

TRACKING S.M.A.R.T. TRANSITIONS: A PROGRAM EVALUATION

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A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice in the Family Nurse Practitioner Program in the School of Nursing

Chapel Hill
2017

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ABSTRACT

Kelly Cadogan: Tracking S.M.A.R.T Transitions: A Program Evaluation
(Under the direction of Julee Waldrop)

Background and Rationale: Compared to their peers, children with special healthcare needs (CSHCN) are at increased risk of poor health outcomes secondary to their transition to the adult healthcare system. Various programs have been proposed to facilitate more successful transitions for CSHCN. Due to the novelty of such programs, few have been evaluated for their effectiveness in improving the transition experiences of CSHCN.

Purpose: The purpose of this project was to evaluate compliance with the seven core domains of the social-ecological model of adolescent and young adult readiness for transition (SMART) model and improve upon the Duke Complex Care Clinic by performing a program evaluation, implementation of a pilot patient transition readiness tracking tool and a patient/parent survey.

Methodology: Cross-sectional data was acquired from patient and parent surveys and data from retrospective chart reviews to determine clinic compliance with the SMART model. Following the initial program evaluation, a pilot transition readiness tracking tool was implemented.

Results: Fifty patient records were included and 72% had all seven SMART domains documented and were considered 100% complete. Overall the charts were 94.58% complete. Transition beliefs and expectations was the lowest represented domain found only in 76% of

patient charts. No correlation was found between gender, age, number of clinic visits or disease type and completeness of documentation of all domains.

Twenty-three patients/parents were surveyed over 18 weeks. Seventeen questions were asked using a five-point Likert scale; the average scaled response was 3.74/5. A total of 15 patients were included in the pilot testing of the transition tracking tool. Of the 15 patients, 11 patients had one goal entered; two patients had three goals while the remaining two patients had two goals; no follow-up was completed on any of the patients' goals.

Conclusions: Transition beliefs and expectations should be further assessed and addressed in patient transition visits. Overall patients and parents were satisfied with their care at the clinic and the support given by providers and caregivers yet expressed low confidence in their ability to transition successfully. Further modification of the patient tracking tool and clinic flow should improve patient transition outcomes.

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LIST OF ABBREVIATIONS

AAFP	American Academy of Family Physicians
AAP	American Academy of Pediatrics
ACA	Affordable Care Act
ACP	American College of Physicians
AYA	Adolescent and young adults
CARDIO	Cardiology
CDC	Center for Disease Control
CSHCN	Children with special healthcare needs
DEVE	Developmental
DNP	Doctor of nursing practice
EMR	Electronic medical record
ENDO	Endocrinology
ENT	Ear, Nose and Throat
HRSA	Health Resources and Services Administration
GI	Gastrointestinal
GU	Genitourinary
GYN	Gynecology
HEME	Hematology
MCHB	Maternal and Child Health Bureau
MSK	Musculoskeletal
NEURO	Neurology
ONC	Oncology

PSYCH	Psychology
RESP	Respiratory
SES	Socioeconomic status
SMART	Social-ecological model of adolescent and young adult readiness for transition
USDHHS	United States department of health and human services

CHAPTER 1: INTRODUCTION

Background and Significance

Children with special health care needs (CSHCN) are youth with chronic health conditions who require more health and related services than average children (United States Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2013). It is estimated that 750,000 CSHCN transition from the pediatric to the adult health care setting in the United States every year (Scal & Ireland, 2005). Often, CSHCN develop worsening 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., 2010). The United States Department of Health and Human Services (USDHHS), Health Resources and Services Administration (HRSA), and the Maternal and Child Health Bureau (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 the change to adult care, transitional care programs and interventions provide support through provider, parent, and patient education and guidance. The American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), the American College of Physicians (ACP), and Healthy People 2020 endorse the use of transitional care programs (AAP, AAFP, & ACP, 2002; USDHHS, 2011). To further aid providers’ facilitation of the transition process among their adolescent patients, the Social-ecological Model

of Adolescent and young adult Readiness for Transition (SMART) was created to identify criteria reflective of transition readiness with a focus on the social-ecological variables of transition in all CSHCN (Schwartz et al., 2013; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011).

Problem Statement

Insufficient data is available to affirm the efficacy of transition care programs for CSHCN. Although various institutions have endorsed transitional care programs, little has been done to study the programs' effectiveness at improving patient outcomes (Pai & Ostendorf, 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). Systematic evaluation of established transitional care programs, based on recommended standards, can determine their effect on quality of care and patient satisfaction and suggest recommendations for future program improvement.

Local Problem

Within the Duke Complex Care clinic (formally the Duke Transition clinic) there is great need for a program evaluation. The clinic's current function is consultative with the aim of improving transition outcomes in CSHCN, and augmenting research in the field of transitional care of adolescents moving to adult care, as well as educating physicians during their rotation in transitional care within residency training programs. While much has been done to educate resident physicians regarding the challenges and techniques within transitional care, little information has been gathered to determine the quality of care that young adults receive in the clinic. Therefore, a program evaluation is needed to measure the effectiveness of the aim of the clinic: quality transitional care for clinic participants. The evaluation will become the baseline from which quality improvements can be implemented and evaluated in an ongoing manner.

Preliminary evaluation, based on key stakeholder conversations reveals a need for an implementation of a patient and/or parent survey that measures transition attitudes, readiness and satisfaction. A concurrent chart review measuring core elements of the SMART model (the model of care which the clinic uses) in provider transitional care plans will be followed by implementation of a pilot transition readiness tracking tool.

Purpose of Project

The purpose of this project was to evaluate compliance and improve the compliance of the Duke Complex Care clinic with the seven core domains of the SMART model by performing a program evaluation, piloting the implementation of a patient transition readiness tracking tool, and assessing patient/parent satisfaction with care.

CHAPTER 2: REVIEW OF LITERATURE

Individuals of all ages and social strata undergo transitions at some point in their lives. Anthropologically, transitions are an expected part of every adolescent's life (Gennep, 1961). These "rites of passage" refer to the change from one phase of life to another as well as signal a successful integration into a society's culture (Gennep, 1961). Similarly, adolescents experience a cultural shift when they transition from pediatric to adult health care. Such changes are referred to as "care transitions" within the medical field (Geary & Schumacher, 2014).

As they reach young adulthood, CSHCN transition from the pediatric to adult health care setting. Unfortunately, as they transition, the children face a system that is unprepared for their unique health care needs, and the children frequently have difficulty navigating such a system (Scal & Ireland, 2005). This lack of preparation often has an adverse impact on the lives of CSHCN. Unsuccessful transitions have the potential to affect health outcomes, as reflected by decreased clinic attendance, increased hospital admission rates, decreased medication adherence, and lower compliance with illness-specific tasks (e.g. blood glucose monitoring) (Bloom et al., 2012; McManus et al., 2013; McPheeters et al., 2014; Pai & Ostendorf, 2011; Watson, Parr, Joyce, May, & Le Couteur, 2011). Studies measuring post-transition social outcomes for CSHCN have postulated that poor transitions have an adverse impact on life satisfaction including decreased employment, increased use of public assistance, and increased depression and anxiety in CSHCN who experience a substandard transition (Bloom et al., 2012; Kaufman & Pinzon, 2007; McPheeters et al., 2014; Watson et al., 2011).

Prevalence

Adolescent patients and their families are cognizant of their lack of preparation for transition. A survey conducted in 2010 by the USDHHS, HRSA, and the MCHB measured CSHCN transition readiness (USDHHS et al., 2013). In this survey, only 40% of the parents of CSHCN felt that providers had adequately prepared their child for transition to adult care, and only 31.6% had received all of the needed guidance to transition to adult care (USDHHS et al., 2013). Due to this perceived lack of support, only 21.6% of CSHCN involved in the survey successfully transitioned to adult health care (USDHHS et al., 2013). A successful transition is defined as a patient having routine preventive care in the adult setting and continuous health insurance coverage both of which can have an impact on the rest of the adult lives of CSHCN (McPheeters et al., 2014; Oswald et al., 2013).

Inadequate transitional care affects many of the youth in the United States. An estimated 9.4 million children in the United States have a special health care need, and of the youth between the ages of 12 and 17, approximately 18.4% in the United States have a special health care need (McManus et al., 2013; USDHHS et al., 2013). Owing to advances in the medical field, an estimated 90% of CSHCN are expected to survive into adulthood, and that percentage continues to rise with ongoing developments in pharmacology and knowledge of disease processes and treatments (Bloom et al., 2012). With the ever-increasing number of CSHCN transitioning into adult health care, it is imperative that they experience successful care transitions, lest they risk developing poor medical, psychological, and social outcomes (McPheeters et al., 2014; Sharma et al., 2014).

Barriers to Transition Success

Poor transitional outcomes often result from the accumulation of several different factors that inhibit adolescents' ability to access the care needed to make a successful transition.

Understanding the complexity of barriers to successful transition further validates the need for comprehensive and inclusive transitional care interventions.

Patient education. The majority of research into transitional care outcomes identifies inadequate patient education as the most common cause of poor patient outcomes (McDonagh, 2005; McManus et al., 2013; Scal & Ireland, 2005; Sharma et al., 2014). Because of the fundamental lack of autonomy during childhood and adolescence, patients often do not receive proper instruction regarding how to manage their individual conditions, which consequently decreases their ability to perform the basic self-care tasks necessary to maintain their health status (McDonagh, 2005; Okumura, Saunders, & Rehm, 2015). Upon transitioning to adult health care, an insufficient understanding of disease significance, process, and management decreases patients' probability of scheduling and attending necessary follow-up appointments, reduces medication compliance rates, and increases hospital admissions (Bloom et al., 2012; McDonagh, 2005; McPheeters et al., 2014; Pai & Ostendorf, 2011).

Culture differences. Studies have shown that, upon their transition to adult care, CSHCN often are unable to perform tasks such as appointment scheduling, refilling medications, and communicating with their adult health care providers (Kaufman & Pinzon, 2007; Okumura et al., 2015). This lack of experience is sometimes attributed to a cultural difference between pediatric and adult health care systems (Kaufman & Pinzon, 2007; Reiss, Gibson, & Walker, 2005; Rosen, Blum, Britto, Sawyer, & Siegel, 2003). Within the context of pediatric health care, patients are prompted by providers to address necessary medication refills, follow-up

appointments are often automatically generated, the in-office staff make referrals, and parents are encouraged to attend the adolescents' appointments (McPheeters et al., 2014). Conversely, clinics within the adult health care system typically have a culture that expects patient autonomy and independence in disease management (McPheeters et al., 2014). CSHCN and their families, along with their pediatric providers, often are unaware of or unprepared for the cultural differences between pediatric and adult providers and, consequently, have not been prepared to function autonomously within the new health care system (Geary & Schumacher, 2014; MCPheeters et al., 2014).

Insurance and cost. Insurance coverage and cost of transition interventions also influence transition success (Bloom et al., 2012; Hergenroeder, Wiemann, & Cohen, 2015; Pai & Ostendorf, 2011; Reiss et al., 2005; Rosen et al., 2003; Scal & Ireland, 2005; Sharma et al., 2014). Many CSHCN lose insurance coverage during their period of transition (Bloom et al., 2012; Hergenroeder et al., 2015; Reiss et al., 2005; Sharma et al., 2014). Lack of insurance drastically decreases the use of the medical system as a whole by CSHCN, and they often are unable to afford programs that address transitional care (Lotstein, McPherson, Strickland, & Newacheck, 2005; McDonagh, 2005; Pai & Ostendorf, 2011; Scal & Ireland, 2005; Sharma et al., 2014). With the 2010 Affordable Care Act (ACA), parental insurance coverage was extended to cover youth up to 26 years of age with the aim of improving adolescent insurance coverage (Hergenroeder et al., 2015). Currently, there is no research to show the impact of the law on transition outcomes in CSHCN.

In addition, providers are also often reluctant to offer transitional care programs, because insurance typically does not cover their cost. Transitional care education and programs are time-consuming, expensive, and logistically difficult to facilitate, and insurance providers often do not

adequately reimburse for the service (Jameson, 2011; Scal, Evans, Blozis, Okinow, & Blum, 1999; White, 2002).

Provider knowledge. Another common barrier to transition success is provider experience. Providers in the adult health care setting are often untrained in the diseases of childhood and are intimidated by the complexity of conditions experienced by CSHCN. These two shortcomings consequently decrease the quality of care given to CSHCN and the likelihood of providers admitting them into their practice (Bloom et al., 2012; Gold, Martin, Breckbill, Avitzur, & Kaufman, 2015; Lotstein et al., 2005; McDonagh, 2005; McPheeters et al., 2014; Nehring, Betz, & Lobo, 2015; Reiss et al., 2005).

Non-modifiable factors. Non-modifiable risk factors, such as race, socioeconomic status (SES), and gender, also worsen transition outcomes. Poor transitions are associated with low SES, more complex disease type, ethnic minorities, and emotional and developmental delays associated with disease processes and maturity (Lotstein, McPherson, Strickland, & Newacheck, 2005; McManus et al., 2013; Oswald et al., 2013; Pai & Ostendorf, 2011; Reiss, Gibson, & Walker, 2005; van Staa, Jedeloo, van Meeteren, & Latour, 2011; USDHHS et al., 2013). Ecological risk factors, such as gender, SES, and language are strong indicators of future transition success (Javalkar, Johnson, Kshirsagar, Detwiler, & Ferris, 2016).

Patient developmental level also affects transition outcomes. Attitudes and behaviors associated with adolescence can have an adverse impact on transition outcomes because of adolescents' desire to be liked by peers and to participate in risky behaviors (Kaufman & Pinzon, 2007; McDonagh, 2005; Paone, Wigle, & Saewyc, 2006). These behaviors decrease compliance with disease-specific tasks, medication, and appropriate follow-up with providers (McDonagh, 2005; McDonagh, Shaw, & Southwood, 2006; McPheeters et al., 2014). To circumvent the

prevalent attitudes and behaviors of adolescence studies have found that exploring patients' views and preferences surrounding their transitions can improve outcomes (Aldiss et al., 2015; Hislop, Mason, Parr, Vale, & Colver, 2016).

Transitional Care Recommendations

Although it can take many forms, transitional care includes interventions that optimize the quality of life of CSHCN and ensure that CSHCN receive the services needed to maintain their standard level of health. Transitional care also implies that CSHCN receive continued access to quality clinical care (McPheeters et al., 2014). To improve upon the transition process, various interventions and frameworks of care have been created to guide providers and patients through the transition process (McNeil, 2011; MCPheeters et al., 2014; Scal & Ireland, 2005). However, because of patients' various disease states and developmental levels, along with cultural expectations, providers and researchers have been unable to recommend one standardized model for all adolescents experiencing health care transitions (Kaufman & Pinzon, 2007). A variety of transitional interventions, frameworks, and patient and family training programs have been developed to address these issues (McPheeters et al., 2014).

Clinical pathways. Frequently studied interventions for transitional care includes individual or disease-specific transition timelines or clinical pathways (McPheeters et al., 2014). Ideally, transition timelines are created years before CSHCN are anticipated to transition to adult care (Gold et al., 2015). These timelines are formal written plans that involve the patient, his or her parents, and the provider (Kaufman & Pinzon, 2007; Nagra, McGinnity, Davis, & Salmon, 2015). The timelines are care plans that not only map out the expected date of transition, but also document goals for patients that prepare them for the transition (Nagra et al., 2015; Paone et al., 2006). Goals are either patient- or disease-specific and commonly include self-care, self-

advocacy, education, and social goals (Betz, 2013; Kaufman & Pinzon, 2007; McDonagh, 2005; Paone et al., 2006; van Staa et al., 2011; Watson, Parr, Joyce, May, & Le Couteur, 2011). The purpose of the timelines is to ensure that patients understand how to care for themselves and function within the adult health care setting (Bloom et al., 2012; Rosen et al., 2003). Programs that focus on known barriers and bottlenecks in the transition process have been shown better prepare patients for transition to adult care (Nieboer et al., 2014).

Transition preparation programs. Another recommended intervention is a transition preparation program. Transition preparation programs differ from transition timelines as they typically transpire over a few sessions, shortly before CSHCN transition to adult care (McPheeters et al., 2014). These formal programs focus on educating patients and their families in either individual or group settings about the transition process, different disease states, and self-advocacy in the adult health care setting (Bloom et al., 2012; F. Campbell et al., 2016; Gold et al., 2015; Okumura et al., 2015; Pai & Ostendorf, 2011; Rosen et al., 2003; Shaw, Southwood, & McDonagh, 2007a). However, the myriad of transition preparation programs described in the literature precludes systematic evaluation.

Addressing non-medical issues. Although the majority of transitional care programs focus exclusively on the medical aspects of care, some programs also include education about non-medical issues associated with transition (Kaufman & Pinzon, 2007). Topics commonly addressed include future employment, post-secondary education, sexual health, and developmental and psychological issues (Bloom et al., 2012; Kaufman & Pinzon, 2007; McDonagh, 2005; McPheeters et al., 2014; Pai & Ostendorf, 2011). Other programs work to closely include the family of the CSHCN within a more holistic approach (Duke & Scal, 2011; Monaghan, Hilliard, & Sweenie, 2013). Developers of such programs theorize that including

education about non-medical issues and involvement of families will improve patient transition outcomes, as transition complications often are partially related to non-medical issues that occur concurrently with transition (Kaufman & Pinzon, 2007).

Six Core Elements of Health Care Transition. The Six Core Elements for transition were created by the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health to mirror best practice recommendations from the AAP, AAFP, and ACP regarding adolescent transitions (Lemly, Weitzman, O'Hare, & O'Hare, 2013; McManus et al., 2014, 2015). The Six Core Elements include transition policy, transition tracking and monitoring, transition readiness assessment, transition planning, transfer of care, and transition completion (McManus et al., 2015). The Core Elements can guide providers, parents, and patients through the appropriate steps to transition to adult care successfully, as well as provide a framework for transitional care that can be completed by providers for any adolescent within the health care system.

Because of the newness of the Core Elements, studies incorporating them into transitional care program evaluation are few. However, portions of the model have been used successfully to shape program design and to restructure existing programs to reflect current guidelines and improve patient outcomes (Lemly et al., 2013; McManus et al., 2014, 2015). Notably, transition tracking and monitoring were recommended as a means to monitor and track the progress of CSHCN as they progress through the transition process to ensure that all transition needs are met before the finalization of the transition (National Alliance to Advance Adolescent Health, n.d.).

Patient tracking. Tracking patient transitions, a concept supported by the Six Core Elements of Health, proposes that CSHCN be identified and monitored through their transition (McManus et al., 2015). Constant assessment of patient and parent transition readiness

throughout the transition process carries the aim of ensuring that CSHCN receive all the appropriate and necessary care, meet transition goals and demonstrate readiness for adult healthcare (Lemly et al., 2013; McManus et al., 2014).

Measuring Outcomes in Transitional Care

Despite the numerous recommendations for transitional care programs, the programs have a continued need for evaluation, as their relative newness means their effect on patient outcomes is not well established (Celona, 2015; Watson et al., 2011). Several transition-specific tools have been developed to evaluate the efficacy of transitional care programs (Celona, 2015; Geary & Schumacher, 2014; Shaw et al., 2007a; Zhang, Ho, & Kennedy, 2014). Although disease-specific evaluation tools are available for transitional outcomes, several other tools have been created to measure transition outcomes, regardless of disease or developmental level. These tools measure patients' perceived readiness, comfort with disease-specific tasks, quality of life, and levels of independence (Campbell et al., 2010; Celona, 2015; Fair et al., 2016; Paone et al., 2006; Shaw et al., 2007; Stinson et al., 2014). Other studies have attempted to measure transition outcomes through patient transfer status (Chu, Maslow, Isenburg, & Chung, 2015; Stinson et al., 2014). Currently, few of the recommended evaluation tools have been used to assess patient outcomes after their transition, and those that have been used need further testing to prove their reliability (McPheeters et al., 2014; Sharma et al., 2014; Shaw et al., 2007a).

Program evaluation. The plethora of medical diseases and transitional program types impedes study of transitional care programs as a whole (McDonagh, Shaw, & Southwood, 2006; van Staa et al., 2011). Program evaluations are useful in the context of transitional care, as they are capable of systematically defining the efficacy of interventions currently in use and defining programs' policies and procedures (Centers for Disease Control and Prevention [CDC], 2015).

When performed well, program evaluations have the potential to guide future changes to programs as well as influence policies and have an impact on outcomes (CDC, 2015).

SMART model of transition readiness. Developed in 2011, the Social-ecological Model of Adolescent and young adult Readiness for Transition (SMART) helped expand the focus of transitional care from patient characteristics (e.g., disease knowledge and skills) to a social-ecological model (Schwartz et al., 2011). The SMART model blends socio-demographics, patient characteristics and modifiable subject variables: knowledge, skills/self-efficacy, beliefs/expectations, goals, relationships, and psychosocial functioning (see Table 1) blends socio-demographics, patient characteristics and modifiable subject variables: knowledge, skills/self-efficacy, beliefs/expectations, goals, relationships, and psychosocial functioning (see Table 1) (Schwartz et al., 2011). While the model encompasses both 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 (see Figure 1). 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).

Components of SMART	Definition	Facilitators of transition	Barriers to transition
<i>Non-modifiable factors</i>			
Socio-demographics/culture	Age, race, socio-economic status (SES)	Older age, Caucasian, high SES	Younger age, minority status, low SES
Access/Insurance	Degree of access to health care	Sufficient insurance, access to providers in both adult and pediatric specialties who can assist in transfer	Lack of insurance, does not have access to providers in both adult and pediatric specialties who can assist in 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
<i>Modifiable factors affecting transition readiness</i>			
Knowledge	Knowledgeable of disease history and health status	Patient, provider, and parents know details of health history.	Patient, provider, and/or parents unknowledgeable of patient health history
Skills/efficacy	Skills related to handling health and transition	Patient is able to manage disease. Parent can support patient self-management	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 experience in adult care will be positive	Believes that an adult provider will not be able to care for patient's needs. 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 amongst patients, providers and parents	Collaborative relationships with the goal of supporting patient's transition	Dependent upon parents or providers. Lack 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 feel unprepared for transition

Table 1. Components of the social-ecological model of AYA (adolescents and young adults) readiness for transition (SMART). Adapted from: (Schwartz et al., 2011, p. 886)

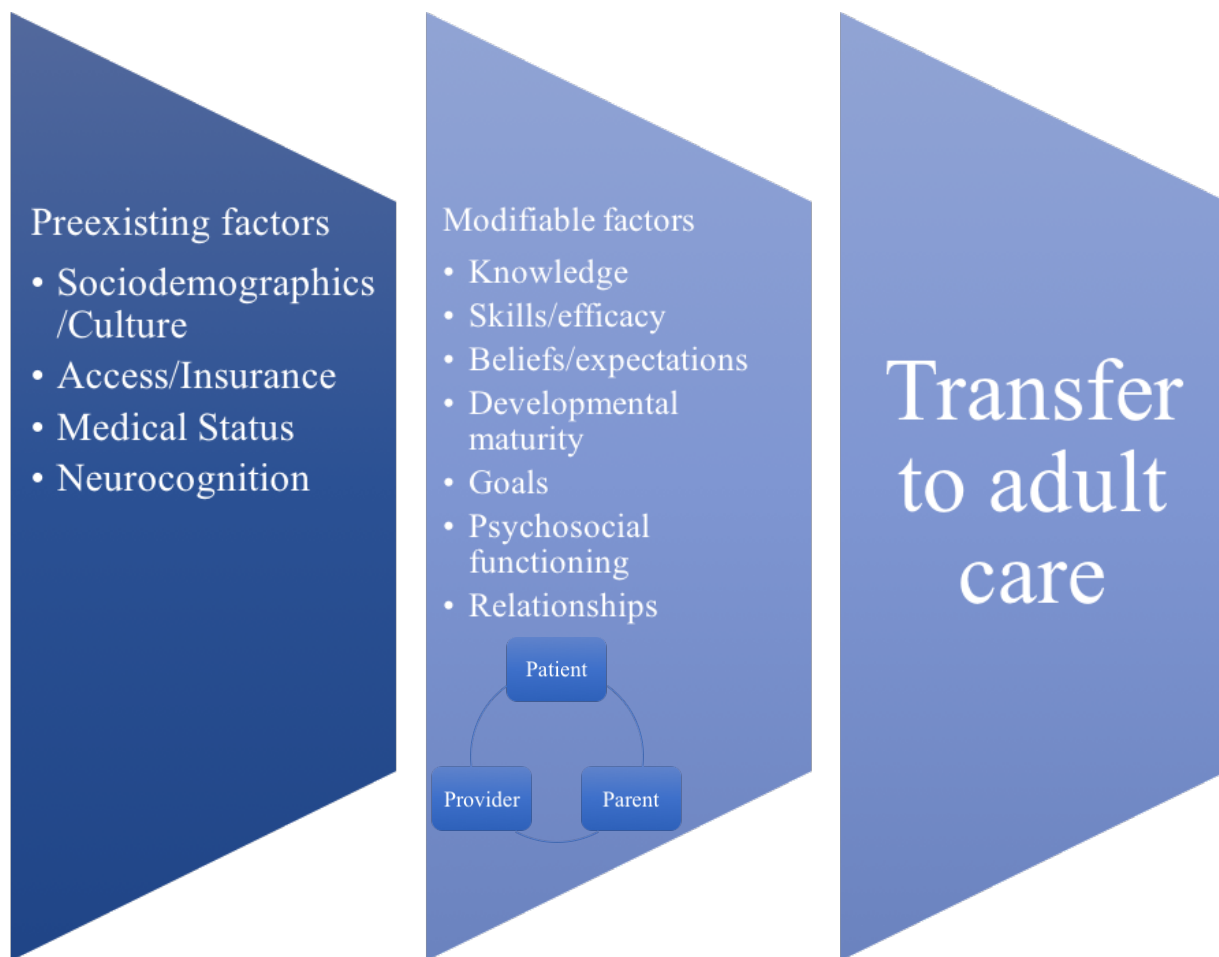


Figure 1. Social-ecological Model of Adolescent and Young Adult Readiness to Transition.
Adapted from (Schwartz et al., 2013)

Patient satisfaction. Patient satisfaction is commonly measured in transitional care programs (McDonagh, 2005; McDonagh et al., 2006; Shaw et al., 2007a; van Staa & Sattoe, 2014; Watson et al., 2011). At the same time, the triple aim of the United States health care system is to improve the experience of care and the health of populations and to reduce per capita costs of health care (Berwick, Nolan, & Whittington, 2008). Transitional care programs aim to improve upon all three areas (McManus et al., 2015; Sharma et al., 2014). Patient

satisfaction surveys are appropriate evaluation tools in the transitional care setting, as they help improve upon the triple aim by measuring patient experience of care.

Gaps in Current Literature

The need for interventions to improve transition outcomes in CSHCN is well established (Bloom et al., 2012; Lotstein et al., 2005; McDonagh, 2005; McPheeters et al., 2014). Although it is important to measure patient outcomes after the implementation of any intervention, some outcomes are difficult to measure objectively. Studies have shown that commonly used assessment scales are not relevant to all CSHCN, and their ability to accurately measure results is not well established (Celona, 2015). Moreover, certain outcomes that are commonly measured in transitional care, such as quality of life, are often unreliable in terms of determining overall success of patient transition success (Shaw et al., 2007). Furthermore, the majority of research in transitional care is cross-sectional with follow-up periods ranging between four and twelve months (Campbell et al., 2016). Increased follow-up periods after an intervention is performed are warranted to ensure that the studied interventions are successful over time (F. Campbell et al., 2016). However, further research is needed to determine if transition programs improve patient outcomes, including quality of life, disease-specific outcomes, medication compliance, and patient satisfaction.

CHAPTER 3: CONCEPTUAL AND THEORETICAL FRAMEWORK

The conceptual framework for this project was the CDC's Framework for Program Evaluation in Public Health. The CDC's Framework provides a guide for performing a program evaluation that assists evaluators both in gathering accurate data and making appropriate conclusions from the evidence (USDHHS & CDC, 2011). The Framework presents four standards and six steps for performing quality program evaluations (see Figure 2) (USDHHS & CDC, 2011).



Figure 2. Centers for Disease Control's Framework for Program Evaluation in Public Health.

Retrieved from: <http://www.cdc.gov/eval/framework/>

Four Standards of Evaluation

The first standard, **utility**, requires the evaluator to determine the need for the proposed evaluation, who will use the results, and if the proposed evaluation meets the user's needs (USDHHS & CDC, 2011). **Feasibility**, the second standard of evaluation, determines the practicality of the program evaluation, given the project's allocated resources and expertise (USDHHS & CDC, 2011). To ensure the program is legal, ethical, and humane in nature, the CDC instituted the third standard of **propriety** (Grembowski, 2016). **Accuracy**, the final standard, encourages the evaluator to gather valid and reliable data within the scope of the proposed evaluation (Grembowski, 2016).

For the proposed project, all four standards were addressed before the final design of the program evaluation began. To determine the efficacy of the program, the Duke Complex Care Clinic demonstrated great need for a program evaluation as the clinic was two years old and had never been evaluated (utility). The project was created to be performed within the skill and scope of the examiner (feasibility), with a design that ensured validity of the results (accuracy). Propriety was protected with a project design that was both ethical and legal as determined by IRB approval.

Six Steps of Evaluation

To guide the process of program evaluation, the CDC Framework includes six steps that facilitate the various stages in a successful program evaluation (see Figure 2) (USDHHS & CDC, 2011). The six steps include 1) engaging stakeholders, 2) describing the program, 3) focusing the evaluation, 4) gathering credible evidence, 5) justifying conclusions, and 6) sharing lessons learned (USDHHS & CDC, 2011). The six steps are meant to be completed as part of a quality improvement cycle; completion of the sixth step of the evaluation should follow the first phase

of the framework to ensure continuous program improvement, if appropriate (USDHHS & CDC, 2011). Adherence to the Framework helps define the scope of program evaluations and guides the process to produce meaningful and valid results for program improvement.

CHAPTER 4: METHODOLOGY

The program evaluation was conducted in two phases. The first phase, the initial program evaluation, used a multiple methods approach in a cross-sectional descriptive design. The evaluation focused on quality of care and patient/family experience and satisfaction. The program evaluation used both cross-sectional and retrospective data collection methods. Cross-sectional data was acquired from patient and parent surveys to assess patient and parent satisfaction, readiness to transition, and perception of the clinic's compliance with the social-ecological model of adolescents and young adults (AYA) readiness for transition (SMART). Retrospective data from chart reviews was gathered to determine if documented transition assessment incorporated the SMART model. The second phase was the implementation of a transition readiness tracking tool. All interventions were approved by the IRB at Duke and given exempt status through UNC's IRB.

Survey Participants

Eligibility requirements for patients to participate in the survey portion of the evaluation were as follows:

- Must be a current patient of transition clinic
- Must be approved by presiding physician for inclusion in the study
- Must be able to speak and read English

Patients were excluded if unable to fill out the survey if their parent determined that he or she was unable to do so for any reason. If the patient was unable to participate in the study, the

parents of the patient were included, if they agreed to participate. Parents were excluded if they were unable to speak and read English.

Patient Record Review

Inclusion of patient record in chart review were current patients that had attended at least one clinic appointment OR past patients who had already completed the transition program within the time frame of July 30, 2014 to May 2016.

Setting

Duke University Health System's approach to transitional care for CSHCN is a novel one. Children with complex medical needs are referred to this separate clinic within the health system that focuses exclusively on transitions. Duke patients who are 14-25 years old can be referred to the transition clinic by their attending pediatric physicians if they are having difficulty adhering to medical regimens, performing adequate self-care, or establishing an independent relationship apart from their parents. The Duke Children's Complex Care Clinic is the foundation of the Duke Children's Transition Program, which is part of the Department of Adolescent Medicine (Duke Children's, 2015). The clinic is primarily staffed by one full-time program coordinator/social worker and two physicians, one specializing in adolescent health and the other in adolescent mental health (Duke Children's, 2015). The remainder of the provider staffing needs is met by physicians in the Duke Hospital Pediatric Residency program.

The clinic serves patients once each week, on Fridays, in various locations throughout the Duke University Health System campus. Currently, the patients served are primarily children with complex health problems that affect a combination of the patient's mental, medical, and physical health. During the project, the clinic was changed to the "Complex Care Clinic" to include children of all ages who have complex medical conditions.

The clinic's model of care centers around the SMART model, which is incorporated into the initial transition assessment that is performed on all children and young adults referred to the clinic. The clinic aims to provide care that meets the individual needs of the participants, with a view to assist them in developing a meaningful life and transitioning into both the adult world and health care setting.

Tools

The patient and parent survey was developed from a modified version of the "Mind the Gap" Scale, with additional questions to measure patient and parent perceptions of clinic implementation of SMART and patient/parent satisfaction (Schwartz et al., 2011; Shaw et al., 2007a) (see Appendices A and B). The survey consisted of one question measuring the number of clinic visits and 17 questions on a five-point Likert scale measuring transition attitudes, general satisfaction, and perceptions of clinic compliance to SMART principles. The final question was a free response to be answered by the subject assessing patient and parent suggestions for clinic improvement. The Flesch-Kincaid formula verified readability, and wording was adjusted to a level of 7.1 (fairly easy), within the range of the average American reading ability (Calderon, Morales, & Liu, 2006). Separate surveys were administered to patients and their parents to adjust to appropriate pronouns and the participant's role in the transition. The survey was conducted in clinic on paper.

The chart review measured patient experience using the definitions of the seven modifiable components of SMART as the measurable outcomes (see Table 1). If any of the seven elements of the SMART model were identified, the presence of the domains was documented.

Procedures

The first three steps of the CDC's Framework for Program Evaluation were addressed during the design process of the proposed project. The first step, engage stakeholders, was done within the context of the transition clinic where clinic needs were assessed, and stakeholder support from providers was gained. The second step, describing the program, occurred after the stakeholder meeting and clinic goals and strategies were evaluated to ensure that the created program would fit with the clinic's needs. Finally, the third step, focus the evaluation design, was met through careful consideration of stakeholder input of a program design that would address the needs of the clinic and support improvement in the care of the patients that it serves.

The implemented program evaluation addressed the final three steps of the CDC's Framework for Program Evaluation in Public Health by systematically gathering credible evidence, justifying conclusions, and then sharing lessons learned (USDHHS & CDC, 2011).

Phase 1

The fourth step of the program evaluation as outlined by the CDC's Framework for program evaluation, *gathering credible evidence*, included a patient satisfaction survey and a patient chart review. The patient and parent survey was conducted with patients and parents who were present for appointments on the survey collection dates. The survey was administered in paper format. A waiver of consent was completed by the participants before the start of the survey; the waiver stated that participation was not mandatory and that anonymity would be safeguarded. No identifying information was included in the survey. Data was collected over 22 clinic days; sample size was determined by the number of patients present at the clinic and the number willing to participate in the survey. For the final question of the survey, the free

response, all responses were recorded as written by the participants and placed on a table to be analyzed for major themes and topics (see Table 5).

The chart review was conducted on a list of past and present patients seen for the purpose of transitioning to adult care. Documentation was evaluated for the presence of the seven modifiable SMART domains. The presence of each domain was determined by the published definitions of each domain by the creators of SMART (see Table 1). The number of completed visits and disease type was also recorded to determine if there was an association between clinic attendance or disease and SMART compliance. The presence or absence of documentation of the seven SMART domains was collected using a data extraction tool (see Appendix C). Data from individual patients was recorded in the order of randomization with no identifying information logged. A sample size of 50 patients was used.

The fifth step of the evaluation, *justifying conclusions*, is part of the data analysis process which was conducted with basic descriptive statistics on the results retrieved from the chart review for the SMART domains. The results helped determine the recommendations for the final step of the program evaluation: sharing lessons learned. Areas that are in need of improvement, as well as areas in which the clinic excels, were identified, and recommendations for future program improvement were created.

Phase 2

After identifying baseline charting compliance, a tracking tool for patient transition goals was developed (see Appendix D). The tool was to be updated with each patient visit and serve as an overview of the patient's journey toward a successful transition. Because many different resident physicians are rotating through this clinic, this overview can help providers focus on areas that still need planning and support without having to search back through the patient

records when they are not familiar with the patient. This tool was piloted in a low-tech manner using a paper form, during a three-month period, each transition patient seen in the transition clinic was to have transition readiness tracking form started.

Data Analysis

Survey

Data analysis was conducted with basic descriptive statistics including mean, median, mode, standard deviation, and frequency distribution to describe the 17 structured-response items in the patient satisfaction survey. A frequency count table was constructed to analyze the subject responses, with appropriate histograms generated. Surveys were scaled by assigning a numerical number to each of the five responses. Typed patient and parent responses were recorded as written and analyzed for major themes.

Results were also turned into a dichotomous variable with strongly disagree, disagree, and neither disagree nor agree counted as disagree and strongly agree and agree were assessed as agree. This dichotomous analysis was completed due to the small sample size.

Chart Review

Data analysis, with basic descriptive statistics, was further deployed to describe the presence of the seven domains in the SMART model of transition readiness. Statistical analysis included standard deviation, mean, median, mode, and frequency distribution. Both a spreadsheet of each chart reviewed and a frequency count table were used.

Data gathered from both the patient and parent survey and chart review for the seven modifiable SMART domains was analyzed and generated into histograms, when appropriate. Implications for future practice changes were produced from the findings.

Post Transition Tracking Tool

The number of patients for which the transition tracking tool was used were counted along with the number of goals per patient and presence of goal follow up. Patient goals were recorded to find common themes within the tool.

CHAPTER 5: RESULTS

Chart Review Results

Demographic data. Fifty patient charts were reviewed. Of these 50 patients, 26 (52%) were female and 24 (48%) were male. Patients ranged in age from 15 to 30 years, with a mean age of 20.56 years. Total number of visits per patient ranged from one to seven with an average of 2.08 visits completed per patient.

Patient medical conditions were sorted into 13 categories: cardiac (CARDIO), developmental (DEVE), endocrinology (ENDO), ear nose and throat (ENT), gastrointestinal (GI), genitourinary (GU), gynecology (GYN), hematology (HEME), musculoskeletal (MSK), neurology (NEURO), oncology (ONC), psychology (PSYCH), and respiratory (RESP). Patients could only be sorted into each disease type once. Patients ranged from having one to four disease types, with a mean of 2.34 disease types and a mode of two disease types (see Figure 3). Most common disease categories were psychological and developmental, with 27 patients in each, and neurology with 20 (see Figure 4).

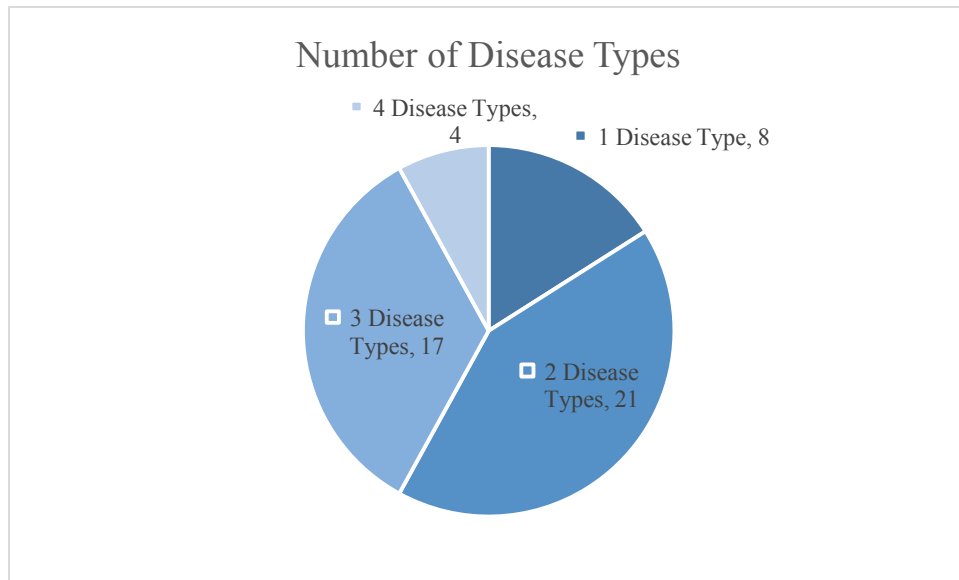


Figure 3. Number of disease type per patient

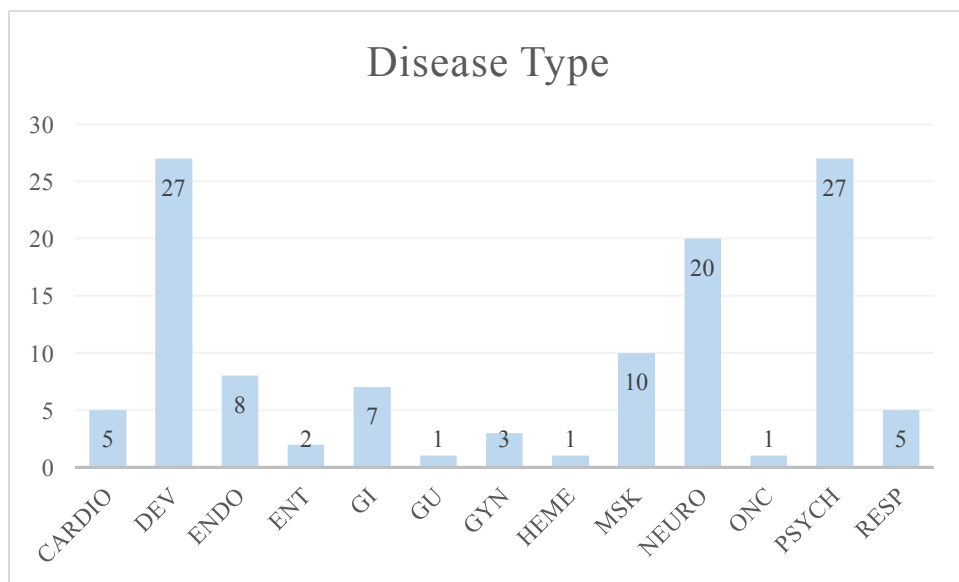


Figure 4. Number of patients per disease type

Presence of SMART domains. The presence of the seven domains under the SMART model was assessed in each patient chart using criteria listed under the modifiable factors in the SMART model (see Table 2). The first domain of knowledge, the fourth domain of developmental maturity, and the sixth domain on relationship/communication were present in 96% of charts reviewed. The second domain, skills/self-efficacy, was present in 98% of charts

reviewed. Transition beliefs and expectations, domain three, was the lowest represented domain in patient charting, with a presence in 76% of patient charts. Domains five and seven goals and motivation and psychosocial/emotions, were addressed in 100% of charts (see Table 2 and Figure 5).

Seven Modifiable SMART Domains		
Domain 1	Knowledge	Understands/Verbalizes knowledge of health status/needs, disease history. Understands benefits of transition
Domain 2	Skills/Self-efficacy	Disease management skills noted or assessed. Recommendations for future disease management charted
Domain 3	Beliefs/Expectations	Patient transition expectations. Understanding of importance of adult provider
Domain 4	Developmental Maturity	Level of autonomy. Developmental level
Domain 5	Goals/Motivation	Patient and provider goals and transition motivation
Domain 6	Relationship/Communication	Parent or guardian present. Level of support from parent/guardian
Domain 7	Psychosocial/Emotions	Family/living situation. Psychological issues addressed, emotions about transition

Table 2. Seven modifiable SMART domains

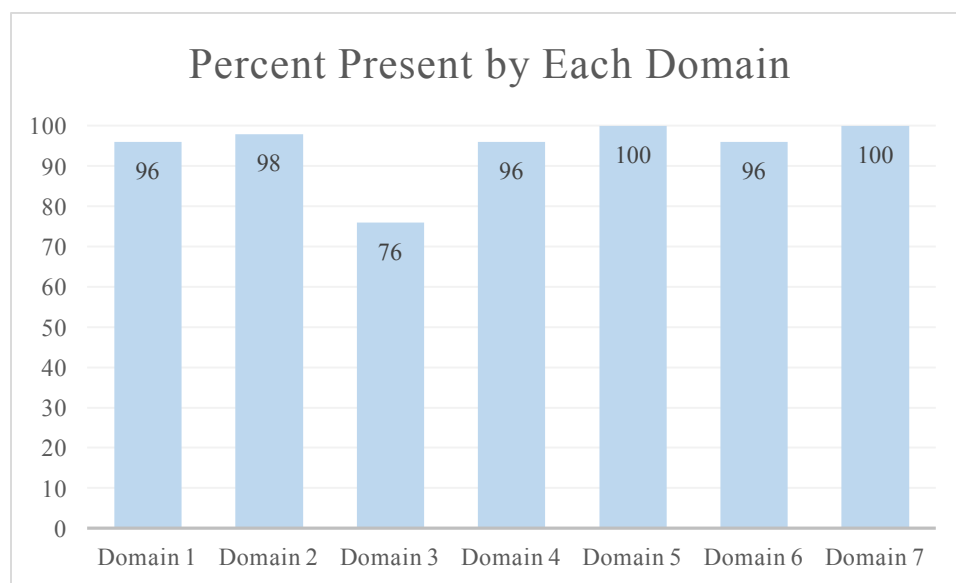


Figure 5. Overall percentage of presence of each SMART domain in patient charts.

Patient charts that exhibited all seven of the SMART domains were considered 100% complete. Of the 50 patients, 36 charts (72%) had all seven SMART domains and were considered 100% complete. Five patients (10%) had five of the seven SMART domains, while nine patients' charts (18%) had six of the seven SMART domains. Overall, the charts were 94.58% complete.

Variable relationships. Correlation coefficients between the number of visits, age, gender, percent of chart completeness, and disease type were calculated using a correlation coefficient. No strong correlation was found among any of the variables (see Table 3).

	<i>% Complete</i>	<i># of Visits</i>	<i>AGE</i>	<i>Gender</i>
% Complete	1			
# of Visits	0.04566169	1		
AGE	0.137940343	0.120939328	1	
Gender	0.235963553	-0.123452106	0.146938674	1
CARDIO	-0.013351572	0.186163124	0.200639735	-0.213504205
DEV	0.141022969	-0.052618085	-0.013261122	0.077108658
ENDO	0.168832664	0.04503979	0.217628157	0.091724923
ENT	-0.033995507	-0.133827455	-0.154185089	-0.008171506
GI	0.054315569	-0.089574378	-0.049660105	0.156903767
GU	0.081615248	-0.093659708	0.060697735	-0.148690429
GYN	-0.113091491	-0.165638977	0.181890307	0.242734018
HEME	0.081615248	-0.093659708	0.060697735	-0.148690429
MSK	0.138083363	-0.05463483	-0.15638097	-0.020016019
NEURO	-0.213440147	0.282524627	-0.086729113	-0.032686023
ONC	0.081615248	-0.093659708	0.060697735	0.137252703
PSYCH	-0.167755578	0.385865955	-0.167184853	-0.003212861
RESP	0.092055575	0.024282147	-0.01573645	0.053376051

Table 3. Correlation between percentage complete, number of clinic visits, age, gender and disease types

Survey Results

Characteristics of the sample. Twenty-three participants were surveyed over the eighteen-week project implementation and data collection period. Fifteen of the 26 patients marked how many visits they had completed to that point. Of the 15 patients who responded,

nine patients (60%) had been to the clinic once, one patient (6%) had been twice, and five patients (40%) had visited five or more times. Seven of the 26 respondents (26.9%) were parents, while the remaining 19 (73%) were patients in the clinic. Only four patients listed their disease type. As a result of the lack of participation in this question, that data has been excluded.

Likert scale results. Seventeen questions were asked using a five-point Likert scale (see Appendices A & B). The average scaled response was 3.74/5, between “agree” and “neither agree nor disagree” (see Table 4). The question with the lowest rating was question 8: “I have the skills needed to manage my health independently,” with a mean score of 2.92 out of 5. The highest rated question was question 12 with a 4.2/5: “My parents support me in my move to the adult system”.

The analysis of the dichotomous variable showed an average agreement percentage of 58.74%. The lowest percentage of agreement was seen with the question “It is the right time for me to move to the adult health system” with 22.4% agreement. The highest percentage of agreement was present for the statement “My parents support me in my move to the adult system” with 80% agreement.

Transition attitudes. The first six survey questions focused on transition attitudes. This section had an overall average score of 3.85/5, which is above the overall survey average (see Table 4). The lowest ranking question was question 5, with a score of 3.15: “I feel ready to move to adult care.” The highest-ranking question was question 6 with a score of 4.08/5 for the statement “the transition clinic is important to my move to adult care.”

Number	TRANSITION ATTITUDES	Mean Score	% Agreement
1	I feel that the transition clinic helps me prepare for my move to adult services	4.04	69.23
2	I feel that the transition clinic provides me with info about other people/groups who can support me	4	73.08
3	The transition clinic helps me to plan for my future	4.04	69.23
4	I feel that the transition clinic helps me be independent	3.81	57.69
5	I feel ready to move to adult care	3.15	34.62
6	The transition clinic is important to my move to adult care	4.08	76
TRANSITION READINESS			
7	It is the right time for me to move to the adult health system	3.19	22.4
8	I have the skills needed to manage my health independently	2.92	40
9	Transitioning to the adult health system is important to me	3.92	64
10	Seeing an adult provider is important to me	3.92	64
11	My move to the adult care will be beneficial to me and my health	3.75	62.5
12	My parents support me in my move to the adult system	4.2	80
13	My doctors support me in my move to the adult system	4.13	75
14	I am not worried about my move to adult care	3.04	28
15	I feel confident in my ability to successfully move to adult care	3.17	33
PATIENT/PARENT SATISFACTION			
16	Overall I am satisfied with the care that I receive here	4.16	76
17	I feel that my transition needs are being met	4.04	73.91

Table 4. Survey questions, mean response, and percent agreement

When viewed as a dichotomous variable overall transition attitudes were rated as 63.3% agree. The lowest ranking question still remained question 5 with 34.62% of respondents in agreement. The statement with the highest agreement level also remained the same; question 6 had an overall score of 76% agreement.

Transition readiness. The second section of the survey focused on transition readiness. The overall average score for this section was 3.58/5 (see Table 4). Question 8 had the lowest ranked response, with 2.92/5 for the statement “I have the skills needed to manage my health

independently,” while the highest-ranking response was for question 12 “my parents support me in my move to the adult system,” with an overall average response of 4.2/5.

Overall, the transition readiness section had 52.1% of respondents in agreement. The statement “It is the right time for me to move to the adult health system” (question 7) had the lowest agreement percentage with only 22.4% of patients in agreement. Question 12 had the highest agreement rate of the section, and the entire survey, with an overall agreement rate of 80%.

Patient/parent satisfaction. The final two questions for patient and parent satisfaction had an overall ranked satisfaction of 4.1/5. However, the last question had the lowest participation rate with 23 of the 26 (88%) participants choosing to answer. Overall, 74.96% of participants were in agreement with the statements for this section.

Free response. When asked if there was anything the clinic could do to improve upon the transition experience, six of the 26 participants responded (see Table 5). With only six respondents a thematic analysis was difficult to extrapolate. Of the six patients who filled out the free response, two patients stated they were satisfied with their care, two were unsure, one praised the provider, and one participant suggested that more information be provided on possible placements.

Response
Dr. Maslow is a great doctor that really cares
Just began at transition clinic
Not that I can think of, this however is most likely because I've only been here once and I am satisfied with my care
No, I am satisfied
I'm not sure
Provide information on all possible placements available. For all accommodations and what is entailed to get in there

Table 5. Free responses by survey participants

Transition Tracking Tool Use

For the use of the transition tracking tool, 15 patients were included in the pilot of the tool. Of the 15 patients, 11 patients had one goal entered; two patients had three goals while the remaining two patients had two goals. Six of the patients were female, and nine were male. No follow up was recorded on the tracking tool for any of the patients after the initial use of the tool. The most common theme of the goals entered for the tracking tool was the encouragement of meaningful social interactions and social independence (club participation, after school activities, developing hobbies, etc.) with 10 of the goals centered around this theme. The second most common goal was in support of medical independence (getting insurance, finding adult providers, refilling medications) with seven of the recorded goals including this theme. Two goals centered around occupational goals (vocational rehab, employment) while another three focused on emotional well-being (improving family relationships, controlling emotions). Finally, one goal was created with the aim of improving the participant's physical fitness. Due to the very small sample size, low participation rate and the level of provider use of the transition tracking tool, no follow-up chart review was completed.

CHAPTER 7: DISCUSSION

Chart Review

The chart review yielded overall positive results. The high rate at which providers addressed the seven SMART domains demonstrated the clinic's commitment to incorporating the SMART model into its practice. The consistent use of an Epic "SmartPhrase" on the patients' electronic medical record (EMR) on new transition patients in the clinic by the resident physicians has provided a space in which to address all of the seven SMART domains. The use of the SmartPhrase on new patient visits is also why there is no correlation between the number of patient visits and the patients' chart completeness since the initial SmartPhrase has almost all of the SMART domains are in as prompts for the patients' initial documentation.

The third domain assessed, transition beliefs and expectations, was charted at the lowest rate of all the other seven SMART domains, with 38 of the 50 (76%) patients reviewed not having any mention of their transition beliefs and expectations in their charts. The third domain recommends that providers assess patient transition expectations, their beliefs related to transition importance, and understanding of the importance of an adult provider (Schwartz et al., 2011). The providers may have possibly had difficulty charting on this domain since it is not well differentiated within the SmartPhrase used for new transition patients. They may also have experienced difficulty with the incorporation of this domain since it is not addressed in most transition literature as an essential aspect of successful transitions, nor is it intuitively recalled when discussing successful transitions. Within the literature transition beliefs and expectations

are mainly discussed in a more theoretical manner in regards to its importance to CSCHN transition. The literature that does mention transition expectations does emphasize its importance as it allows providers and patients to concurrently review patients' goals and expectations and encourage a patient/provider partnership in achieving those goals (Aldiss et al., 2015; Nehring et al., 2015; Sonneveld, Strating, van Staa, & Nieboer, 2013).

Conversely, domains five and seven, the two areas in which there was 100% charting on all patients, are well explored in transition literature and central to the clinic itself. Domain five focuses on patient goals and motivation; this pillar of transition care is seen through much of the literature surrounding CSCHN transitions. Goal setting and patient motivation is a fundamental aspect of literature surrounding transitional care programs as they progress the patients towards independence (Betz, 2013; Jameson, 2011; McDonagh, 2005; McManus et al., 2015).

The large number of patients with psychiatric special needs probably influenced the clinic's strong compliance with the seventh domain, psychosocial and emotional status. Therefore, there was a significant portion of patients with psychiatric issues, resulting in bias towards evaluation of psychological well-being in all other patients. Assessment of patients' psychological status and well-being is closely linked with transitions and has been shown to be important in transition literature (Pai & Ostendorf, 2011; Sacker & Cable, 2010; Schwartz et al., 2014).

Overall, the majority of the charting for the transition patients demonstrated that the clinic has a commitment to the use of the SMART model in its practice. Through embedding the SMART model in the SmartPhrase on the patients' EMR, providers have made the SMART model an integral portion of their practice model. While the resident physicians who rotate

through the clinic may not be aware of the SMART model by name, they will be able to leave the clinic knowing the essential principles taught by the model.

Limitations. The chart review did yield some significant limitations. Since some patients who attended the Complex Care Clinic were not all considered transition patients yet it was impossible to randomize the patient list for the clinic to select the patients for the chart review. This more deliberate selection process could have created a bias toward patients who were more likely to have charts that included more of the SMART domains.

Patient and Parent Survey

Transition attitudes. The first portion of the patient and parent survey, transition attitudes, yielded an overall average of 3.85, placing responses closest to “agree.” Interestingly, the lowest rated statement, “I feel ready to move to adult care” was the most telling for the patients’ feelings towards their transition, with an average rating of 3.15 out of 5 (placing it closest to “neither agree nor disagree”) and an overall agreement percentage of 34.62%. Survey participants gave a high rating towards the statement “The transition clinic is important to my move to adult care” with an average response of 4.08/5 and 76% in agreement.

Patient and parent perceptions of transition readiness could be low due to the patients’ disease severity since they indicated that they felt well supported in their transition by providers and parents (questions 6, 13, 15). Patients within the Complex Care Clinic at Duke (formally the Transitions Clinic) have more complex conditions than patients undergoing simple care transitions. Patient disease severity in relation to transition readiness and success is well supported by the literature in which has been found a negative correlation between transition outcomes and readiness and the severity of the CSHCN’s medical conditions (Oswald et al., 2013; Scal & Ireland, 2005).

Transition readiness. Patient and parent perceived transition readiness was rated as a 3.65/5. The lowest rated statement, with a score of 2.92 out of 5, was in response to “I have the skills needed to manage my health independently,” while the highest-ranking response was for question 12 “my parents support me in my move to the adult system,” with an overall average response of 4.2/5. The highest percentage of participants to agree within the transition readiness section was also for question 12 but the lowest percentage of participants to agree was in response to “It is the right time for me to move to the adult health system”.

These responses indicate a strong support system yet indicate that patients still struggle with health management and readiness, despite the focus of the clinic. These results are surprising when compared to current literature which has shown that transition success is positively affected by strong parental/social support; however, no literature could be found to show the relationship between transition readiness and family support (Duke & Scal, 2011; Joly, 2015; Pai & Ostendorf, 2011).

Patient/parent satisfaction. Patient and parent satisfaction was given an overall ranking of 4.1/5 and 74.96% in agreement. Despite more neutral responses in the prior two sections of the survey (transition readiness and transition attitudes), this section yielded a much higher overall average score. This rating is surprising since the lowest rated questions were questions 8 and 14, related to perceived transition readiness, which received scores between “disagree” and “neither agree nor disagree.” This irregularity in responses is possibly due to the complexity of the patients’ diseases. While they may not have felt that they had all the skills necessary for the transition, due to their particular complicated conditions, they did feel that they received quality care from the transition clinic. This also translated to an overall satisfaction with the level at which the patients’ transition needs were met.

Despite a low perceived transition readiness satisfaction may also have been high due to the clinic structure and providers. According to the literature higher patient and parent satisfaction is correlated with frequent clinic visits, structured clinic programs, strong provider communication; principle which the Duke Complex Care Clinic utilizes in their program (Bloom et al., 2012; Davis, Brown, Taylor, Epstein, & McPheeters, 2014; Monaghan et al., 2013; Shaw, Southwood, & McDonagh, 2007b).

Free response. Due to the low response rate, it is very difficult to extrapolate a relationship between the answers. The most common themes in the free response section was satisfaction with the clinic and uncertain feelings towards the clinic, due to the patients' relative newness. One participant did suggest that more information be provided about patient accommodations and the steps needed to access those accommodations.

Limitations. Due to limitations from the Institutional Review Board leading to the inability of having both patients and parents concurrently fill out the forms, parental responses were few. Since few parents were unable to participate their responses were not analyzed apart from the patient responses. The mixing of both patient and parent responses could have skewed the results.

Another limitation of the survey portion was the small sample size. Since the patients had the opportunity to refuse participation, and because the clinic sees a low number of patients each week, the potential number of willing participants was low.

Transition Tracking Tool

The concept of the transition tracking tool was to promote continuity of patient transitional care through constant provider changes that result from the clinic's position as a rotation for the resident physicians. The tool was developed by the author in conjunction with

the clinic and had the approval of the attending physicians. While the concept was well received, the actual implementation in the practice was problematic. Although the tool was created to ensure continuity of care of the patient from the resident physicians, it was difficult to ensure that each new group of residents had an understanding of the purpose of the tool. The ever-changing nature of providers in the clinic made it very difficult to embed the tracking tool into the workflow of the clinic, because this workflow differed from resident group to resident group.

The tool also faced implementation difficulties with the change of the clinic location. In the middle of the tracking tool implementation the clinic changed from taking place in two different locations on a rotating bi-weekly basis to a fixed clinic location on a weekly basis. The change in location was understandably difficult for the providers and staff, and the minimal embedding of the tracking tool that had occurred at the other previous two locations was temporarily lost with the clinic change. Nonetheless, the providers liked the concept of the tracking tool, even as its implementation neared an end. However, it was not continued into the practice in its current form.

Recommendations

Based on the initial chart review, the clinic is doing well incorporating the SMART model into their charting and clinical practice. While six of the seven SMART domains are well integrated, there is room for improvement within the third domain, beliefs and expectations. Consistently including the third domain in patient charting can be ensured with an edit to the current SmartPhrase in the EHR. Adding an area within the SmartPhrase on beliefs and expectations should improve the frequency at which the third domain is mentioned in patient charting.

However, as evidenced by the second section of the patient and parent survey, the section based on the seven domains of the SMART model, more parent and patient transition education needs to occur. Current recommendations for the Complex Care Clinic include educating patients about the purpose and need for transitional care. While the overall response for the statement “transitioning to the adult health system is important to me” was relatively high, with a score of 3.9/5, perhaps patients and parents can better understand the purpose of the clinic. Increased understanding of clinic purpose could possibly improve patient and parent involvement in the transition process to ensure that all patient and parent perceived transition needs are being met. Through increased patient involvement in transitional care and goals patients’ confidence and readiness for transition may improve from current levels.

While the need for some transition tracking tool remains, a workflow change is needed to better incorporate such a tool. Ensuring that there is a consistent workflow in which residents evaluate patients, attending physicians, social workers, health coaches, and research assistants could perhaps improve the consistency in which a transition tracking tool is completed. The tracking tool may need to be further modified to simplify the process of filling out the form to increase participation. Another possible alternative is to make a transition tracking tool that can be used within the patients’ charts through the use of an Epic DotPhrase that allows users to make patient transition goals within any provider note.

Continued follow-up is also needed to ensure that any changes made to the clinic are beneficial to patients, parents, and providers. While the evaluation techniques do not have to be identical to the current program evaluation, evaluation methods should match the goals of the assessment and the implemented intervention.

Summary/Conclusion

Due to the relative newness of the Duke Children's Complex Care Clinic combined with the emerging field of transitional care, there is little evidence to help guide the development and improvement of transitional care programs. The use of a program evaluation with a chart review, patient and parent survey, and a pilot transition tracking tool helped to further illuminate the evaluated program's strengths, weaknesses, and areas for improvement.

In a novel field, such as transitional care, continued evaluation, improvement, and research are essential to broaden the current knowledge base of this emerging field. It is through these techniques that the lives of CSHCN are improved and their future as adults with a special health care need is enhanced.

APPENDIX A: PARENT CLINIC SURVEY FORM

BACKGROUND DATA					
How many visits to the clinic has your child completed so far?	1	2	3	4	5 or more
What conditions does your child see the doctor for?					
GENERAL SURVEY	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
TRANSITION ATTITUDES					
I feel that the transition clinic helps my son/daughter to prepare for his/her move to adult services					
I feel that the transition clinic provides my son/daughter with info about other people/groups who can support us					
The transition clinic helps my son/daughter to plan for their future					
I feel that the transition clinic helps me to support my son/daughter to independence.					
I feel my son/daughter is ready to move to the adult healthcare system					
The transition clinic is important to my son/daughter's move to adult care					
TRANSITION READINESS					
It is the right time for my son/daughter to move to the adult health system					
My son/daughter has the skills needed to manage his/her health independently					
It is important that my son/daughter transition to the adult health system					
It is important that my child receives care from an adult provider					
My child's move to the adult care will be beneficial to them and their health					
I support my child in their move to adult care					
My child's doctors support them in their move to adult care					
I am not worried about my child's move to adult care					
I feel confident in my child's ability to successfully move to adult care					
PATIENT/PARENT SATISFACTION					
Overall I am satisfied with the care that my child receives here					
I feel that my child's transition needs are being met					
FREE RESPONSE					
Is there anything more that the clinic could do to improve upon your son/daughter's transition experience?					

APPENDIX B: PATIENT SURVEY FORM

BACKGROUND DATA					
How many visits to the clinic have you completed so far?	1	2	3	4	5 or more
What conditions do you see the doctor for?					
GENERAL SURVEY	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
TRANSITION ATTITUDES					
I feel that the transition clinic helps me prepare for my move to adult services					
I feel that the transition clinic provides me with info about other people/groups who can support me					
The transition clinic helps me to plan for my future					
I feel that the transition clinic helps me be independent					
I feel ready to move to adult care					
The transition clinic is important to my move to adult care					
TRANSITION READINESS					
It is the right time for me to move to the adult health system					
I have the skills needed to manage my health independently					
Transitioning to the adult health system is important to me					
Seeing an adult provider is important to me					
My move to the adult care will be beneficial to me and my health					
My parents support me in my move to the adult system					
My doctors support me in my move to the adult system					
I am not worried about my move to adult care					
I feel confident in my ability to successfully move to adult care					
PATIENT/PARENT SATISFACTION					
Overall I am satisfied with the care that I receive here					
I feel that my transition needs are being met					
FREE RESPONSE					
Is there anything more that the clinic could do to improve upon your transition experience?					

APPENDIX C: DATA EXTRACTION TOOL

Patient #	Knowledge- Understands/Verbalizes knowledge of health status/needs, disease history. Understands benefits of transition	Skills/Self-efficacy: Disease management skills noted or assessed. Recommendations for future disease management charted	Beliefs/expectations Patient transition expectations. Understanding of importance of adult provider	Developmental maturity. Level of autonomy. Developmental level	Goals/Motivation. Level of autonomy. Developmental level

Relationships/communication. Parent or guardian present. Level of support from parent/guardian	Psychosocial/emotional situation. Family/living situation. Psychological issues addressed, emotions about transition	# of visits	Disease type	Age	Gender

APPENDIX D: TRANSITION READINESS TRACKING TOOL

Patient Name: _____	MRN: _____	Age: _____
Primary Diagnosis: _____	Transition Complexity <i>Low, moderate or high</i>	
<div style="display: flex; justify-content: space-between;"> Date: _____ Due Date: _____ Date Completed: _____ </div> <div style="margin-top: 5px;"> Goal: _____ </div> <div style="margin-top: 5px;"> Action Items (<i>check if completed</i>): </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="margin-top: 5px;"> Notes </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div>		
<div style="display: flex; justify-content: space-between;"> Date: _____ Due Date: _____ Date Completed: _____ </div> <div style="margin-top: 5px;"> Goal: _____ </div> <div style="margin-top: 5px;"> Action Items (<i>check if completed</i>): </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="margin-top: 5px;"> Notes </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div>		
<div style="display: flex; justify-content: space-between;"> Date: _____ Due Date: _____ Date Completed: _____ </div> <div style="margin-top: 5px;"> Goal: _____ </div> <div style="margin-top: 5px;"> Action Items (<i>check if completed</i>): </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%; text-align: right;"> <u>Due Date:</u> _____ </div> </div> <div style="margin-top: 5px;"> Notes </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <div style="width: 60%;"> <input type="checkbox"/> _____ </div> <div style="width: 35%;"></div> </div>		

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