

Spring 5-2019

Transitioning Pediatric Patients with Special Needs

Dimi Resch

Follow this and additional works at: <https://spark.siu.edu/dnpprojects>

Part of the [Nursing Commons](#)

Recommended Citation

Resch, Dimi, "Transitioning Pediatric Patients with Special Needs" (2019). *Doctor of Nursing Practice Projects*. 65.
<https://spark.siu.edu/dnpprojects/65>

This DNP Project is brought to you for free and open access by the School of Nursing at SPARK. It has been accepted for inclusion in Doctor of Nursing Practice Projects by an authorized administrator of SPARK. For more information, please contact magraser@siue.edu.

Transitioning Pediatric Patients with Special Needs

Introduction of the Problem

Transitioning a child's health care from pediatric focused practice to an adult practitioner can be challenging, especially for children with chronic or complex needs. Given the importance of an accurate health history to ensuring effective care, the ideal transition would include providing the adult practitioner with information that would facilitate seamless and appropriate care. Ideally the transition of care would include sharing of information among the patient, family, primary care and specialty providers, and all collaborating team members. Unfortunately, there are no specific guidelines, procedures, or approaches for transitioning pediatric patients with special needs into adult primary care. Evidence supports establishing a structured policy or procedure for transitioning pediatric patients with special needs to an adult primary care setting. According to researchers, transitional guidelines are needed for consistency among pediatric providers and adult providers who care for patients with special needs. A provider in a small, Midwest pediatric primary care clinic agrees that transition from a pediatric to an adult-centered practice requires collaboration among the providers for patients with special needs. Providing those patients with a successful transition is key in delivering appropriate care for patients with special needs.

Literature Review

The literature search was performed through the databases EBSCO Host- CINAHL Plus with Full Text, Medline Complete, PubMed, Cochrane Database of Systematic Reviews, ScienceDirect, and Scopus. The keywords used included transition care, children with special health care needs, transitions to adulthood, youth, adolescents, special health care needs, self-management, chronic illness, health care services, young adult, young adulthood, and children with disabilities. The time frame of the search was limited to sources published in 2010 through

2018, resulting in a large quantity of articles. After applying the inclusion and exclusion criteria, a total of 22 articles were reviewed.

A variety of transition systems and approaches intended to shift children with chronic illnesses from a pediatric care focus to adult care settings were identified. Although many transition processes have been researched, one specific guideline for primary care practices has not been developed, but recommendations have been shared in the literature (Lewis, 2015). Multiple authors recommended guidelines to include assigning a provider; teaching the provider skills related to specialty needs; writing a transition plan; providing medical summaries; and providing continuous coverage, tracking of patient, planning tools, portable medical summary, and an action plan (Herzer et al., 2010; McManus et al., 2013). There is not one specific model identified that is all inclusive of necessary criteria that can be used for providing the most efficient transition. Abraham et al. (2016) developed a specific model used for emergency situations, the Emergency Information Form (EIF). This form contained pertinent information including the name of specialty physicians, list of diagnoses, and the baseline care for the pediatric patients. According to results of a systematic review by Gabriel, McManus, Rogers, and White (2017), the EIF resulted in positive patient outcomes.

In addition, various gaps, barriers, recommendations, and expectations for transitional care guidelines have been researched. According to Berens, Jan, Szalda, and Hanna (2017), the gaps and barriers included the need for universal record access, more support from coordinators, and consideration of cultural differences between the adult and pediatric setting. Other barriers identified by Betz, Lobo, Nehring, and Bui (2013) included services no longer provided in adult care, lack of information and referrals, and insufficient education and communication. One important barrier identified in the evidence was lack of education. Education is vital for the

patient and the provider receiving the patient. Other recommendations included timing of the transfer, service coordination, and environment (Betz et al., 2013). This recommendation incorporated education for providers and education for self-care management. Patients and families reported the desire for more education, stating it would help them feel more comfortable prior to transition (Betz et al., 2013). Another recommendation that was relevant to the communication is an established relationship between the pediatric and the adult providers. According to Gray et al. (2017), it was important to establish a system where the pediatric provider communicated with the adult provider before and after the transfer. The gaps, barriers, and recommendations identified can inform the development of guidelines for transition to adult care settings for pediatric patients with special needs.

Project Methods

A structured policy or procedure for transitioning pediatric patients with special needs to an adult primary care setting in a small, Midwest pediatric primary care practice is needed. The primary goal of this project was to develop a communication tool for pediatric providers to aid in the transition of patients with special needs into the adult primary care setting. The tool will be used in a pediatric primary care setting; pediatric providers will complete the tool and periodically reevaluate the information to assist the patient and family with transition. It will provide the family guidance with selecting an adult provider who specializes in their child's needs. It will provide the adult provider with pertinent medical information regarding the patient's health including baseline vitals and assessment, allergies, current medications, past medical history, diagnoses, daily schedule, likes and dislikes, and patient/family goals. The EIF or Emergency Information Form was used to guide the development of this communication tool.

The quality improvement project was approved by the Southern Illinois University Edwardsville Institutional Review Board (IRB) on April 11, 2018. Current evidence, the DNP

project team, adult primary care providers, pediatric primary care providers, a social worker, a special needs teacher, and parents of a pediatric patient with special needs guided the development of the communication tool. The student hosted sessions via telephone and in person with each of these experts and once the tool was complete, these experts reviewed the tool for appropriateness and effectiveness pertaining to their area of expertise.

Evaluation

After feedback from the experts was considered and the tool was finalized, a S.W.O.T Analysis (Strengths, Weaknesses, Opportunities, and Threats) was performed to help identify implementation factors. The strengths were identified as increased patient and family satisfaction, cost effective and quality improvement, decreasing “falling through the cracks” or not addressing an individual patient’s need in the transition process and leaving them on their own, provider comfort with handoff, and commitment of the practice. The weaknesses included limitation of the number of adult providers who care for patients with special needs, length of the form and time to complete, unfamiliarity of the tool, amount of information to be gathered, and necessity of form to be continually updated. The opportunities identified included implementation of the transition process in a small Midwest pediatric practice, increased collaboration and communication among providers, improved patient outcomes, increase search for adult providers willing to accept these patients into their clinical practice, and an increased number of patients with complex needs being identified. Lastly, the threats included insufficient training; more paperwork, therefore losing information in the charts; increased parent stress; provider resistance to change; and lack of insurance reimbursement for time spent completing the tool for individual patients.

Impact on Practice

This project impacted the practice at the microsystem level. Continuation of this project has been identified by one of the providers in the clinic. One future project could include initiation of the form in the small Midwest practice and assessing the usability and efficacy of the tool. This project increased knowledge related to the transition process and the need for a universal guideline for providers. Long-term impacts could include providing patient and families with successful and smooth transitions into adult care. This would then lead to improved patient outcomes.

Conclusions

This project centered on the need for guidelines related to transitional care. Utilizing a communication tool specific to the patient can provide pertinent medical details needed for transitioning patients. With the tool in place, patients and families can feel more comfort related to the transition of their child through enhanced communication with the future adult provider and their pediatric provider, whom they trust. This tool can become part of the management plan at visits leading up to transition. This will allow for updates and accurate information to be given to the adult provider when it is time to transition. According to Davidson et al. (2017), transition should be considered one of the developmental milestones and should be addressed at every visit (Davidson, Doyle, & Silver, 2017). With the improvement of healthcare delivery and technology, 90% of pediatric patients with chronic illness are living into adulthood (Okumura et al., 2015). Providing them with a successful, uninterrupted, smooth transition is key to having healthy adults with special needs.

Author Contact Information

Dimi Resch: djollif@siue.edu