3) describe the components of a pediatric transition education program; 4) discuss needs and expectations for successful transition to adult care; and 5) identify barriers and solutions to effective transition of young adults to adult care. The day consisted of a morning education program including lectures on “Trials and Tribulations of Working with Teens with Chronic Illness” by Daryl Lynch, MD; “Empowering Young Adults with Chronic Kidney Failure and Their Renal Teams in Adult Dialysis Units” by Erica Perry, MSW; and “Barriers to Adherence” by Bradley Warady, MD. The highlight of the morning was a panel presentation by the recently transferred young adults who spoke on the challenges of transitioning from pediatric to adult renal care.

The afternoon consisted of roundtable discussions to explore the barriers and solutions to the transition and transfer of care processes. Three subcommittees with the following goals were developed from the roundtable discussions: 1) “Create Independence” subcommittee: create and nurture independence among pediatric patients; 2) “Integration of Pediatric/Adult Care” subcommittee: integrate adult care concepts into

the pediatric setting; and 3) “Adult Provider Information” subcommittee: provide adult provider information to pediatric patients prior to the transfer of care. Throughout the following year, a Transition Steering Committee oversaw the progress of each subcommittee to maintain organization and consistency within the collaborative effort.

The group reconvened in October 2011 to evaluate outcomes, monitor successes, and further improve the transition process. The objectives for the day were to: 1) identify current research related to transition; 2) discuss ways to utilize social media, Skype, telemedicine, and texting to enhance the transition process; 3) describe how the enhanced transition program has impacted patients, families, and staff; 4) review accomplishments of the transition workgroups; and 5) plan for pediatric and adult dialysis/transplant professionals to develop a follow-up assessment process for transition. The day consisted of a morning educational program that included a literature review of research on transition initiatives in nephrology and other disease areas by Bradley Warady, MD, and “Technology/Social Media: Ways to Enhance Transition” by Ron Nicholis, MD, and Kim Gandy, MD. In addition, two current Children’s Mercy Hospital patients talked about ways they use social media, text reminders, phone alarms, and email in their lives, and provided suggestions for using technology in the medical setting to improve adherence.

In addition to the presentations, the subcommittees formed at the 2010 collaborative meeting reported their development and progress. The “Create Independence” subcommittee reported on continued progress with implementation of the K.E.Y.S. transition program. From 2010 to 2011, multiple patients who were planned to be transferred to one local transplant program, St. Luke’s Hospital, were able to attend a “meet and greet” session at Children’s Mercy Hospital.

At this event, these transitioning pediatric patients had an opportunity to meet with the adult care team, prior to the transfer of care. Due to the success of the intervention, “meet and greet” sessions with other local programs that admit some of our transitioning patients are being discussed as well. There has also been an increase in the use of MedActionPlan.com text message reminders (medication schedule and discharge instructions) that have fostered independence and have resulted in improved adherence with medical care responsibilities.

The “Integration of Pediatric/Adult Care” subcommittee created four forms to utilize in the transition/transfer process. The following forms focus on the last two years of patient care in the pediatric setting: 1) Transition/Transfer Process Form: This form outlines the steps required for a successful transfer of care from pediatric to adult centers. Tasks are identified in a timeline and are clearly marked by each responsible medical team member. Tasks begin two years prior to transfer and continue for 90 days post-transfer. Each form is modality-specific. Major differences between dialysis and transplant forms are that the Children’s Mercy Hospital social worker attends the 30- and 90-day care plan meetings at the transitioning dialysis patient’s adult facility. Hemodialysis patients will dialyze in the adult facility for one week prior to the transfer of care and return to Children’s Mercy for debriefing and discussion regarding their experiences. 2) Communication Form: This form provides an opportunity for the patients to make the adult medical care providers aware of how they prefer to communicate. It is completed with the assistance of the pediatric social worker. The form is sent to the adult program prior to the transfer of care. 3) Patient/Provider Questionnaire: This form was developed by the subcommittee with the help of a few recently transitioned patients. It provides a list of questions for patients to ask when visiting or evaluating an adult program prior to the transfer of care. 4) Transition Care Plan: This form is used to facilitate discussion between the pediatric medical team and the patient after the initial visit with the adult nephrologist or during the one week of hemodialysis during the transition period. The medical team at Children’s Mercy helps the patient complete this form about his or her experience, with specific attention to questions that remain unanswered, or anything the patient may feel unprepared for prior to completing the transfer process. This completed form is subsequently sent to the adult program just prior to the transfer of care.

The “Adult Provider Information” subcommittee reported the development of a resource notebook with helpful information about area adult nephrology facilities and programs. The book currently has information about local adult dialysis and transplant programs in the Kansas City area. It contains pictures of facilities and staff, general operation guidelines, and helpful hints for each program. It provides another way for patients from Children’s Mercy Hospital to become familiar with different adult programs without having to physically visit each one.

During the afternoon, round table discussions were held to explore different aspects of the transition and transfer of care processes. The goal for Roundtable One was to identify patient strengths, challenges, and level of responsibility for medical care at the time of transfer, and to identify how transition education may continue after transfer has occurred. Ideas for improvement included: instituting monthly clinic visits with the adult nephrologist for at least the initial three months following the transfer of care; attempting “buddy transfers” by transferring more than one patient at a time, with patients using each other as sounding boards and for encouragement; and developing a community-based support group as a resource for transitioned patients, functioning somewhat like an alumni group; and planning “meet and greet” sessions throughout the year and having patients start attending the sessions two years prior to transfer.

The goal for Roundtable Two was to create a post-transfer tool to collect data from patients who have transitioned to adult care. Discussion focused on what information to collect from transitioned patients, as well as how and when to collect it. Recommendations for the questionnaire/tools included: 1) The survey would be administered at intervals of one and six months, post-transfer of care. The questions would remain consistent. 2) Questions would target the specific interventions implemented in the transition program (K.E.Y.S. program, “meet and greet,” tour of the adult facility, etc.). 3) Develop an independence tool that rates patients’ success on various items, including adherence, goals, and quality of life.

CONCLUSION

It is evident from the research that transition education programs should begin in preadolescence, and should include involvement of both pediatric and adult-care providers. These programs are essential for a successful transfer of care process. Post-transfer, the next step in the process is to evaluate, from a patient’s perspective, if the transition program is effective, and to modify it to meet the needs of patients and health care providers alike. It will be a key goal to fully implement the ideas developed by the transition collaboration group to establish consistent practices surrounding the transfer of care. A standardized and comprehensive pediatric transfer of care program is an essential component of any plan designed to provide high-quality health care to adolescents and young adults with chronic health conditions. As the quality of medical care improves and pediatric patients with chronic diseases live longer, providers will need to continue to identify best practice models for this growing population. Programs and efforts like those being conducted at Children’s Mercy Hospital and similar institutions will hopefully result in positive outcomes for patients.

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