

A Framework for Transitioning Patients From Pediatric to Adult Health Settings for Patients with Neurogenic Bladder

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Background: Adolescents with neurogenic bladder are a vulnerable population that severely lacks consistent transitional care from pediatric to adult urology settings. **Aims:** Our practice determined that 100 patients with spina bifida and other neurogenic bladder conditions were not appropriately transferred to the adult setting once reaching adulthood. **Methods:** We initiated a transitional program to establish a dedicated and formal process for adolescent patients to transition to adult urology. The REACH clinic implements a formalized staging framework to facilitate migration of adolescents and young adults to the adult health setting. A social worker was incorporated to act as a patient advocate, behavioral health consultant, and resource specialist. **Results:** To date 45 patients have been enrolled in the transition program. We have identified and categorized according to the appropriate stage. The REACH clinic has appropriately outlined the goals and mission of the program and resources utilized are financially practical and feasible by conducting a monthly combined clinic. The program has been instrumental in improving tracking and monitoring of these patients through their transition period. **Conclusion:** Through the efforts of the pediatric and adult urology teams, the REACH program is a dedicated framework that provides structure for transition of the adolescent patient. The addition of a social worker has resulted in enriched rapport and will likely result in improved compliance. This program allows for surveillance and evaluation of patient outcome indicators in this patient population. We believe that early introduction and frequent encounters with the adult urologic team is crucial to successful transitions. *NeuroUrol. Urodynam.* 36:973–978, 2017. © 2016 Wiley Periodicals, Inc.

Key words: adolescence; adult; neurogenic bladder; spina bifida; transition; urology

INTRODUCTION

Adolescence and young adulthood is a challenging developmental stage that compounded with chronic illness results in monumental obstacles to effective shifting from pediatric to adult settings. Unfortunately, failure of transition in this vulnerable population is attributed to inadequate preparation and education for the transition process.^{1,2} Research highlights the devastating conclusion that only half of adolescents and young adults were formally and properly prepared for transition.³ Inefficient and inadequate transition leads to a variety of health complications and adverse outcomes that with consistency and continuity of health care services could otherwise have been prevented or detected early.^{4,5} Advanced health care technology and intervention has led to improved survival of patients with chronic illnesses beyond adolescence and young adulthood therefore, multiplying the concern of insufficient transitions in this population.⁶

In the United States (US), there are approximately 1,500 babies born annually with SB.⁷ The incidence has decreased by 31% since synthetic folic acid fortification to grain products became mandatory in the US in 1998 and prenatal and community health care emphasized the importance of dietary folic acid intake worldwide.⁸ According to the Centers for Disease Control and Prevention, the prevalence rate of SB was 3.06 per 10,000 in 2006.^{7,9} In the US there are currently ~25,000 children ages 0–19 years and about 166,000 of all ages currently affected by SB.¹⁰ The critical improvements over the last century in the medical and surgical management of SB patients with the introduction of the ventriculoperitoneal shunt, antibiotics, and intermittent catheterization have allowed affected individuals to reach a normal life span. Today 85–90% of children are surviving into adulthood and

compared to 1975; twice as many newborns with SB survived in the US in 1995.^{11,12}

The aging patient with SB and other neurologic bladder disease, have to endure many urological challenges that require regular routine evaluation and treatment. Urological care of these patients focuses on management of the urinary bladder, prevention of symptomatic urinary tract infections (UTIs), and most importantly protection of the renal system. However, improving and maintaining quality of life is essential to patients and has to be incorporated in the management plan of each patient.⁹ The chronic urological health issues are further compromised by inadequate transitional care from the pediatric to adult urology providers. There is general agreement among caregivers and healthcare providers that the transition care process is deficient and in dire need of attention.² There is a gap with consistent transitions of patients with neurogenic bladder once reaching late adolescence to young adulthood in the urology practice setting.¹³ Relevant explanations include lack of resources and access, dysfunctional transition introductions from pediatric to adult providers, intimidation of a new environment, and inadequate preparation for independence and self-efficacy secondary to dependency on the pediatric care team.^{14–16}

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In urology, there is currently no standard protocol to follow when transitioning these patients from pediatric to adult services. The REACH urology transition clinic recommends a staging model and framework for patients with chronic illness or disease of congenital and/or long-term diagnoses that require urological care. In accordance with collaborative efforts of pediatric and adult urology teams, a T1–T4 staging transition program has been introduced and implemented. The staging system identifies crucial milestones and establishes a formalized program for pediatric patients to successfully transition to the adult urology care environment.

MATERIALS AND METHODS

REACH Transition Program

The REACH transition clinic has been established to facilitate the transitional care process from pediatric to adult urological care for patients with neurogenic bladder disease. The program prioritizes interventions that improve quality of life and health outcomes in affected individuals. This transition clinic was conceptualized as a joint project between the pediatric and adult sections of urology and has been active for approximately 24 months. Initial discussions started as a response to the fact that pediatric providers noted poor patient compliance in the adolescence and young adult population as well as with poor follow up and a high no show rate. At the same time, adult providers noted an increasing influx of non-transitioned adults via the emergency rooms and referrals from outside primary care providers. Before the REACH clinic was instituted the adult urology practice identified 100 adult neurogenic bladder patients who had inadequate transition experiences from pediatrics to adult health settings.

The REACH transition clinic aspires to become the model for urology based transition care programs for this vulnerable population, and thus to develop evidence-based protocols to be shared with other urology programs and centers. The knowledge potential of a successful urology transitional care clinic enables the prospective ability to establish guidelines, recommendations, and lead as an example to facilitate future urological based programs. The sharing of protocols among centers will promote evidence-based care as data can be collected, compared, and evaluation tools can be validated.

The REACH transition program is comprised of a pediatric urologist, an adult urologist, two urological trained nurse practitioners (one pediatric and the other family practice background), a clinical social worker specializing in urology, and several other clinical staff including a medical assistant, and two patient service representatives. The clinic is held once monthly with the entire team present. The clinic includes patients of any age. Patients below age 14 are seen only by the pediatric providers. The transition process begins at age 14 with an introduction to the transition process. The program was developed using readily available tools and resources for transitional care processes. The clinic utilizes a unique framework with stages through dedicated milestones to facilitate progression to a successful transition. Patients enrolled to the REACH clinic are provided an initial education/introduction packet including the framework and team members. The waiting area is designed to encourage communication between patients and their families. Community representatives with programs relevant to this patient population (summer camps for children with chronic illness, adaptive sports, peer support groups, etc.) meet with the families in the waiting area during clinic days. Programming also involves events where patients

and families can meet one another to provide peer support, share resources, and engage in activities to promote health and wellness. Mixing different patient ages allows patients and families to share encouraging experiences, give and receive support, and exchange contact information if desired.

The utilized resources are financially practical and feasible by conducting a monthly combined clinic with the pediatric and adult teams. The program does not require additional clinical support or supplies and operates through existing organizational facilities and by scheduling existing patients by categorizing according to diagnosis and stage of transition.

Mission Statement

The REACH clinic provides transitional urologic care and social support services to the growing population of adolescents/young adults with neurologic bladder disease as they graduate from pediatric to adult healthcare.

REACH Vision

The REACH clinic strives to progress the transition process from pediatric to adult care to improve the physical health and elevate the quality of life of patients with neurogenic bladder disease.

Patient Population

Patients with neurologic bladder disease of all ages. Diagnoses spectrum includes but not limited to spina bifida, spinal cord injury, cerebral palsy, bladder and cloacal exstrophy, cloacal malformation, posterior urethral valves, pelvic and spinal tumors, trauma, infections, and other genetic, neurological, acquired, or congenital diseases.

Program Goals

The goals of the REACH clinic are:

- (1) Facilitate the transition process from pediatric to adult care for patients with neurogenic bladder disease.
- (2) Provide high quality, state of the art health care.
- (3) Provide improvements in quality of life.
- (4) Provide continuous care and follow up.

Achievement of these goals will be realized by:

- (1) Providing a specialized health care team from pediatric and adult urology specialties.
- (2) Provide a comfortable and relaxed clinic atmosphere.
- (3) Provide information towards health and life challenges.
- (4) Encourage exchange between affected individuals and their families.
- (5) Organize and maintain support groups.
- (6) Facilitate interaction with local support and advocacy groups.

Successful transition is aimed to prevent urgent urologic healthcare issues and to promote a bridge to gap the period from pediatric to adult urologic healthcare services. The REACH clinic strives to support this vulnerable population throughout their lifespan. The REACH clinic assists these patients and their

caregivers to have access to reliable urologic healthcare services from birth to adolescence and a smooth transition into adult urology healthcare. We communicate with other healthcare professionals in the surrounding communities to provide guidance and advice concerning patients with chronic urological healthcare needs. As part of an academic institution, we work closely as a team to provide cutting edge management and strategies. Through continuing research and healthcare endeavors, we provide the most innovative and individualized urological healthcare services.

REACH T-staging Framework

The T-staging framework has systematic and well-defined criteria for each transition stage to provide structure and methodology for consistent transition protocols. The framework is comprised of stages T0–T4 (Fig. 1). Presently there are 45 patients in our program in active transition or T1–T4 stages. Additionally there are 110 patients in the T0 stage seen only by pediatric urology. Adult patients that did not participate in the REACH formal transition clinic are monitored and categorized as T4x for long-term surveillance and tracking. Although suggested ages are mentioned, readiness for transition is of more emphasis for progression through the stages. The team stresses with the patient and caregivers the importance of the transition process and long-term implications for their health care. It is also important that ultimately the patient decides when she/he is ready to move on to the next stage.

T0

T0 stage are patients not yet old enough to transition but have been identified and categorized eligible to transition once reaching adolescence. The age of these patients ranges from birth to 12–14 years old. Patients and their families/caregivers are managed by the pediatric team only.

T1

T1 is the first stage of active transition. Once patients reach adolescence they are introduced to the program. The typical age ranges from 12 to 15 years old depending on the individual maturity and readiness of the patient and caregivers. The pediatric urologist remains the primary provider. At each visit, discussion of transition is initiated and a readiness assessment is performed by the REACH team. This tool evaluates the patient’s understanding of their medical diagnoses, surgical history, medications, allergies, and processes to access care. The family, medical team, and the patient prioritize goals to improve self-efficacy and independence for each patient.

T2

T2 is the second stage of active transition. This stage patients are typically >16 years old and have demonstrated more advanced readiness to begin interjection of the adult team. The patients are still in the care of the pediatric team but the adult team is introduced. At this stage, validated questionnaires are given to evaluate common issues including independence, bladder and bowel, and quality of life indicators. Sexual education is offered. A medical passport is developed with the assistance of the patient and family/caregivers to provide support toward responsibility and independence of healthcare. The clinical social worker performs an evaluation of potential barriers to transition such as intellectual ability, education, limited social support, mental health concerns, transportation, finances, adaptive equipment, and insurance coverage. At that time, if any foreseen obstacles are identified, the social worker assists the patient and family in locating appropriate resources, which may include monthly peer support groups held in our pediatric clinic. Readiness scores are developed as a sum of reaching transition milestones derived from questionnaires, team assessment, and most importantly patient and family input.

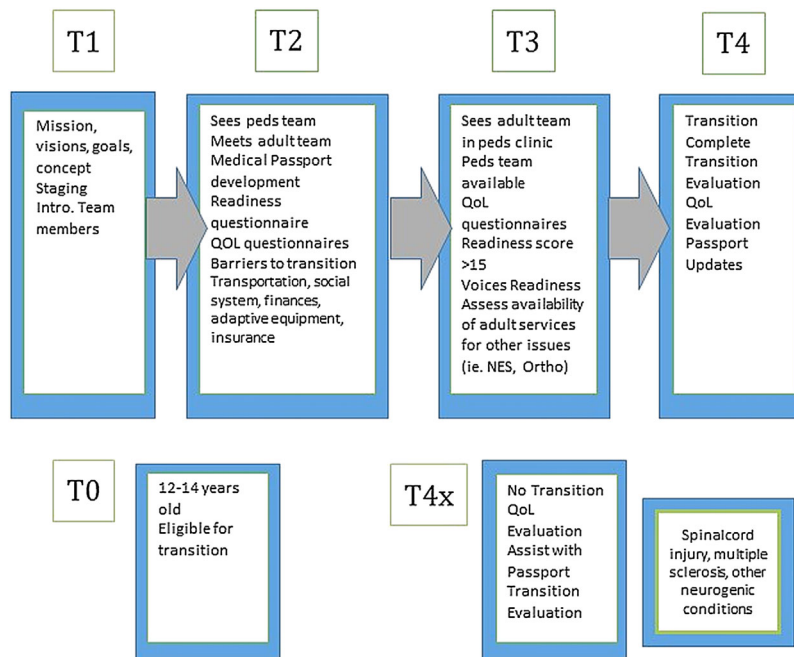


Fig. 1. REACH framework.

T3

T3 is the third stage of active transition. At this stage, the patient has demonstrated a readiness to transition into adult care determined by a readiness score of >15, determinate by the REACH team, and again with patient and family/caregivers input. The visits continue to be conducted in the familiar pediatric clinic setting with availability of the pediatric team. However, the care is now provided by the adult team. The validated questionnaires are again performed to assess independence, bladder and bowel, and quality of life indicators. Additionally if desired, sexual health is discussed and applicable questionnaires are implemented. Our social worker continues to re-assess any barriers to transition to adult care during this stage. The patient's goals for independence are revisited and appropriate interventions are instituted as indicated. In general, T3 is typically 1–2 visits because the patient is well prepared and ready to be seen in the adult setting. The patients have become accustomed to their new adult provider and are reassured the care will be the consistent but now housed in the adult clinic setting.

T4

T4 is the final stage of active transition. At this stage, the patient has successfully graduated the program and are now adult patients seen by the adult providers in the adult setting. Transition is considered complete and a transition satisfaction survey is performed to evaluate the transition process. For patients who have limited social support and continue to have barriers to accessing care, the social worker continues to provide support services for the adult patients who have transitioned to adult care.

Transition Readiness Assessment

The transition readiness assessment is a 12 question survey adapted from resources provided by the organization GotTransition.org (see Supplementary Material). The items on the survey are evaluated by the social worker to assess the patients' self-care perception and present independence in healthcare practices. The survey maximum score is 30. The determined readiness milestones have been agreed to be 15 or greater on the readiness assessment and general consensus from the patient, family, and transition care team to progress to the next transition phase.

Transition Satisfaction Survey

The transition satisfaction survey instrument was adapted from available resources from GotTransition.org (see Supplementary Material). This questionnaire is implemented after transition is complete to evaluate the patients' experience and perception of the transition process. The 20 question survey assesses experience of transition but also the experience with their new adult provider. An evaluation of 15 completed surveys from young adult patients who did not have a formal transition, the pediatric experience was rated highly however on preparation and readiness for adult transition only 42.9% felt prepared for seeing their adult provider. Moreover, 26.7% requested more and earlier information on their new adult providers. The median age for visit to adult provider was 20 years old.

Validated Questionnaires

Beginning in T2 stage, validated and reliable questionnaires are employed to assess quality of life and independence, incontinence,

bowel function, and sexual health as indicated. These instruments and surveys are useful to quantify and compare prior scores of these common issues and challenges for the neurogenic bladder and bowel population. These study instruments include SCIM, SF-8 Health inventory, ICIQ, UDI-6, IIQ-7, OAB-V8, OAB-q, neurogenic bowel dysfunction score, SHIM, and SIDI-F.

Clinical Tests

The REACH clinic exercises routine assessments including a detailed history and physical, routine urodynamic studies, renal ultrasound or other upper tract imaging, urine analysis, post void residuals and other labs as indicated, as well as aforementioned questionnaires and surveys (Fig. 2).

Surgical Management

Common health problems or quality of life issues in this population include bladder and bowel incontinence and/or retention and constipation, upper tract disease, kidney, bladder, and ureteral stones, UTIs, and sexual dysfunction with or without infertility. There are several treatments for these clinical issues including surgical and non-surgical interventions. There are many minimally invasive and open reconstructive procedures available. Both the pediatric and adult team consult with each other before performing procedures and assist each other in the operating room as well as coordinating pre- and post-operative management. In some instances, referral or consultation with other specialties is necessary (Fig. 3).

RESULTS

Current Patient Numbers in the REACH Clinic

Stage	Number
Stage T0	110
Stage T1	20
Stage T2	13
Stage T3	3
Stage T4	9
Stage T4×	100

EFFECTIVENESS OF A DEDICATED FRAMEWORK

- Future research and comparisons: The endeavors of tracking and monitoring both populations will allow future comparisons of the groups; formal and informal transition to adult health care settings of these patients,
- Expansion of the REACH transition model to other centers and/or disciplines,
- Reduction of emergency room visits by providing continuous health care,
- Improve long-term outcomes by:
 - Communication between pediatric and adult specialties,
 - Social work,
 - Research,
 - Establishment of a transition clinic fellowship,
 - Education for health care providers.
- Decrease health care costs secondary to morbidity and mortality.

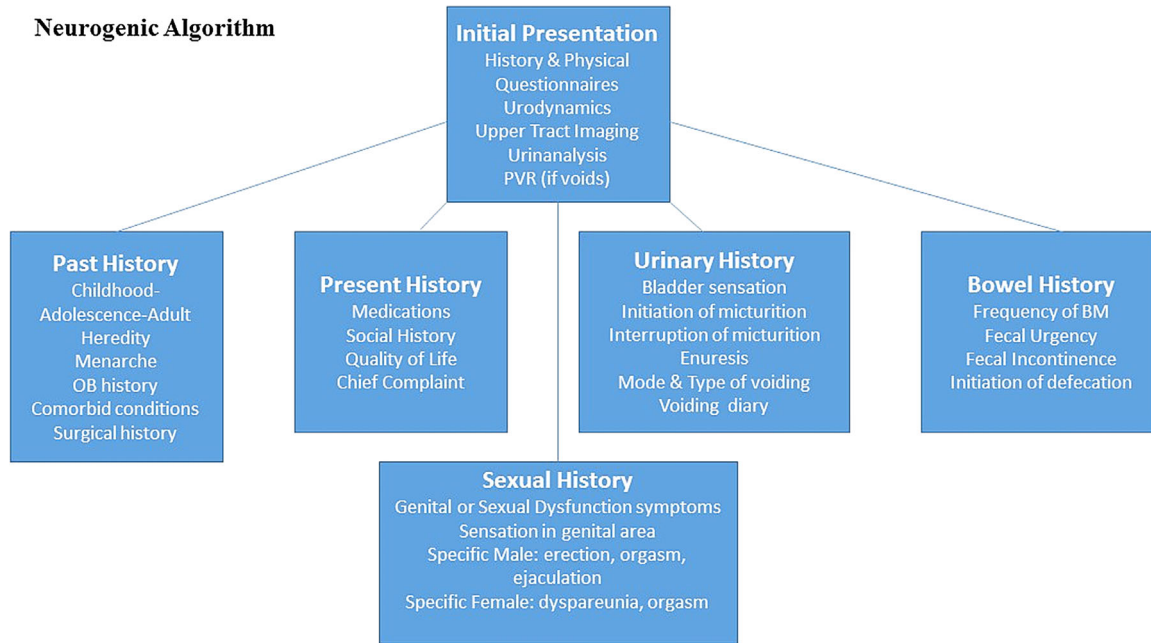


Fig. 2. REACH algorithm I.

CONCLUSION

Improved survival rates of patients with SB and other neurogenic bladder disease reaching adulthood is a significant consideration for pediatric and adult urology health care teams.¹⁷⁻¹⁹ The literature on transitional care processes in patients with chronic illnesses or diseases, including SB, emphasizes the desperate situation of transition processes in regard to health care costs, morbidity and mortality, and the evident need to transform or augment the transition process.^{3,20,21} However, with the apparent need to augment transitional care, there is a lack of consensus on how to

appropriately and adequately achieve successful health care transitions with limited recommendations or direction.¹⁷⁻²¹ This transition program was developed in a response to the obvious need to improve transitional care processes in the aging pediatric patient population with chronic neurogenic bladder conditions.²²

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Diagnoses & Treatment Algorithm

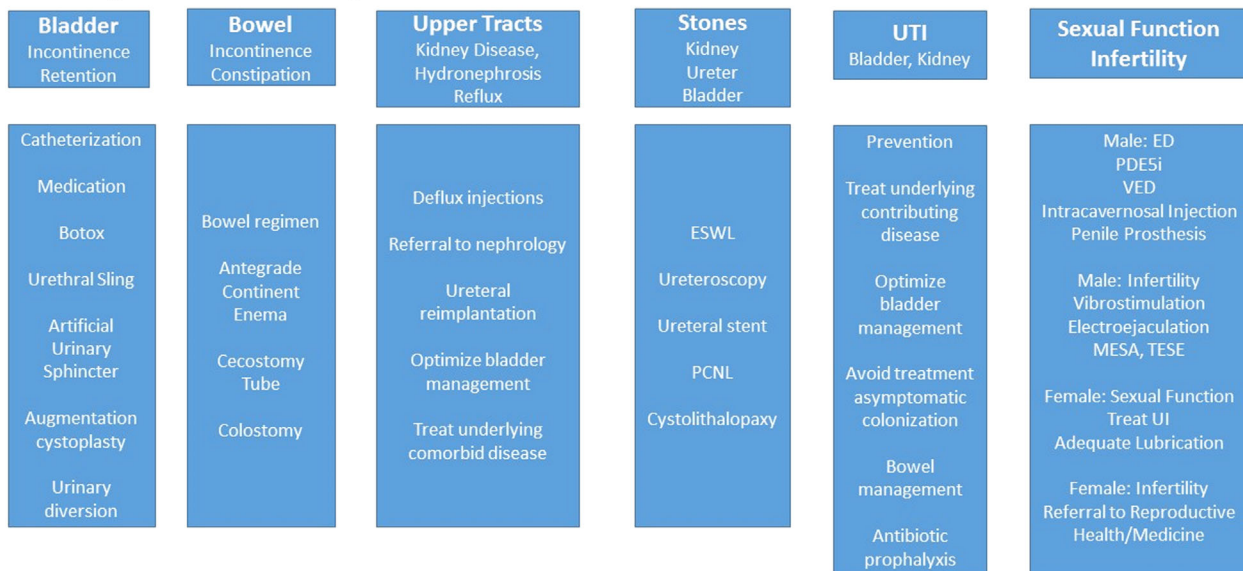


Fig. 3. REACH algorithm II.

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Supporting Information

Additional supporting information can be found in the supporting information tab for this article.