S.M.A.R.T. Transitions: A Program Evaluation

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ABSTRACT

Introduction: Various programs have been proposed to facilitate more successful transitions from pediatric to adult care for children with special health care needs. Few have been evaluated for their effectiveness. The purpose of this project was to systematically evaluate the Duke Complex Care Clinic using the social–ecological model of adolescent and young adult readiness for transition (SMART).

Methods: Cross-sectional data were acquired from surveys of 23 patient/parent dyads and from retrospective chart reviews for 50 patients. After the initial program evaluation, a pilot transition readiness tracking tool was implemented.

Results: Documentation of compliance with the SMART domains was high. Despite high satisfaction with the clinic and a focus on transition, many of the patient/parent dyads expressed low confidence in their ability to transition successfully.

Conclusions: Transition beliefs and expectations should be further assessed and addressed in transition care visits. Further modification of the patient tracking tool and clinic flow may improve patient transition outcomes. J Pediatr Health Care. (2018) *32*, e81-e90.

KEY WORDS

Adolescents, program evaluation, special health care needs, transition program, young adult

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INTRODUCTION

Children with special health care needs (CSHCN) are youth with chronic health conditions who require more health and related services than average children (U.S. Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2013). An estimated 9.4 million children in the United States have a special health care need (U.S. Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2013). Many CSHCN experience poor health outcomes when they move to adult care, including poor disease-specific outcomes, decreased medication compliance, decreased follow-up care, and decreased quality of life (Campbell et al., 2016; Hergenroeder, Wiemann, & Cohen, 2015; Joly, 2015). The USDHHS, HRSA, and MCHB recommend that "youth with special health care needs receive the services necessary to make appropriate transitions to adult health care" (2013, p. 46).

To facilitate transition to adult care, transitional care programs and interventions provide support through provider, parent, and patient education and guidance. The (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians, 2002) endorse the use of transitional care programs.

Although various institutions have endorsed transitional care programs, little has been done to study the programs' effectiveness at improving patient outcomes (Pai & Ostendorf, 2011; Watson, Parr, Joyce, May, & Le Couteur, 2011). This lack of information creates a large gap in clinical knowledge about the proper use, implementation, and efficacy of transitional care interventions (Sharma, O'Hare, Antonelli, & Sawicki, 2014; Watson et al., 2011). Systematic evaluation of established transitional care programs, based on recommended standards and models of care, can help determine their effect on quality of care and patient satisfaction and suggest recommendations for future program improvement.

Various interventions and care frameworks have been created to improve the transition process (Hislop, Mason, Parr, Vale, & Colver, 2016; McNeil, 2011; McPheeters et al., 2014; Nagra, McGinnity, Davis, & Salmon, 2015; Sharma et al., 2014; Schwartz et al., 2014; van Staa, Jedeloo, van Meeteren, & Latour, 2011; Watson et al., 2011). The social–ecological model of adolescent and young adult readiness for transition (SMART) expanded the focus of transitional care from patient characteristics (e.g., disease knowledge and skills) to a social–ecological model (Schwartz et al., 2013; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). The SMART model blends modifiable subject variables: knowledge, skills/self-efficacy, beliefs/expectations, development, goals, relationships, and psychosocial functioning with sociodemographics and patient characteristics (Table 1). Although the model encompasses patient, parent, and provider aspects of transition, it also identifies areas responsive to potential interventions in the medical setting related to the modifiable subject variables. Creators of the SMART model postulate that addressing the seven modifiable domains within the context of adolescent transition will improve transition readiness and success in adult-oriented care (Schwartz et al., 2011).

The Duke Complex Care Clinic was established in 2014 to provide consultative services to youth and families with the aim of improving transition outcomes in CSHCN and has not previously been evaluated. The model on which the clinic operates is the SMART (Schwartz et al., 2011, 2013). A program evaluation was designed to systematically measure how well the clinic was meeting its aim of providing quality transitional care for clinic participants. The evaluation results will be used as a baseline from which quality improvements can be implemented and evaluated in an ongoing manner. The purposes of this project were (a) to evaluate the compliance of the Duke Complex Care Clinic with the seven core domains of the SMART model and (b) to assess patient and parent satisfaction by performing a program evaluation.

As they reach young adulthood, CSHCN transition from the pediatric to adult health care settings.

TABLE 1. Components of the social–ecological model of adolescent and young adult readiness for transition (SMART)[a]

Components of SMART	Definition	Facilitators of Transition	Barriers to Transition
Nonmodifiable factors			
Sociodemographics/ culture	Age, race, SES	Older age, White, high SES	Younger age, minority race/ ethnicity, low SES
Access/insurance	Degree of access to health care	Sufficient insurance, access to providers in both adult and pediatric specialties who can assist with transfer	Lack of insurance, does not have access to providers in both adult and pediatric specialties who can assist with transfer
Health status	Disease type/history, associated health problems	Medical condition common in adulthood can be cared for by adult provider	Medical status necessitates pediatric expertise
Neurocognition	Neurocognitive status	Average or above average IQ	Cognitively impaired
Modifiable factors affecting transition readiness			
Knowledge	Knowledgeable about disease history and health status	Patient, provider, and parents know details of health history	Patient, provider, and/or parents unknowledgeable about patient health history
Skills/efficacy	Skills related to handling health and transition	Patient is able to manage disease Parent can support patient self-management	Patient is not able to autonomously manage disease
Beliefs/expectations	Beliefs related to transition and/or adult care	Understands that an adult provider is needed	Believes that an adult provider will not be able to care for patient's needs
		Believes experience in adult care will be positive	Feels that the experience in adult care will be negative
Development	Developmental maturity needed for successful transition	Developmentally mature, functioning autonomously	Developmentally immature, not functioning autonomously
Goals	Goals related to transition	Goals enable patient autonomy and effective transition to adult care	Staying with pediatric providers with no interest in transition
Relationships	Relationship among patients, providers, and parents	Collaborative relationships with the goal of supporting patient's transition	Dependent on parents or providers Lacks support for transition to adult care
Psychosocial functioning	Psychological conditions, family functioning, emotions regarding transition	Psychologically healthy, family functions well, handles stressors appropriately, feels prepared for transition	In current psychological crisis, family is unsupportive concerned or feels unprepared for transition

Note. *IQ, intelligence quotient; SES, socioeconomic status.*
[a]*Adapted from Schwartz et al. (2011, p. 886).*