# Aging out of Pediatrics: Preparing Adolescents for Health Care Transition Using Illustration-based Anticipatory Guidance

Benjamin Jones

Edson College of Nursing and Health Innovation, Arizona State University

#### Abstract

## **Objective**

Health care transition (HCT) for adolescents without special health care needs in the primary care setting has received inadequate attention, as represented by national surveys, when compared to adolescents with special health care needs. Barriers to transition such as lack of knowledge and preparation have been known to hinder HCT despite the knowledge gap and weak evidence related to non-special needs adolescent transition. Application of anticipatory guidance education related to care transition may improve transition readiness scores of adolescents without special health care needs.

#### Methods

Utilizing Meleis' transition theory with the Plan-Do-Study-Act framework, a quasi-experimental study was conducted comparing transition readiness scores between baseline and intervention groups of adolescents 14 years or older attending their well checks at a small pediatric primary care site. The intervention consisted of two videos developed from *Got Transition*<sup>TM</sup>'s (n.d.) Six Core Elements for specific adolescent age ranges.

#### **Results**

Statistical analysis reveals that the subgroup and overall transition readiness scores for both age groups, 14-15 and 16-18 years of age, when comparing the baseline groups to the intervention groups, have mixed significance (p = .419, p = .074, respectively). However, when asking the respondents about their understanding of the transition process and their role in that process, 75% and 62.5%, respectively, at minimum agreed the intervention was helpful.

#### **Conclusion**

The findings were mixed, indicating the educational videos did have a short-term impact on adolescent transition readiness scores for the 16-18 years old group only. Future focus on long-term follow up throughout the adolescent period may yield better data.

*Keywords:* adolescents, transition to adult care, anticipatory guidance, transition readiness, primary care

## Aging out of Pediatrics: Preparing Adolescents for Health Care Transition Using Illustration-based Anticipatory Guidance

In the realm of primary care, children's healthcare needs are usually delineated from adult healthcare needs. This is most readily seen at the community level via the establishment of pediatric-focused primary care offices versus a traditional family practice, and in how health care for pediatric patients is approached differently than the health care of adult patients. However, regardless of type of office a pediatric patient is attending for primary care services, a transition to an adult health care office or adult style of health care must occur. More importantly, this transition is not necessarily a simple or straightforward process and applies to all adolescents despite a history of focus on adolescents with special health care needs (SHCN).

#### **Problem Statement**

Pediatric primary care, despite having a strong focus on anticipatory guidance and planning as it relates to development, has not given health care transition (HCT) and transition readiness the same considerations as other areas of childhood development and health care. HCT is a process designed to move an adolescent from a pediatric care model to an adult model, which may or may not include the adolescent switching to a new provider (White et al., 2018). Transition readiness can be defined as the process of decision- and action-making of adolescents, parents, and providers to build the capacity of all involved to attend to all aspects of transition (van Staa et al., 2011). The concept of transition readiness has been applied and well-studied in specialty populations among adolescents with SHCN. However, research has indicated that these individuals are self-managing aspects of their medical conditions while adolescents without SHCN, in comparison, have less experience and management skills in regards to their health care

(Eaton et al., 2017). Research suggests that transition readiness could be applied to adolescents without SHCN (Eaton et al., 2017).

On a national scale, transition planning is poorly attended to despite the development and availability of standards and structured HCT planning and implementation guidelines (American Academy of Pediatrics et al., 2011; *Got Transition*<sup>TM</sup>, n.d.). Transition planning is a national performance measure included in the National Survey of Children's Health (NSCH). Findings from the 2016 NSCH survey suggested that 17% of youth with SHCN and 14% of youth without SHCN met the overall transition measure (Lebrun-Harris et al., 2018). Review of the data on those measures on the same 2016 dataset suggests with caution, that for Arizona, 23% of youth with SHCN and 11% of youth without SHCN met the overall transition measure in full (Child and Adolescent Health Measurement Initiative, 2016). For the 2017-2018 NSCH years combined, youth without SHCN met the overall transition measure at a average of 14% nationally and 8% for Arizona, again interpreted with caution (Child and Adolescent Health Measurement Initiative, 2018). Similarly, in the Syverson et al. (2016) study 64% of adolescent participants had not discussed transition to an adult provider and 67% had not discussed insurance needs.

Trending health care utilization rates from childhood through young adulthood, data from 2010 to 2016 indicates that health care coverage and access tend to worsen with age (Spencer et al., 2018). Further compounding the problem of HCT for adolescents, numerous barriers to successful HCT exist. The following are some of the more common barriers that providers and patients can face in HCT: abrupt or unplanned transitions, negative beliefs about or lack of confidence in adult health care providers, hesitancy to leave pediatric provider due to long-standing relationship, poor provider-to-provider communication, limited knowledge or self-

management skills, lack of education and training for providers, lack of accessible and qualified providers, inability of services to flex according to patient needs, and uninformed patient needs (Campbell et al., 2016; Gray et al., 2018; White et al., 2018).

## **Purpose & Rationale**

Given that healthcare is increasingly focused on the quality of care being delivered, and with how reimbursement is becoming tied to quality measures, primary care practitioners should consider adolescent transition to adult care an issue with the potential to impact future health outcomes. And based on the reports of low transition readiness among both children with and children without SHCN, HCT is an area of pediatric health care that needs to be addressed with targeted interventions. The purpose of this study is to attempt to address the inattention to adolescent HCT through implementation of an illustration-based anticipatory guidance intervention in the primary care setting.

## **Background & Significance**

#### **Adolescents Nearing Adulthood**

The adolescent period of life is a complex time where children are beginning to assume the role and responsibility of managing their own care and making decisions that can potentially last a lifetime. Structured transition interventions suggest a potential positive effect on population health, consumer experience, service utilization, and barrier reduction (Gabriel et al., 2017). While much of the research in recent years has looked at health care transition and health outcomes among children with special health care needs, foundational consensus (National Library of Medicine Medicine, 2002) and development of the underlying structure of HCT (American Academy of Pediatrics et al., 2011) outline the need for HCT planning for all adolescents, not just youth with SHCN.

## **Structured Transition Planning or Anticipated Guidance for Adolescents**

Anticipatory guidance is a mainstay of pediatric primary care patient education as it creates a space for dialog and discussion of health topics during the primary care visit (Hagan et al., 2017). Transition to adult health care planning falls under that category as it engages the adolescent during a crucial time of development in which the adolescent is assuming more responsibility over their life, including their health management. The standard recommendation for this period is to allow them the space to assert their autonomy while providing guidance from a health care perspective (*Got Transition*<sup>TM</sup>, n.d.; Hagan et al., 2017)

When anticipatory guidance for HCT is provided to youth with SHCN, transition readiness scores tended to be higher than those who did not receive anticipatory guidance (Syverson et al., 2016). Furthermore, from a broad perspective aimed at outcomes, structured transition interventions among various adolescent patient population groups tended to result in positive outcomes within the areas of population health, consumer experience, and service utilization (Gabriel et al., 2017). Even within the hospital setting, patients with previous familiarity to HCT preparation tended to have increased motivation and sense of competence in their transition skills (Dwyer-Matzky et al., 2018).

The comparison to receiving anticipatory guidance for HCT is identified as no formal discussion or education provision for adolescents transitioning from a pediatric model to an adult model of care. The majority of adolescents and young adults, both with SHCN and without SHCN, who do not receive adequate preparation and support for transitioning to adult care are at risk for worse health outcomes when compared to patients who do receive preparation and support (Gabriel et al., 2017).

Transition Readiness Among Adolescent and Young Adult Patients and Families

Transition readiness, as a term, and its specific use to describe a set of outcome measures, lacks homogeneity across the various measurement tools that exist (Straus, 2019). Currently, measures focus on the transition process and exclude health outcomes, which is realized in the questions on the NSCH survey pertaining to adolescent HCT (Sharma et al., 2014). In terms of associated factors, increases in the following areas suggest potential increases in transition readiness: knowledge, self-efficacy, belief in self-care, self-regulation, expectations, health management skills (Espeleta et al., 2019; Hart et al., 2017; Sawicki et al., 2014b; Stewart et al., 2017). However, other studies suggest that age is a factor associated with increased transition readiness scores (Jensen et al., 2017; Lapp & Chase, 2018; Rosen et al., 2016; Sawicki et al., 2014a).

Unfortunately, evidence is mixed in regards to linking transition interventions and transition readiness with quality of life and health-related outcomes (Campbell et al., 2016; Chu et al., 2015; Gabriel et al., 2017). Furthermore, while it is evident from the literature review that the original intention of adolescent HCT applied to all adolescents, scholarly focus has largely been placed on specific sub-populations within the larger population of adolescents, which further compounds the problem of studying transition readiness outcomes. While there are limited studies involving HCT for the general adolescent population, support for further HCT research does exist (Eaton et al., 2017; White et al., 2018). Attention to transition readiness is warranted as part of the larger pursuit to establish quality care outcomes for HCT (Eaton et al., 2017).

#### **Internal Evidence**

At a small pediatric health clinic in the southwestern United States with a maturing patient population, informal reports from staff indicate that some adolescents continue to make

use of the health office from a health care standpoint despite being adults based on their age. While no formal investigation was conducted into the reasons of why these patients maintained care at the clinic, informal discussions with staff indicate the following reasons for failing to transition: strong patient-provider and family-provider relationships, difficulty finding providers willing to accept children with SHCN, and convenience during school holidays for college age students. These reasons coincide with the previously discussed barriers to HCT. A preliminary survey of the patient database revealed several patients age 19 or older with established care at the clinic (Appendix A). However, a more thorough search of the primary care site's database conducted from January 1, 2019 to December 18, 2019 revealed 35 unique visits by patients aged 19 to 22 years old.

This investigation has led to the clinically relevant PICOT question, "In adolescent primary care patients without SHCN nearing adulthood (P), how does an anticipatory guidance adjunct (I), compared to no guidance adjunct (C), affect their readiness to transition to adult primary care (O)?"

## Search Strategy

A literature review was conducted on databases specific to the field of health care to obtain the most recent evidence relevant to the topic of this paper. The three databases searched were the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, and the Cochrane Library. The searches within each database was conducted in a uniform manner based on the stated PICO question. Key terms for the population of interest included: pediatric\*, teen\*, adolescen\*, paediatric\*, and young adult. The intervention search was conducted using the following key terms: care transition, care transition planning, transition plan, transition from pediatric to adult health, health-care transition, healthcare transition, health care transition,

transition of care, anticipatory guidance, transition intervention, transition to adult care, and transition education. The term transition to adult care constituted a Medical Subject Heading (MeSH) term within the PubMed and the Cochrane Library databases. Outcomes were searched using the following key terms: transition readiness, transitional readiness, readiness assessment, self-care, patient adherence, and patient satisfaction. A publication date filter of March 2015 and newer was enacted across all three databases. Furthermore, filters were placed on both the CINAHL and PubMed searches and included the following: English language, human subjects, and adolescent age group (13-18 years).

The initial CINAHL search yielded 114,909 results. After applying the above stated filters, the search yielded 101 results. The initial PubMed search yielded 36,672 results. Application of the same filters yielded 187 results. The initial search of the Cochrane Library yielded 32 results. Applying the publication date filter yielded 25 results. This resulted in a grand total of 320 studies, which after screening for duplicates and relevance was reduced to 253 results. Further abstract scanning reduced the number to 204 results.

Inclusion criteria included studies and interventions directed at examining or modifying transition readiness as it relates to HCT for adolescents in the primary care setting. Exclusion criteria was numerous and included the following: adult only, acute care settings, scoping reviews, purely qualitative studies, purely parent or proxy input, and measurement tool validation studies. Ten potential articles were then identified for further appraisal and placed in an evaluation table (Appendix B).

#### **Critical Appraisal of the Evidence**

Appraisal of the evidence table (Appendix B) revealed that the studies involving adolescent HCT obtained from the literature search were some of the most recent studies to date;

however, numerous factors limit their overall strength. The first major issue with the studies is the overall weak level of evidence, represented by the majority as level IV evidence. This is further represented by the majority of the studies being cross-sectional or retrospective in design. In general, the studies did not explicitly state the frameworks used to guide the studies, but overall they appeared to adhere to either Zimmerman's (2000) empowerment theory or Meleis' (2010) theory of transitions. Furthermore, while the samples were sufficiently consistent across most studies in terms of age range, size, and setting within the United States of America, the sampling method employed was convenience sampling due to the majority of the studies being connected with a specialty clinic and due to the cross-sectional design. However, a large amount of heterogeneity resulted from the samples not being consistent due to the various levels of chronic conditions included by some studies compared to other studies that focused on a singular chronic disease or subspecialty.

Appraisal of the measurement tools, independent variables, and dependent variables used throughout the studies varied widely in terms of specifics; however, in more than half of the studies, key tools and variables could be tied to the constructs of HCT planning and transition readiness. The key variables that can be tied to the construct of transition readiness include the following: transition readiness, self-efficacy, self-management, personal health knowledge, patient activation, and competence. Given the limitations of the study designs implemented as a whole, analysis of the majority of the studies relied on linear and logistic regressions, along with t-tests and chi-square tests where appropriate, in addition to the normal descriptive statistics.

Overall, the analysis of the findings with a focus on the construct of transition readiness indicated that adolescents were better prepared for HCT when planning or education was provided. Also, when taking age into consideration, older adolescents were better prepared for

HCT compared to younger adolescents. In terms of bias, while most studies have no overt bias present, given the design of most of the studies as well as the use of convenience sampling, the potential for selection bias exists across most of the studies.

## **Synthesis of the Evidence**

Deriving a synthesis table (Appendix C) from the aforementioned evaluation table (Appendix B) reveals a general gap in the knowledge of adolescent HCT as it relates to the general adolescent population. The synthesis indicates that while the majority of the studies involved measuring an aspect of the transition readiness construct, there are inherent issues drawing a straightforward comparison from across all of the studies. However, there are two potential considerations that can be drawn regarding adolescent HCT. The first consideration is that planning or education targeting the HCT process, regardless of how the education occurred, seems to favor improved readiness. The second consideration is that demographics can have an impact on transition readiness.

The conclusion that can be drawn from the synthesis of the evidence is that despite the wide focus on various pieces of the larger transition readiness construct, there exists a gap in the knowledge of adolescent HCT. This gap is especially noticeable as it relates to the general population of adolescents as the focus has primarily been on adolescents with special health care needs or chronic conditions. Furthermore, given the inherent weakness of the studies, standardization of approach to HCT interventions is warranted. Addressing these two areas will allow for a more standardized assessment of HCT for adolescents while minimizing the influence of factors associated with chronic disease.

#### **Implementation Framework**

The implementation framework best suited for an intervention aimed at improving the health care transition process of adolescents is the PDSA model, also known as the Plan-Do-Check-Act model (Gorenflo & Moran, 2009). The PDSA model condenses the evidence-based problem-solving approach of quality improvement into four stages. The diagram presented in Appendix D represents the major stages and progression of the PDSA model.

Plan, the first stage, is characterized by the development of an action plan after identification and research of present issues and potential areas for improvement. Do, the second stage, is the implementation stage of the model during which general observations are performed and study relevant data is collected. The third stage, Study, compares the results to the intended aim of the Plan stage, identifies unintended effects, and determines overall feasibility. The fourth stage, Act, is the determination stage in which the intervention is either formalized as part of the new routine, subjected to another cycle of the PDSA or abandoned all together.

The PDSA model is well suited to address the quality improvement issue of adolescent health care transition due to its adaptability and cyclical nature. The Plan stage is generalizable to a primary care office and seeks to gain input from a variety of sources. The primary issue presents internally via the number of unique visits by young adults older than 18, and externally by the low rates of transition preparedness nationwide among adolescents, as well as by the lack of evidence evaluating transition readiness among the general population of adolescents. The plan of action surrounding this issue will be focused on providing education of HCT using an illustration-based anticipatory guidance adjunct at adolescent well-check appointments.

Specifically, the anticipatory guidance education intervention will be based on various aspects of *Got Transition* 's (n.d.) six core elements.

The stages of Do and Study allow for a thorough implementation and evaluation of a quality improvement initiative with a subsequent decision point of whether to formally integrate the initiative or take a different path. The exact specifics of the Do stage will be covered extensively in the Methods section. The resulting data would then be subject to a quantitative assessment. Utilizing this framework also allowed for changes to be made in either real-time during implementation, or after completion. At which point the Act portion of the PDSA model is enacted and the decision is made to either redo the study with changes or accept the results.

#### **Theoretical Framework**

The evidence indicates a gap in the knowledge of adolescent transition to an adult health model as it relates to adolescents, especially those without special health care needs. To address this area, Meleis' (2010) transition theory embodies the construct of transition as a complex, interconnected process on multiple levels. The framework can be broken into three distinct categories of concepts: the nature of transition, transition conditions, and patterns of response. The diagram in Appendix E portrays the major concepts and relationships of Meleis' transition theory.

The nature of transitions category is defined by the type, patterns, and properties of the transition. Of the four types of transitions described by Meleis, adolescent HCT falls under both the developmental and situational types of transition simultaneously throughout the HCT process. Meleis further breaks down the construct into essential properties: awareness, engagement, change and difference, time span, and critical points and events. While all of these properties are present and relate to each other within HCT, certain properties such as engagement, changes, and time span will tend to carry more weight. However, the significance of each of the properties will be highly dependent on the situation and involved individuals.

The next concept of Meleis' (2010) transition theory is that of conditions. While adolescents move through the HCT process, their transition will be affected by personal, community, or societal factors that may either aid or hinder the process. The next concept of Meleis' (2010) transition theory is patterns of response, which is comprised of process and outcome indicators. Process indicators include the ideas of perceived connectedness, interaction, confidence, and coping, while outcome indicators may include skill or behavior mastery along with integrative identities (Im, 2014). The final concept of Meleis' (2010) transition theory is nursing therapeutics. There are three measures that constitute Meleis' description of nursing therapeutics and can be applied to an intervention, they are as follows: assessment of readiness, preparation for transition, and role supplementation.

Given the major concepts of Meleis' (2010) transition theory and their interconnectedness, the framework this theory provides will benefit and guide an anticipatory guidance intervention aimed at preparing adolescents for HCT. The main connections drawn between Meleis' theory and an anticipatory guidance intervention targeting HCT are the ideas of awareness, engagement, and time as major factors addressing transition. Anticipatory guidance will benefit both the medical staff and the adolescent in that it can help address the adolescent where they are, allowing space for autonomy, as well as allowing for the medical staff to best adapt their time based on the needs of the adolescent.

#### **Outcomes**

Establishing feasibility and benefit with adolescent HCT is difficult given that outcomes measuring benefit and cost would require a lengthy study period. A more conservative approach is to measure the readiness of adolescents as they approach adulthood since the American Academy of Pediatrics supports structured HCT initiatives and indicates the need for assessing

progress (White et al., 2018). This encompasses the idea that higher readiness scores will be obtained from adolescents closer to adulthood given the use of anticipatory guidance. Measuring transition readiness will be accomplished through the use of the 20 question Transition Readiness Assessment Questionnaire (TRAQ) (Wood et al., 2014). The TRAQ has been established as valid and reliable (Wood et al., 2014). The intent of focusing on transition readiness among the general adolescent population, those without SHCN, is to better prepare adolescents for taking on their developing adult role through empowering them in their health care, which is congruent with Meleis' (2010) transition theory framework.

However, while transition readiness is relatively new, limited evidence from studies involving youth with special health care needs suggest there are potential benefits to addressing HCT in a structured manner (Gabriel et al., 2017). Although, it should be noted that a snapshot view of anticipatory guidance and transition readiness is not an indicator that adolescent HCT will occur. Future research will be needed to establish if transition readiness has implications beyond the pediatric period and whether or not the barriers inhibiting adolescents from making a timely transition can be mitigated.

#### Methods

## **Study Design**

A quasi-experimental design was used to answer the following quality improvement question:

1. For adolescent primary care patients nearing adulthood, does use of an illustration-based anticipatory guidance intervention with a well-check visit in the primary care setting affect the transition readiness of an adolescent post-visit?

#### **Population and Setting**

The site of the study was a small private pediatric clinic located in the southwest United States. The medical staff was composed of 2 medical doctors, 2 nurse practitioners, and 1 registered nurse. Other staff include medical assistants, scribes, and requisite front office staff. The office serves a relatively balanced mix of private and public insured pediatric patients. The goal of the organization is to be a provider of comprehensive primary care as well as a medical home for all patients, including those with SHCN and those without SHCN. The focus of this study was on the adolescent population without SHCN.

#### **Ethical Considerations**

IRB approval was sought given the population of focus being adolescents. The adolescent participants were consented via a standardized consent. The consent process occurred prior to either taking the survey in the baseline phase or watching the anticipatory guidance video illustration in the intervention phase. Along with the digital survey link sent in the week following the intervention component, participants were reminded that their participation in the study was not mandatory and that their response to the survey questions could be submitted as incomplete. This approach ensured sufficient knowledge was provided to the participant regarding the study. Information gathered as part of the study did not include any identifiable information and thus ensured the protection of privacy of all the participants. Furthermore, consents were kept separate from survey responses to achieve anonymity of results.

#### **Instruments**

Transition readiness of adolescent patients was assessed through the use of the Transition Readiness Assessment Questionnaire (TRAQ) developed by Wood et al. (2014). The Transition Readiness Assessment Questionnaire is a 20-item scale that measures an adolescent's readiness to transition to adult care. The TRAQ is further divided into 5 subscales: managing medications,

appointment keeping, tracking health issues, talking with providers, and managing daily activities. While the TRAQ scales use a 5-point Likert-type format, with a range of possible scores between 20-100, the intention is for the provider to evaluate the skills of the individual and determine future areas of focus for transition preparation versus looking at just the overall score. Specifically, the 5-point scale assesses an adolescents self-reported skill level description ranging from "No, I do not know how" to "Yes, I always do this when I need to."

Overall, TRAQ is a reliable instrument with a Cronbach's alpha of 0.94 (Wood et al., 2014). TRAQ is also reliable for 4 of the 5 subscales of measurement with a Cronbach's alpha range of 0.9 to 0.77 (Wood et al., 2014). The subscale of managing daily activities had a Cronbach's alpha of 0.67, which is below the 0.7 score of acceptable reliability.

Data related to intervention comprehension, as well as demographic data, was collected by a primary investigator developed form. The focus of the data pertaining to intervention comprehension was on the following topics: the ability of the intervention to help adolescents understand the transition process, as well as describe the role of the adolescent in HCT. The sociodemographic data gathered included the following: age, gender, and grade level.

## **Project Timeline**

Implementation of the quality improvement study began in the fall of 2020. The anticipated length of the study was 2 months, with 4 weeks devoted to baseline data collection and another 4 weeks devoted to intervention application and data measurement. Appendix F represents the original, proposed timeline of the quality improvement study. The timeline for the implementation phase was ultimately adjusted due to a lack of participant response and the following timeline detailed in this section constituted the final methodology utilized for this study.

The primary investigator identified adolescent patients with well-checks. For the baseline data collection period, adolescents and legal guardian were provided information on the study, consented if appropriate, and surveyed if agreeing to participation in the study. For the intervention phase, at the scheduled well-check appointment, the adolescent participant and legal guardian were provided information on the study, consented if appropriate, and given time to view the HCT anticipatory guidance video illustration. A link to a digital survey was sent to the participant via their provided email 1 week after the adolescent well-check. Following completion of the study period, the data collected was then digitized and uploaded to the Intellectus Statistics<sup>TM</sup> statistics package for analysis.

## **Budget**

Funding for this project was provided by the principle investigator. Equipment needed to produce the illustration-based anticipatory guidance constituted the bulk of the budget.

Purchasing of materials required for physical versions of the consents and instruments were included in the overall costs. Where applicable, utilization of free video hosting and communication strategies were implemented for conduction of the project. Refer to Appendix G for the cost breakdown of the project budget.

#### Results

#### **Outcomes**

Data collected from the project was analyzed using Intellectus Statistics<sup>TM</sup>. Summary statistics were calculated for each interval and ratio variable; frequencies and percentages were calculated for each nominal and ordinal variable split by age group. Missing data points utilized Intellectus Statistics<sup>TM</sup> imputation algorithms to provide substitute values needed to avoid purging incomplete responses and to conduct analyses of the data. The imputation algorithms

used by Intellectus Statistics<sup>TM</sup> applied random sampling within the specified categories for nominal and ordinal variables, whereas regression imputation used for scale variables utilized categorical averages combined with predicted error (*Intellectus Statistics*, n.d.).

## Frequencies and Percentages

For the 14-15 years of age group (n = 21), the baseline group responses (n = 17, 81%) was larger than the intervention group responses (n = 4, 19%). In the 16-18 years of age group (n = 19), the baseline group responses (n = 15, 79%) was larger than the intervention group responses (n = 4, 21%). Frequencies and percentages are presented in Table H1 and Table H2.

## Summary Statistics

For the 14-15 years of age group, the baseline group had an average age of 14.29 (SD=0.47,  $SE_M=0.11$ , Min=14.00, Max=15.00, Skewness=0.90, Skewness=-1.18, Skewn

## MANOVA for the 14-15 Years of Age Group

A multivariate analysis of variance (MANOVA) was conducted to assess if there were significant differences in the linear combination of the TRAQ subgroup scores and overall TRAQ score between the baseline and intervention groups. In order to conduct a MANOVA analysis of collected data, the following assumptions were assessed: multivariate normality, homogeneity of covariance matrices, multivariate outliers, and absence of multicollinearity.

To assess the assumption of multivariate normality, the squared Mahalanobis distances were calculated for the model residuals and plotted against the quantiles of Chi-squared distribution (DeCarlo, 1997; Field, 2018). Through the use of a scatterplot, multivariate normality can be assumed if the points form a relatively straight line; strong deviations potentially indicate nonreliability, hindering the assumption of multivariate normality. The scatterplot for normality is presented in Figure II.

Due to the unique properties of the data, some of the covariance matrices could not be calculated. This resulted in the inability to conduct the Box's M test.

Regarding multivariate outliers, identification of influential points were evaluated by using the calculated Mahalanobis distances compared to a  $\chi^2$  distribution (Newton & Rudestam, 2012). An outlier was defined as any Mahalanobis distance that exceeds 22.46, the 0.999 quantile of a  $\chi^2$  distribution with 6 degrees of freedom (Kline, 2015). No outliers were identified in the model.

Evaluating the multicollinearity of the dependent variables through the use of a correlation matrix revealed that all variable combinations had correlations less than 0.9 in absolute value. This indicated that the results were unlikely to be significantly influenced by multicollinearity. The correlation matrix is presented in Table H3.

## MANOVA for the 16-18 Years of Age Group

A multivariate analysis of variance (MANOVA) was conducted to assess if there were significant differences in the linear combination of the TRAQ subgroup scores and overall TRAQ score between the baseline and intervention groups. In order to conduct a MANOVA analysis of collected data, the following assumptions were assessed: multivariate normality, homogeneity of covariance matrices, multivariate outliers, and absence of multicollinearity.

To assess the assumption of multivariate normality, the squared Mahalanobis distances were calculated for the model residuals and plotted against the quantiles of Chi-squared distribution (DeCarlo, 1997; Field, 2018). Through the use of a scatterplot, multivariate normality can be assumed if the points form a relatively straight line; strong deviations potentially indicate nonreliability, hindering the assumption of multivariate normality. The scatterplot for normality is presented in Figure I2.

Due to the unique properties of the data, some of the covariance matrices could not be calculated. This resulted in the inability to conduct the Box's M test.

Regarding multivariate outliers, identification of influential points were evaluated by using the calculated Mahalanobis distances compared to a  $\chi^2$  distribution (Newton & Rudestam, 2012). An outlier was defined as any Mahalanobis distance that exceeds 22.46, the 0.999 quantile of a  $\chi^2$  distribution with 6 degrees of freedom (Kline, 2015). No outliers were identified in the model.

Evaluating the multicollinearity of the dependent variables through the use of a correlation matrix revealed that the combination of the Tracking Health Issues Score and Overall TRAQ Score variables had correlations greater than 0.9 in absolute value which suggests the possibility of singularities. Singularities occur when two variables are identical or nearly identical. When present correlations are greater than 0.9 or less than -0.9, the results may be moderately biased. The correlation matrix is presented in Table H4.

## Statistical Results

The implementation of this study is essentially a small exploratory pilot study in application. Given the importance of addressing a shortcoming in health care transition planning among adolescents, the level of significance was reduced, otherwise future research may not be

explored. Significance was tested at the p <0.10 level due to the importance of needing to detect small to moderate differences where small sample sizes are concerned, with p values of >0.05 but <0.10 are referred to as trend (Fugate Woods et al., 1997).

The overall result for the 14-15 years of age group was not significant, F(6, 14) = 1.08, p = .419,  $\eta^2 p = 0.32$ , suggesting the linear combination of the TRAQ subgroup scores and overall score was similar between both the baseline and intervention groups. The MANOVA results are presented in Table H5.

The overall results for the 16-18 years of age group was significant, F(6, 12) = 2.61, p = 0.74,  $\eta^2 p = 0.57$ , suggesting the linear combination of the TRAQ subgroup scores and overall score was significantly different between both the baseline and intervention groups, indicating the potential for a trend. The MANOVA results are presented in Table H6.

Post hoc analysis of variance (ANOVA) of each dependent variable was conducted to further examine the effects of the baseline and intervention groups of the 16-18 years of age group. Of the six dependent variables, which are the five subgroups and the overall score of the TRAQ, the ANOVA conducted on the subgroup of Talking with Providers, when examined with an alpha value of 0.10, indicated a significant difference, F(1, 17) = 4.47, p = .049, among baseline and intervention groups. Refer to Table H7 for the ANOVA results and Table H8 for means and standard deviation associated with the Talking with Providers subgroup. The post hoc analyses of the other subgroups and the overall score were not significant.

## Clinical Significance

Statistically, the null hypothesis cannot be rejected for the 14-15 years of age group, and the null hypothesis can be rejected for the 16-18 years of age group. However, the significant effect of the intervention on the 16-18 years of age group should be interpreted with caution as

the mean score for the Talking with Providers subgroup appeared to be negatively affected when comparing the baseline group to the intervention group in the post hoc analysis, which is contradictory to intervention expectations.

In addition, from a clinical standpoint, the majority of adolescents in both of the intervention groups agreed that the intervention videos helped the participants to understand the process of transition as well as described their role in the transition process; respectively 75% and 62.5%. The results are presented as part of the descriptive statistics in Table H9.

## Impact and Sustainability

Encompassing the statistical and clinical outcomes, an educational video intervention aimed at improving transition readiness in the adolescent population of a pediatric primary care office may be useful for older adolescents. Also, given the supportive findings related to the perceived understanding by the adolescent of the transition process and their role in that process, use of an educational adjunct may be useful. Despite the data only showing the possibility of an increase in transition readiness with illustration-based anticipatory guidance, broaching the subject of transitioning to adult health care early and at regular intervals ascribes to the concept of anticipatory guidance. Continuing this intervention would help to address the needs of adolescents from a knowledge perspective, as well as promote discussion with providers, as they approach the age of adulthood. From a time utilization perspective, incorporating an educational anticipatory guidance video during a patient's idle time in the office, such as that experienced by adolescents sitting during the 15-minute waiting period following the human papillomavirus (HPV) vaccine, is a potentially opportune time considering the end utility is questionable. While not explored except for a brief week, which will be discussed in the following section, a link to

the videos could be sent out before or after adolescent visits via the site's secure health messaging platform as a way to avoid taking time away from the providers.

#### Discussion

#### **Limitations and Barriers**

While this project intended to measure the efficacy of using the site's secure health messaging platform as a pre-appointment communications education initiative, concerns arose over limited enrollment in the health information portal associated with the messaging platform and lack of response. Due to these issues, modifications were made after one week to recruit for the intervention phase while adolescents were in the office with plans to provide the survey digitally a week after the appointment. However, it should be noted that changing the implementation strategy for surveying adolescents in the intervention phase likely affected the responses when compared to surveying the baseline groups in the health office setting, which may explain the negative effect on the Talking with Providers subgroup in the post hoc analyses.

Despite HCT being conceived of as a process where the goal is to increase an adolescent's readiness as they approach the age of adulthood, the relevance of the TRAQ survey may not be realized until close to time of transition. While not measured, it was reported off-hand by some parents that the survey questions were not appropriate, in the sense of relevance, for younger adolescents. This limitation is a function of misunderstanding the purpose of the survey, and its relation to HCT and long-term planning, then of health care in the current moment.

Another major limitation was the low response rate in the intervention phase despite the alteration to the implementation method. While 18 participants consented and watched one of the video interventions, only 8 of those participants responded to the survey sent by email in the

weeks following their appointment. Surveying the participants in the office before they left would not have been ideal due to the aspects of health care transition that involve discussion between the adolescent and their parents regarding their healthcare. An example of this can be identified in the various levels of insurance coverage and whether it is private or covered by the government. In continuing with the example, families with private insurance are likely to keep the adolescent on their health insurance policy as allowed by law up to the age of 26. Whereas adolescents utilizing Medicaid-backed coverage will need to address their situation via a different avenue.

Furthermore, the low response rate of the intervention group likely affected the significant outcome noted with the 16-18 years old group. Specifically, the post hoc significance noted with that group indicated a negative effect from application of the intervention, where the Talking with Providers subgroup is concerned.

Another factor to take into consideration is that both the baseline and intervention phases of this study were conducted during the COVID-19 pandemic. The total effect the pandemic had on adolescent primary care well-check visit rates is uncertain. However, given that public messaging at the time from the CDC (2020) was to limit non-essential public travel and activities, opting instead for alternative means of accessing primary care doctors, it should be assumed the site at which the study was conducted did not reach their average adolescent well-check visit rates.

#### **Literature Connections**

Similar to other studies evaluating transition readiness among adolescents, the data collected indicated an increase in average transition readiness scores that correlated with increasing adolescent age (r = 0.56, p < .001). Specifically, Jensen et al. (2017) and Sawicki et

al. (2014a) note the correlation of higher average TRAQ scores with older adolescents. Refer to graph in Appendix J, which displays the average TRAQ scores according to age group, and the scatterplot in Appendix K, which displays the regression correlation between age and average TRAQ scores of the baseline group.

#### **Future Research**

Considering the incidental findings regarding the utility of video interventions in increasing self-reported process and role understanding, a long-term approach to the assessment period should be explored. Again, going back to the idea that individual adolescent health needs in the adult period are highly dependent on multiple factors, allowing the adolescent and family more time to discuss future plans may be beneficial and may increase transition readiness scores over a longer period of time than anticipated by this study. Since readiness is a process with the goal of the adolescent being prepared for the adult role transition, and readiness appears to grow with age, a time-series focusing on yearly intervals may be a more appropriate fit. Furthermore, utilization of time by providers to check-in with adolescents regarding their transition readiness at future visits may serve as timely reminders to continue to consider the different aspects of transition readiness as the adolescent approaches adulthood.

#### Conclusion

Overall, this study produced mixed results relating to significant difference in short-term transition readiness scores using illustration-based anticipatory guidance education focusing on transition preparation. In the short-term, illustration-based anticipatory guidance may potentially impact HCT for adolescents 16-18 years of age despite the conflicting issues presented by the post hoc analyses. More importantly, this study adds to the body of knowledge surrounding HCT through the use of a novel approach to addressing an area of historically low preparation, as

indicated by national surveys, specifically for adolescents without SHCN. Clearly, more research is needed regarding the educational needs for adolescents preparing for transition from pediatric to adult health care providers, or at the very least to an adult health care model.

#### References

- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley, W. C., & Sagerman, P. J. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, *128*(1), 182–200. <a href="https://doi.org/10.1542/peds.2011-0969">https://doi.org/10.1542/peds.2011-0969</a>
- Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., While, A., & Gibson, F. (2016). Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews*, 2016(4), CD009794. <a href="https://doi.org/10.1002/14651858.CD009794.pub2">https://doi.org/10.1002/14651858.CD009794.pub2</a>
- CDC. (2020). <a href="https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/doctor-visits-medicine.html">https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/doctor-visits-medicine.html</a>
- Child and Adolescent Health Measurement Initiative. (2016). *Title V National Performance Measures (NPMs) Across State Comparison Table, 2016 NSCH.* Data Resource Center for Child and Adolescent Health Supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB); Data Resource Center for Child and Adolescent Health. https://www.childhealthdata.org
- Child and Adolescent Health Measurement Initiative. (2018). *Title V National Performance Measures (NPMs) Across State Comparison Table, 2017-2018 NSCH (two years combined)*. Data Resource Center for Child and Adolescent Health Supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). <a href="https://www.childhealthdata.org">https://www.childhealthdata.org</a> Chu, P. Y., Maslow, G. R., von Isenburg, M., & Chung, R. J. (2015). Systematic review of the

- impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *Journal of Pediatric Nursing*, *30*(5), e19-27. https://doi.org/10.1016/j.pedn.2015.05.022
- DeCarlo, L. T. (1997). On the meaning and use of kurtosis. *Psychological Methods*, *2*(3), 292–307. <a href="https://doi.org/10.1037/1082-989X.2.3.292">https://doi.org/10.1037/1082-989X.2.3.292</a>
- Dwyer-Matzky, K., Blatt, A., Asselin, B. L., & Wood, D. L. (2018). Lack of preparedness for pediatric to adult-oriented health care transition in hospitalized adolescents and young adults. *Academic Pediatrics*, 18(1), 102–110. https://doi.org/10.1016/j.acap.2017.07.008
- Eaton, C. K., Davis, M. F., Gutierrez-Colina, A. M., LaMotte, J., Blount, R. L., & Suveg, C. (2017). Different demands, same goal: Promoting transition readiness in adolescents and young adults with and without medical conditions. *The Journal of Adolescent Health:*Official Publication of the Society for Adolescent Medicine, 60(6), 727–733.

  <a href="https://doi.org/10.1016/j.jadohealth.2017.01.002">https://doi.org/10.1016/j.jadohealth.2017.01.002</a>
- Espeleta, H. C., Bakula, D. M., Delozier, A. M., Perez, M. N., Sharkey, C. M., & Mullins, L. L. (2019). Transition readiness: The linkage between adverse childhood experiences (ACEs) and health-related quality of life. *Translational Behavioral Medicine*, *9*(3), 533–540. https://doi.org/10.1093/tbm/iby130
- Field, A. P. (2018). *Discovering statistics using IBM SPSS statistics* (5th ed.). Sage Publications Inc.
- Fugate Woods, N., Lentz, M., Sullivan Mitchell, E., Heitkemper, M., & Shaver, J. (1997). PMS after 40: Persistence of a stress-related symptom pattern. *Research in Nursing & Health*, 20(4), 329–340. <a href="https://doi.org/10.1002/(SICI)1098-240X(199708)20:4<329::AID-NUR6>3.0.CO;2-I

- Gabriel, P., Mcmanus, M., Rogers, K., & White, P. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *The Journal of Pediatrics*, 188, 263-269.e15. <a href="https://doi.org/10.1016/j.jpeds.2017.05.066">https://doi.org/10.1016/j.jpeds.2017.05.066</a>
- Gorenflo, G., & Moran, J. W. (2009). *The ABCs of PDCA*.

  <a href="http://www.phf.org/resourcestools/Documents/ABCs\_of\_PDCA.pdf">http://www.phf.org/resourcestools/Documents/ABCs\_of\_PDCA.pdf</a>
- Got Transition<sup>TM</sup>. (n.d.). Retrieved June 16, 2019, from https://www.gottransition.org/index.cfm
- Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2018). Barriers to transition from pediatric to adult care: A systematic review. *Journal of Pediatric Psychology*, 43(5), 488–502. https://doi.org/10.1093/jpepsy/jsx142
- Gumidyala, A. P., Greenley, R. N., Plevinsky, J. M., Poulopoulos, N., Cabrera, J., Lerner, D., Noe, J. D., Walkiewicz, D., Werlin, S., & Kahn, S. A. (2018). Moving on: Transition readiness in adolescents and young adults with IBD. *Inflammatory Bowel Diseases*, 24(3), 482–489. https://doi.org/10.1093/ibd/izx051
- Hagan, J. F., Shaw, J. S., & Duncan, P. M. (2017). *Bright futures: Guidelines for health supervision of infants, children, and adolescents* (4th ed.). American Academy of Pediatrics.
- Hart, L. C., Pollock, M., Brown, A., Shah, N., Chung, R. J., Sloane, R., & Maslow, G. R. (2019).
  Where did they go? Tracking young adult follow-up during the transition from pediatric to adult-oriented care. *Clinical Pediatrics*, 58(11–12), 1277–1283.
  <a href="https://doi.org/10.1177/0009922819852980">https://doi.org/10.1177/0009922819852980</a>
- Hart, L. C., Pollock, M., Hill, S., & Maslow, G. (2017). Association of transition readiness to intentional self-regulation and hopeful future expectations in youth with illness. *Academic Pediatrics*, 17(4), 450–455. https://doi.org/10.1016/j.acap.2016.12.004

- Im, E.-O. (2014). Theory of transitions. In M. J. Smith & P. Liehr (Eds.), *Middle Range Theory for Nursing* (3rd ed., pp. 253–276). Springer Publishing Company, LLC.
- Intellectus Statistics. (n.d.). Retrieved April 9, 2021, from <a href="https://www.intellectusstatistics.com/faqs/">https://www.intellectusstatistics.com/faqs/</a>
- Jensen, P. T., Karnes, J., Jones, K., Lehman, A., Rennebohm, R., Higgins, G. C., Spencer, C. H., & Ardoin, S. P. (2015). Quantitative evaluation of a pediatric rheumatology transition program. *Pediatric Rheumatology Online Journal*, 13, 17. <a href="https://doi.org/10.1186/s12969-015-0013-0">https://doi.org/10.1186/s12969-015-0013-0</a>
- Jensen, P. T., Paul, G. V, LaCount, S., Peng, J., Spencer, C. H., Higgins, G. C., Boyle, B., Kamboj, M., Smallwood, C., & Ardoin, S. P. (2017). Assessment of transition readiness in adolescents and young adults with chronic health conditions. *Pediatric Rheumatology Online Journal*, 15(1), 70. https://doi.org/10.1186/s12969-017-0197-6
- Johnson, M. A. J., Javalkar, K., van Tilburg, M., Haberman, C., Rak, E., & Ferris, M. E. (2015). The relationship of transition readiness, self-efficacy, and adherence to preferred health learning method by youths with chronic conditions. *Journal of Pediatric Nursing*, 30(5), e83-90. https://doi.org/10.1016/j.pedn.2015.05.014
- Kline, R. B. (2015). *Principles and practice of structural equation modeling* (4th ed.). Guilford Press.
- Lapp, V., & Chase, S. K. (2018). How do youth with cystic fibrosis perceive their readiness to transition to adult healthcare compared to their caregivers' views? *Journal of Pediatric Nursing*, 43, 104–110. https://doi.org/10.1016/j.pedn.2018.09.012
- Lebrun-Harris, L. A., McManus, M. A., Ilango, S. M., Cyr, M., McLellan, S. B., Mann, M. Y., & White, P. H. (2018). Transition planning among US youth with and without special health

- care needs. *Pediatrics*, 142(4), e20180194. https://doi.org/10.1542/peds.2018-0194
- Lemke, M., Kappel, R., McCarter, R., D'Angelo, L., & Tuchman, L. K. (2018). Perceptions of health care transition care coordination in patients with chronic illness. *Pediatrics*, *141*(5). <a href="https://doi.org/10.1542/peds.2017-3168">https://doi.org/10.1542/peds.2017-3168</a>
- Mackie, A. S., Rempel, G. R., Kovacs, A. H., Kaufman, M., Rankin, K. N., Jelen, A., Yaskina, M., Sananes, R., Oechslin, E., Dragieva, D., Mustafa, S., Williams, E., Schuh, M.,
  Manlhiot, C., Anthony, S. J., Magill-Evans, J., Nicholas, D., & McCrindle, B. W. (2018).
  Transition intervention for adolescents with congenital heart disease. *Journal of the American College of Cardiology*, 71(16), 1768–1777.
  <a href="https://doi.org/10.1016/j.jacc.2018.02.043">https://doi.org/10.1016/j.jacc.2018.02.043</a>
- Meleis, A. (2010). Transitions theory: Middle range and situation specific theories in nursing research and practice. New York: Springer Publishing Company.
- Meleis, A. I., Sawyer, L. M., Im, E.-O., Hilfinger Messias, D. K., & Schumacher, K. (2000).

  Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, 23(1), 12–28. https://doi.org/10.1097/00012272-200009000-00006
- National Library of Medicine Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110(6), 1304–1306.
- Newton, R. R., & Rudestam, K. E. (2012). *Your statistical consultant* (2nd ed.). SAGE Publications.
- Rosen, D., Annunziato, R., Colombel, J. F., Dubinsky, M., & Benkov, K. (2016). Transition of inflammatory bowel disease care: Assessment of transition readiness factors and disease outcomes in a young adult population. *Inflammatory Bowel Diseases*, 22(3), 702–708. <a href="https://doi.org/10.1097/MIB.0000000000000000033">https://doi.org/10.1097/MIB.00000000000000000033</a>

- Sawicki, G. S., Kelemen, S., & Weitzman, E. R. (2014a). Ready, Set, Stop: Mismatch Between
   Self-Care Beliefs, Transition Readiness Skills, and Transition Planning Among
   Adolescents, Young Adults, and Parents. *Clinical Pediatrics*, 53(11), 1062–1068.
   <a href="https://doi.org/10.1177/0009922814541169">https://doi.org/10.1177/0009922814541169</a>
- Sawicki, G. S., Kelemen, S., & Weitzman, E. R. (2014b). Ready, set, stop: Mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parents. *Clinical Pediatrics*, *53*(11), 1062–1068.

  <a href="https://doi.org/10.1177/0009922814541169">https://doi.org/10.1177/0009922814541169</a>
- Schmidt, S., Herrmann-Garitz, C., Bomba, F., & Thyen, U. (2015). A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults.

  \*Patient Education and Counseling, 99(3), 421–428.

  https://doi.org/10.1016/j.pec.2015.10.024
- Sharma, N., O'hare, K., Antonelli, R. C., & Sawicki, G. S. (2014). Transition care: Future directions in education, health policy, and outcomes research. *Academic Pediatrics*, *14*(2), 120–127. <a href="https://doi.org/10.1016/j.acap.2013.11.007">https://doi.org/10.1016/j.acap.2013.11.007</a>
- Spencer, D. L., McManus, M., Call, K. T., Turner, J., Harwood, C., White, P., & Alarcon, G. (2018). Health care coverage and access among children, adolescents, and young adults, 2010-2016: Implications for future health reforms. *The Journal of Adolescent Health:*Official Publication of the Society for Adolescent Medicine, 62(6), 667–673.

  <a href="https://doi.org/10.1016/j.jadohealth.2017.12.012">https://doi.org/10.1016/j.jadohealth.2017.12.012</a>
- Stewart, K. T., Chahal, N., Kovacs, A. H., Manlhiot, C., Jelen, A., Collins, T., & McCrindle, B. W. (2017). Readiness for transition to adult health care for young adolescents with

- congenital heart disease. *Pediatric Cardiology*, *38*(4), 778–786. https://doi.org/10.1007/s00246-017-1580-2
- Straus, E. J. (2019). Challenges in measuring healthcare transition readiness: Taking stock and looking forward. *Journal of Pediatric Nursing*, *46*, 109–117. https://doi.org/10.1016/j.pedn.2019.03.016
- Syverson, E. P., McCarter, R., He, J., D'Angelo, L., Tuchman, L. K., D'Angelo, L., & Tuchman, L. K. (2016). Adolescents' perceptions of transition importance, readiness, and likelihood of future success: The role of anticipatory guidance. *Clinical Pediatrics*, 55(11), 1020–1025. https://doi.org/10.1177/0009922816666882
- Uzark, K., Smith, C., Donohue, J., Yu, S., Afton, K., Norris, M., & Cotts, T. (2015). Assessment of transition readiness in adolescents and young adults with heart disease. *The Journal of Pediatrics*, *167*(6), 1233–1238. <a href="https://doi.org/10.1016/j.jpeds.2015.07.043">https://doi.org/10.1016/j.jpeds.2015.07.043</a>
- van Staa, A., van Der Stege, H. A., Jedeloo, S., Moll, H. A., & Hilberink, S. R. (2011).

  Readiness to transfer to adult care of adolescents with chronic conditions: Exploration of associated factors. *Journal of Adolescent Health*, 48(3), 295–302.

  <a href="https://doi.org/10.1016/j.jadohealth.2010.07.009">https://doi.org/10.1016/j.jadohealth.2010.07.009</a>
- White, P. H., Cooley, W. C., Transition Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, *142*(5), e20182587. <a href="https://doi.org/10.1542/peds.2018-2587">https://doi.org/10.1542/peds.2018-2587</a>
- Wood, D. L., Sawicki, G. S., Miller, M. D., Smotherman, C., Lukens-Bull, K., Livingood, W. C., Ferris, M., & Kraemer, D. F. (2014). The transition readiness assessment questionnaire (TRAQ): Its factor structure, reliability, and validity. *Academic Pediatrics*, *14*(4), 415–422.

https://doi.org/10.1016/j.acap.2014.03.008

- Zhong, Y., Gilleskie, D. B., van Tilburg, M. A. L., Hooper, S. R., Rak, E., Javalkar, K., Nazareth, M., Pitts, B., Ndugga, M., Jain, N., Hart, L., Bhansali, S., Richards, J., Detwiler, R. K., True, K., de Pomposo, A. S. F., & Ferris, M. E. (2018). Longitudinal self-management and/or transition readiness per the TRxANSITION index among patients with chronic conditions in pediatric or adult care settings. *The Journal of Pediatrics*, 203, 361-370.e1. https://doi.org/10.1016/j.jpeds.2018.06.052
- Zimmerman, M. A. (2000). Empowerment theory: Psychological, organizational, and community levels of analysis. In *Handbook of community psychology*. (pp. 43–63). Kluwer Academic Publishers. <a href="https://doi.org/10.1007/978-1-4615-4193-6">https://doi.org/10.1007/978-1-4615-4193-6</a> 2

Appendix A

Adolescent Patient Population by Age at a Small Southwest Pediatric Health Clinic as of

September 2019

Age	Number of
	Patients
12	420
13	333
14	340
15	294
16	257
17	200
18	174
19	131
20	83
21	67

# Appendix B

#### **Evaluation of Quantitative Studies**

**Table 1**Evaluation Table of Quantitative Studies

Citation	Theory/	Design/ Method	Sample/ Setting	Major Variables	Measurement/	Data Analysis	Findings/	Level/Quality of
	Conceptual			& Definitions	Instrumentation		Results	Evidence;
	Framework							Decision for
								practice/
								application to
								practice
Gumidyala et al.	Inferring	Design:	n= 106	IV –	Physician global	Analysis via	- ↑ AYA age and	LOE:
(2018)	Zimmermann's	CS study		- Age	assessment	IBM SPSS	↑ AYA self-	IV
	empowerment		70.7% (n=75)	- Gender	rating	Statistics v.20	efficacy and ↑	
Moving On:	concept	Purpose: To	completed	- Disease			AYA patient-	Strengths:
Transition	containing 3	describe TR in	questionnaire	Duration	Study developed	- descriptive	provider	- incudes both
Readiness in	components:	adolescents with		- Disease	patient-provider	statistics	communication	AYA and PR of
Adolescents and	intrapersonal,	IBD and to	Demographics:	Severity	transition-related	- bivariate	were each	TR
Young Adults	interactional,	identify	- 86.7%		communication	correlations	associated with ↑	- explored
with IBD	and behavioral	associated	Caucasian	DV –	questionnaire	- multiple	AYA-RTQ with	patient-provider
		factors.	- 53.3% male	- Self-efficacy		regression	effect sizes	communication
Country: USA			- 74.7% crohn's	- AYA-RTQ-	RTQ	analyses with	ranging from	in relation to TR
			disease	overall		forward entry	small to medium	
Funding:			- 22.7%	- AYA-RTQ-	Inflammatory	- probability of F		Weaknesses:
American			ulcerative colitis	adolescent	Bowel Disease	used for	- transition	- focus on IBD;
Psychological			- 57.3% no	responsibility	Self-Efficacy	regression	communication	not generalizable
Association and			disease activity	- PR-RTQ-	Scale (IBD-SES)	- Effect size	and age were	across general
Bucksbaum			at enrollment	overall			significant and	population
Institute				- PR-RTQ-			had a large effect	- recruitment
			Sample: IBD	adolescent			on AYA RTQ-	from patients
Bias: May have			patients 16-22	responsibility			overall scores	adhering to
an inclusive			years of age				[Multiple R =	clinic visits
sampling bias							0.58; F $(4, 63) =$	- relied on self-
given			Site: 3 outpatient				16.48, P <	report
recruitment			pediatric IBD				0.001]	- poor response
during clinic			clinics					rate

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/
								application to practice
visits. Self-report method may be impacted by social desire biases.			associated with Midwestern children's hospitals  Inclusion: - IBD diagnosis for minimum of 1 year - age 16-22 years old - parent/legal guardian participation  Exclusion: - significant communication or cognitive impairment - non-English speaking parent - any other chronic medical condition requiring medication use				- transition age, communication, gender, and self-efficacy had an overall significant effect on AYA RTQ-responsibility scores [Multiple R = 0.59; F (4, 63) = 11.58, P < 0.001]	Application to practice: - Despite limited ability generalize, does indicate associations between good communication and TR, as well as supports the notion that older adolescents tend to have greater TR.  Limitations: - limited diversity of sample - required parent participation shifted recruitment towards younger age sample

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
Hart et al. (2019) Where Did They Go? Tracking Young Adult Follow-up During the Transition from Pediatric to Adult-Oriented Care Country: USA Funding: National Research Service Award Grant Bias: Conflicts of Interests: Dr Shah is a speaker for Novartis and Alexion	Inferring Meleis' Theory of Transitions	Design: Retrospective  Purpose: To retrospectively evaluate health record data of young adult clinic attendance during the transition period.	n=1623  Attrition Rates: - 40% lost from pediatric care - 16% lost from adult care  Demographics: - mean age at end of study: 21 years old - mean number of visits during the study: 20 - 53% female - 50% white - 45% black  Sample: - minimum age of 18 at end of study period - Chronic disease history: diabetes, sickle cell, lupus, IBD, HIV, CF	IV – - diagnosis  DV – - odds of successful transfer - dropping out of care - gap in care - transitional care self-assessment score	Medical Home Health Care Transition Index - Transitional Care Self- Assessment (6 Core Elements)  Gap in care – transitional care quality	Analysis via STATA v.14 Random-effects logistic regression	↑ number of successful transitions associated with ↓ gap times between last pediatric visit and first adult visit, and ↑ clinic transition scores  ↑ clinic transition scores associated with ↑ odds of successful transfer and ↓ loss to follow-up	LOE: IV  Strengths: - rare examination of transition and visit gap measurement  Weaknesses: - single site study - may not generalize to other settings - transition score was self-reported measure - design did not account for pediatric patient that left for college only to return for adult care later - high attrition rates

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
			Site: single, large southeastern health center: 6 clinics					Application to practice: - attention given to the area of transitional care at the practice level may increase successful transitions  Limitations: - not all patients transferred - unable to track if loss to follow-up was due to seeking care elsewhere - longitudinal snapshot -
Jensen et al. (2015)  Quantitative Evaluation of a Pediatric Rheumatology	Inferring Meleis' Theory of Transitions	Design: CS study  Purpose: To assess and quantify transition	n=210  Demographics: - 79% female - median age: 18 years	IV – - transition program plan development with social worker	Continuation of services with adult provider at 6-8 months after initial visit	Analysis via STAS/STAT v9.2 Descriptive statistics	IG - 51% saw an adult rheumatologist at least once - 42% saw an adult	LOE: IV  Strengths: - length of study  Weaknesses:

#### Table 1

#### Evaluation Table of Quantitative Studies

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
Transition Program  Country: USA  Funding: Not indicated  Bias: Potential design and sampling bias		outcomes of adolescents as they transition to adult providers through the use of social worker-centered transition program.	- age range: 15-26 years  Sample: n=210 - minimum age of 16 years old  Control: n=26 - eligible and consented but did not meet with social worker  Site: pediatric rheumatology clinic at a single, tertiary care, freestanding pediatric hospital	DV – - transition success		Two-sided chi-square	rheumatologist more than once - 10% did not return to provider after initial visit - 15% never saw an adult rheumatologist  Significant difference between transition group and CG in terms of successful and not successful transitions (p = 0.002)	- lack of information and demographics on CG - single center - small study - low response rate - unequal intervention and CGs - intervention not adequately described  Application to Practice: - Not generalizable due to specific patient population, lack of intervention description, and
Johnson et al. (2015)	None specified	Cross-sectional quantitative study	n= 160 response rate: 20.48%	IV – Preferred learning method: -Handout	STARx Questionnaire	SPSS v21	Information obtained from internet and care	poor methodology LOE: IV

42

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
The relationship				-Internet	Modified	Chi square tests	providers	Strengths:
of transition		Purpose:	Convenience	-Health care	diabetes	for categorical	associated with	-novel approach
readiness, self-		To compare	sampling	providers	management	variables	greater transition	to gathering
efficacy, and		preferred		-Family/parents	self-efficacy		readiness.	preference data
adherence to		learning methods	Age range: 6-16	-Other youth	questionnaire	t-tests for		and potential
preferred health		of youth with	Male:84	-Other		continuous	Transition	associations
learning method		CC and the	Female:76		Morisky	variables	Readiness:	
by youths with		associations	Predominantly	DV –	Medication	T.	Internet: p=.021	Weakness:
CC.		between those	Caucasian:	-STARx	Adherence Scale	Linear	-no use:	-convenience
E V N		methods and the	77.5%	-Self-efficacy		regressions with	37.36±14	sample
Funding: Not stated		following: transition	Participants	-Non-adherence		age as control	-use: 42.69±11.59	-cross-sectional design
stated		readiness, self-	attendees of			Separate	Health care	-online survey
		efficacy, and	Victory Junction			regressions for	providers:	restricts
Country: USA		medication	Camp, NC 2014			each DV	p=.004	responses to
Country. OSA		adherence.	with CC via an			Cach D v	-no use:	those with
Bias: Potential –		adiference.	online survey.				35.57±14	convenient
unable to assess			omme survey.				-use:	access to
non-responders			Inclusion				41.57±12.49	computer and
vs responders			Criteria: Victory					internet, as well
1			Junction Camp				Self-efficacy:	as higher
			attendee				Internet: p=.007	socioeconomic
							-no use:	means
			Exclusion				52.96±25.15	-establishes
			Criteria: None				-use:	preference of
							63.14±20.07	source, not use
							Health care	-poor response
							providers:	rate
							p=.001	

43

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to
							-no use: 49.35±25.32 -use: 61.59±21.69  Doctors as a source of health info significant predictor of health care transition readiness (β = 0.310; p = .002)	practice  Application to practice: Limited ability to make associations. May indicate that health care providers and the internet are important sources of information for the successful transition from pediatrics to adult medicine, but are not the only sources. Providers should ascertain patient preferences and attempt to be as flexible as possible while ensuring appropriate guidance regarding patient's

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice preferred
								method.
Lemke et al. (2018)  Perceptions of Health Care Transition Care Coordination in Patients with Chronic Illness  Country: USA  Funding: Maternal and Child Health Research Program, Maternal and Child Health Bureau, Health Resources and Services  Administration, Department of Health and Human Services	Inferring Meleis' Theory of Transitions	Design: RCT  Purpose: To evaluate the effectiveness of HCT care coordination through measurement of patient-level perception and perceived quality of care	n=209  Setting: Urban academic AM practice in tertiary referral HS for pediatrics  Demographics: 208 African Americans  Mean age: 19 ± 1.7 Age range: 16-22  Stratified by complexity and age for IG and CG balance	IV – AAP- AAFP-ACP 6 core elements in addition to enhanced usual care - readiness assessment - planning and preparation - monthly action plan updates - transition checklist - medical summary  Control – Enhanced usual care  DV – - PACIC scores - CPCQ scores	(PACIC) – Patient Assessment of Chronic Illness Care (CPCQ) – Client Perceptions or Coordination Questionnaire	- X <sup>2</sup> - t-test - linear regression - logistic regression	-↑PACIC score at 12 months for IG vs CG (p = .01) - IG had ↑ scores for patient activation (p = .01), problem solving (p = .02), and coordination/ follow-up (p < .01) -↑odds of IG having talked to provider about future care (p < .01)	LOE: III  Strengths: - cohort of a variety of conditions along with a comparison group - structured intervention plan implemented over an adequate period of time  Weaknesses: - demographic homogeneity - not all of the participants transferred care during study period - intervention may have varied depending on

#### Table 1

## Evaluation Table of Quantitative Studies

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
Bias: Potential for selection bias								patient engagement and availability
due to CVS								Application to practice: - intervention generalizable across a variety of conditions and complexity levels. Also generalizable to those with chronic conditions and those of low SES
Mackie et al. (2018)	Inferring Zimmermann's	Design: Cluster RCT	n=173	IV – 2 nurse-led face-to-face	- TRAQ - Williams' self-	- Mann-Whitney U test	Intervention participants 1.8	LOE: III
Transition Intervention for Adolescents With Congenital Heart Disease Country: Canada	empowerment concept containing 3 components: intrapersonal, interactional, and behavioral	Purpose: To evaluate the impact of nurse-led transition interventions on lapses in care with secondary aims of	Site: 2 tertiary care pediatric cardiology clinics  Demographics: Age: range 16- 17 years	sessions without parents  Control – usual care  DV –  - time to first adult	management	- Cox regression - t-test	times more likely to have appointment within 1 month (95% confidence interval: 1.1 to 2.9; Cox regression, p 1/4 0.018).	Strengths: - well designed comparison and follow-up of patient transfers to adult providers  Weaknesses:
		aims of evaluating	17 years	adult appointment			0.018).	Weaknesses

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
Funding: the Heart and Stroke Foundation of Canada, Canadian Institutes of Health Research Bias: Potential selection bias		participants' disease knowledge, self-management and self-advocacy skills, and cardiac procedures post-enrollment.	Sample: 2 parallel groups of adolescents	- disease knowledge scores - self- management scores - self-advocacy scores - incidence of cardiac re- intervention - transition readiness			↑ participation and knowledge of IG compared to CG  ↑ TRAQ self-management index scores at 1, 6, 12, and 18 months for the IG  28% of the IG and 33% of the CG failed to return	- high failure to return rates - potential differences of intervention provided to IG - long-term impact of self-management skills remains unknown  Application to practice: - TRAQ shows some potential as a measure of TR across the transition period - limited generalizability outside of cardiology
Schmidt et al. (2015)	Zimmermann's empowerment	Quasi- experimental	n=325	IV – 2 day group training	1. Health-related TCS	RMVCA with age as covariate	Transition workshop	LOE: III
( 2)	concept	controlled trial	Demographics:	transition	2. General Self-		significantly	Strengths:
A multicenter	containing 3		Adolescents 15	workshop (x8	Efficacy Scale	ANCOVA	affected	-well defined
prospective	components:	Partial	years or older	60-90 min	(GSE)		transition	education
quasi-	intrapersonal,	randomization		modules)			competence,	intervention

Table 1

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults.  Funding: Federal Ministry of Education and Research  Country: Germany  Bias: Potential recruitment bias	interactional, and behavioral	Purpose: To evaluate the effectiveness of generic patient education program for adolescents with a chronic condition during their transition to adult care and to quantify changes in health service participation and patient-reported outcomes.	with diagnosis of DM, CF, or IBD  Age range: 13-22  175 males; 150 females  DM: 186 IBD: 99 CF: 40  No previous patient education: 132 One previous patient education: 57 More than one previous patient education: 121	Topics: "transfer to adult medicine, orientation in the health system, future planning and occupation/caree r, separation from parents, communication about illness with peers and partners, stress management and activation of resources"  Control – Treatment-asusual  DV – Primary:	3. Patient Activation Measure 13 (PAM13-D) 4. Self-report version of the Child Health Care Questionnaire on Satisfaction, Utilization, and Needs (CHS- SUN self) 5. QoL: EUROHIS QOL-8, DISABKIDS Chronic Generic Measure	Post-hoc analyses Used statistical Package for the Social Sciences SPSS v22	self-efficacy, and satisfaction  Change in scores from pre- and post-intervention to 6 month follow-up: TCS: F=38.69, p<.001, η2=.125 TC-c: F=29.03, p<.001, η2=.099 Self-efficacy: F=2.98, p=.05, η2=.011	practice -included control group  Weakness: -CF group underpowered -generic QoL instruments may be too broad for certain conditions -6-month follow- up too short to determine long- term effect on health outcomes and cost savings -inability to randomize participants at inpatient centers involved due to organizational
due to limited clinic locations			Inclusion criteria: -Diagnosed with DM, CF, or IBD -15 years or older	health-related transition competence, self-efficacy, patient activation, and				restrictions  Application to Practice:

48

49

#### Table 1

## Evaluation Table of Quantitative Studies

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
			Exclusion criteria: -Younger than 15 years -Learning disability -Insufficient German language skills to preclude participation in a discussion	satisfaction with health care. Secondary: QoL				educational transition program may improve transitional care for adolescents with CC
Syverson et al. (2016)  Adolescents' perceptions of transition importance, readiness, and likelihood of future success: The role of AG.  Funding: HRSA of the US	None specified.	Design: Cross-sectional RCT Purpose: Assesses how AG affects patient perception of the HCT process.	n=209 Snowball sampling Stratified by: Age: 2 groups (16-18 years and 19-22 years) Care Coordination: 3 groups (low, moderate, high)	IV – AG: 1. transition 2. insurance 3. needs 4. encouragement of responsibility  DV – Perception 1. Transition Importance 2. Transition Readiness 3. Transition	Survey: NSCSHCN transition assessment questions – yes or no  Perception questions on a 10-point Likert- type scale  Proxy allowed for participants	Care Coordination Assignment Tool v1.0 – determine level of care coordination needs Linear regression for relationships between IV and DV	Transition AG in any 3 categories (transition, insurance, needs) resulted in significantly higher means ratings of perceived readiness and confidence of success.  Transition —	LOE: IV  Strengths: -samples from various levels of care coordination needs  Weakness: -largely homozygous for race and socioeconomic
Department of HHS			Age range: 16- 22 years	Successful	unable to answer for themselves	Multiple variable analyses to	Readiness: Mean: 6.8	status

Table 1

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for
	Traine work							practice/
								application to
								practice
						account for age	95% CI: 5.9-7.6	-response rates
Country: USA			53% Female			and level of care	P: .023	not discussed
D' M			200			coordination	Transition –	-cross-sectional
Bias: None			208 participants				Success:	design
recognized			African				Mean: 7.2	-use of proxy for
			American				95% CI: 6.5-7.9 P: .028	subset of
			District of				P: .028	participants
			Columbia-based				Insurance –	Application to
			Medicaid health				Readiness:	Practice: Limited
			plan for SSI-				Mean: 7.0	associations.
			eligible				95% CI: 6.1-7.9	Low rates of
			YWSHCN				P: .006	AG. However,
								those who did
			Site:				Insurance –	report AG
			Hospital based				Success:	seemed to
			urban academic				Mean: 7.5	positively affect
			adolescent health				95% CI: 6.7-8.2	their perceptions
			clinic				P: .003	of transition
			T 1				N. 1	readiness and
			Inclusion				Needs –	confidence of
			criteria: recruited				Readiness:	success.
			as part of a				Mean: 6.6 95% CI: 5.9-7.3	
			larger longitudinal				P: .018	Limitations:
			study, inclusion				1010	Homogeneousne
			criteria not				Needs –	ss of ethnic
			discussed				Success:	background and
							Mean: 7.2	socioeconomic

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
			Exclusion criteria: Not discussed				95% CI: 6.7-7.8 P: <.001	status of cohort limits generalizability.
Uzark et al. (2015)  Assessment of Transition Readiness in Adolescents and Young Adults with Heart Disease  Country: USA  Funding: University of Michigan Cardiovascular Center  Bias: May have an inclusive sampling bias given CVS.	Inferring Zimmermann's empowerment concept containing 3 components: intrapersonal, interactional, and behavioral	CS study  Purpose: Evaluate transition readiness, information seeking and QoL in patients 13-25 years of age with CHD or heart transplant as well as evaluate delivering a TRA via e- tablet.	n=164 CVS  Demographics: - median age 18.1 years - age range: 13- 25.5 years - race: 90.2% white - male sex: 59.8%  Site: University of Michigan Congenital Heart Center	IV – 1. Age 2. Gender 3. Diagnosis  DV – 1. Transition readiness 2. Knowledge deficits 3. Self-efficacy 4. Self-management behavior 5. Psychosocial QoL	Modified TRA – CHD specific - developed from the STARx and TRXANSITION Scale  Pediatric Quality of Life Inventory (PedsQL)	- descriptive statistics - 2-sample t test - X² test (Fisher exact test) -bivariate relations of Pearson or Spearman correlation coefficients - sig level of 0.05, 2-sided tests	Among CHD patients: - ↑ knowledge associated with ↑ self-efficacy - Transition knowledge deficits and ↓ self-efficacy associated with ↓ psychosocial QoL - ↑ age associated with ↓ knowledge deficits and ↑ self-efficacy and self-management	LOE: IV  Strengths: ->90% response rate - trialed use of e-tablet system for data collection  Weaknesses: - parent education level and socioeconomic data not assessed - transition process not standardized  Application to practice: Limited associations further limited by sample. TRA may provide insight into care

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for
								practice/ application to
								practice deficits,
								especially as it
								relates to
								adolescents with CHG. QoL may
								be affected by
								better patient
								knowledge and
								self-efficacy as
								well.
								Limitations:
								- single-center
								study
								- lack of
								geographic and racial diversity
								- study
								population limits
								generalizability
Zhong et al.	Inferring Meleis'	Design:	n= 566	IV –	TRxANSITION	Analysis via	<b>-</b> ↑	LOE: IV
(2018)	Theory of	Longitudinal	CT IC	- age	Index	STATA 13.0	TRxANSITION	
T - '41' - 1	Transitions	observational	CVS	- gender		1	Index scores	Strengths:
Longitudinal Self-		Purpose:	Demographics:	- race - guardians at		- descriptive statistics	with \( \) age, but at diminishing rate	- length of study
Management		Evaluate the	- 54.1% female	home		- compared 2	- ↑ intellectual	Weaknesses:
and/or Transition		roles of key	- 43.6%	- driving time to		empirical models	limitations \	- data collection
Readiness per		individual,	Caucasian	site		coefficients	TRxANSITION	interviewers not
the		family, and				- regression	Index scores	

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to practice
TRXANSITION Index among Patients with Chronic Conditions in Pediatric or Adult Care Settings Country: USA Funding: Not stated. Bias: May have an inclusive sampling bias given CVS.		illness characteristics on longitudinal HCT readiness in pediatrics and self-management skills in the adult setting, conduct from 2006 to 2015.	- 42.2% African American - avg age at baseline: 17.3 - age range at baseline: 12-31  Site: University of North Carolina Hospitals	- intellectual limitation - insurance: pubic, self-pay - socioeconomic - disease-related characteristics  DV – - TRXANSITION Index Score		- sensitivity analyses - effect size - significant difference	- † years of diagnosis ↓ TRxANSITION Index scores	consistent with patients - different samples depending on collection of 1 score or multiple scores - re-interviews not on uniform intervals - varied but limited chronic disorder list - medical care and primary care data not captured  Application to Practice: Can apply knowledge of ideal times to approach HCT readiness as adolescents approach adulthood to the care visit to achieve efficient

Table 1

Evaluation Table of Quantitative Studies

Citation	Theory/ Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables & Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Results	Level/Quality of Evidence; Decision for practice/ application to
								practice
								use of time and applicability. Will help tailor learning needs depending on demographic data.
								Limitations: - single- institution - change in data collection methods lost data as variables updated - limited data on parent education - limited data on
								socioeconomic variables

# AGING OUT OF PEDIATRICS Appendix C

# **Synthesis of Evaluation Table**

Synthesis of Evaluation Table

	Categories				Study b	y Main A	uthor				
Major Category	Subcategory	Gumidyala	Hart	Jensen	Johnson	Lemke	Mackie	Schmidt	Syverson	Uzark	Zhong
	Year	2018	2019	2015	2015	2018	2018	2015	2016	2015	2018
Study Info	Design	CS	R	CS	CS	RCT	RCT	QE	CS RCT	CS	LO
Study IIII0	LOE	IV	IV	IV	IV	III	III	III	IV	IV	IV
	Country	USA	USA	USA	USA	USA	Canada	Germany	USA	USA	USA
	n	106	1623	210	160	209	173	325	209	164	566
	Mean Age (years)	Not	21.13 (at end of	18	12.2	19	17	16.8	19	18.1	17.3
		provided	study)								
	Range (years)	16-22	18 (min age at	15-26	6-16	16-22	16-17	13-22	16-22	13-	12-31
Sample			end of study)							25.5	
	% Males	53	47	21	52.5	52.6	51	54	47	60	46
	Chronic Conditions or	IBD	DB, SC, Lupus,	Rheumatology	Various	Various	Cardiology	DB, CF,	Various	CHD	Various
	Specialty		IBD, HIV, CF					IBD			
	Proxy					X			X		
	Academic					X			X	X	**
Setting	Outpatient	X	X	X		X	X	X	X	X	X
•	Inpatient							X			
	Online				X						
	Transition Readiness	X			X		X		X	X	X
	Transitional Care Quality		X		<b>T</b> 7						
	Medication Adherence				X						
Measurement	Self-Efficacy	X			X			X			
Construct	Self-Management					X	X	X			
	QoL							X		X	
	Patient Satisfaction	***						X			
	Disease Severity	X								<b></b>	***
	Demographics	X	37							X	X
	Disease and Associated	X	X							X	X
W.C	Characteristics			37	37	37	37	37	37		
IV Constructs	Transition Planning or			X	X	X	X	X	X		
	Education					V					
	Readiness Assessment					X					X
DV Constant	Socioeconomic Factors	V			V			X		V	X
<b>DV Constructs</b>	Self-efficacy	X			X			X		X	

Key: CF- cystic fibrosis; CHD- congenital heart disease; CS- cross-sectional study; DB- diabetes; GSE- general self-efficacy scale; HIV- human immunodeficiency virus; IBD- irritable bowel disease; LO- longitudinal observational study; QE- quasi-experimental controlled trial; QoL- quality of life; R- retrospective; RCT- randomized controlled trial; SC- sickle cell

Jensen

Johnson

Lemke

Study by Main Author

Mackie

Schmidt

Syverson Uzark

Zhong

Gumidyala

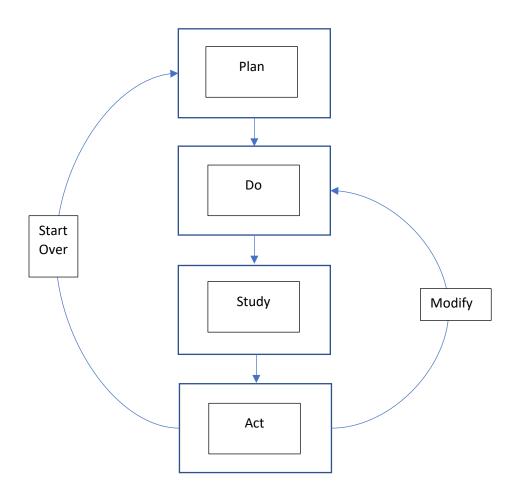
**Subcategory** 

Categories

Hart

**Major Category** 

Appendix D
Plan-Do-Study-Act Model

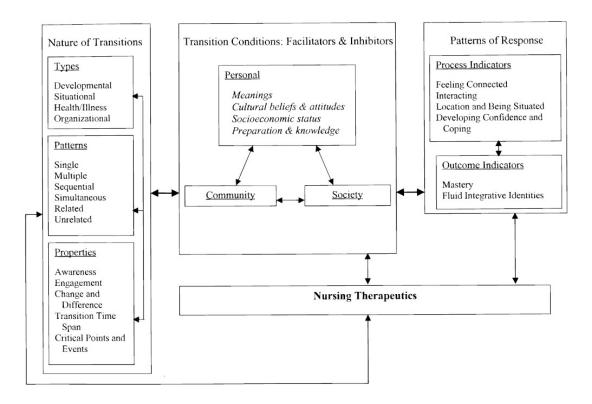


#### Appendix E

#### Meleis' Transition Theory

Figure 1

Model of Meleis' Transition Theory



*Note*. From "Experiencing transitions: An emerging middle-range theory," by A. Meleis, L. Sawyer, E. Im, D. Hilfinger Messias, and K. Schumacher, 2000, *Advances in Nursing Science*, 23(1), p. 12 (https://doi.org/10.1097/00012272-200009000-00006).

#### Appendix F

#### **Project Timeline**

- A. Implementing an Educational Primer for Health Care Transition
  - a. Identification of candidates via scheduled appointments
    - i. Sample population: adolescents ages 14 20
  - b. Baseline Phase
    - i. The investigator will contact potential participants, and their legal guardians as needed, at their adolescent well-check appointment and provide information on the study and conduct the survey if adolescent and legal guardian agree to participation.
  - c. Intervention Phase
    - i. The investigator will contact potential participants, and their legal guardians as needed, at their adolescent well-check appointment and provide information on the study.
    - ii. If participation is agreed on by the adolescent and their legal guardian, if needed, then health care transition explainer video will be shown.
    - iii. Link to digital survey will be sent to participant provided email 1 week following the adolescent well-check..

AGING OUT OF PEDIATRICS

# Appendix G

# **Itemized Budget**

	Phase	Subcategory	Activities or Items	Cost (hr)	Cost (	\$) S	ubtotal	Runni	ng Total	Notes
irect Costs	Plan	Equipment / IT	Studio Microphone		\$ 108	.09				
			Animation Software		\$ 231	.00				
			Web hosting for animation video		\$ 201	.00				3 months purchased for trialing intervention hosting
			Web hosting for survey		\$ -	-				Free hosting through ASU QuestionPro account
			File Box		\$ 3	.74				Lockable file box
			Pad lock		\$ 9	.67				For locking file box
			Clipboard		\$ 6	.48				
			Goggles		\$ 14	.04				
			File tabs		\$ 2	.03				
			Hanging File Folders		\$ 4	.03				
					\$ -	-				for use when interacting with patients
					\$ -	- \$	580.08	\$	580.08	
		Intervention	Script and develop anticipatory guidance animation with voiceover		\$ .	- \$	-	\$	580.08	
		Supplies	Study cover letters and consents for baseline phase (266 pages; 0.13/page)		\$ 34	.58				
			Study cover letters and consents for intervention phase(### pages; 0.12/page)		\$ .	-				
			Permanent markers		\$ 3	.92				
			Envelopes		\$ 3	.00				
			Pens			.36 \$	46.86	\$	626.94	
	Do		Aggregate list of adolescent patient appointments and send out link to video via patient			-				
			Hand out surveys to participants (80 participants; 10 minutes per participant)	14	\$ -	-				
	Study	Analysis	Intellectus Statistics - Cloud-based		\$ -	-				ASU provided account access as part of tuition costs
direct Cost	Plan	Equipment / IT	Microsoft Office Suite		_	-				
		Intervention	Data Bandwidth / Internet		Υ	-				
		Supplies			\$ .	-				
	Do		PI handing out surveys (80 participants; 10 minutes per participant)			-				
					Υ	-				
	Study	Analysis	Data Bandwidth / Internet		\$ .	-				
				48				\$ 1	,787.09	

Appendix H
Results Tables

**Table H1**Frequency Table for Nominal and Ordinal Variables Filtered by Age

Age Group	14-15 Years of Age	16-18 Years of Age
Group		
Baseline	17 (81%)	15 (79%)
Intervention	4 (19%)	4 (21%)
Gender		
Male	7 (33%)	8 (42%)
Female	12 (57%)	11 (58%)
Not Answered	2 (10%)	0 (0%)
School Grade Level		
8	4 (19%)	0 (0%)
9	13 (62%)	0 (0%)
10	4 (19%)	1 (5%)
11	0 (0%)	7 (37%)
12	0 (0%)	10 (53%)
College or Trade School	0 (0%)	1 (5%)
Age in Years Grouped		
14 -15 Years of Age	21 (100%)	0 (0%)
16-18 Years of Age	0 (0%)	19 (100%)

Note. Due to rounding errors, column wise percentages may not equal 100%.

**Table H2**Frequency Table for Nominal and Ordinal Variables Filtered by Age Group and Study Group

Age Group	14-15	Years of Age	16-18 Years of Age		
Variable	Baseline	Intervention	Baseline	Intervention	
Group					
Baseline	17 (100%)	0 (0%)	15 (100%)	0 (0%)	
Intervention	0 (0%)	4 (100%)	0 (0%)	4 (100%)	
Gender					
Male	4 (24%)	3 (75%)	6 (40%)	2 (50%)	
Female	11 (65%)	1 (25%)	9 (60%)	2 (50%)	
Not Answered	2 (12%)	0 (0%)	0 (0%)	0 (0%)	
School Grade Level					

8	4 (24%)	0 (0%)	0 (0%)	0 (0%)
9	10 (59%)	3 (75%)	0 (0%)	0 (0%)
10	3 (18%)	1 (25%)	1 (7%)	0 (0%)
11	0 (0%)	0 (0%)	4 (27%)	3 (75%)
12	0 (0%)	0 (0%)	9 (60%)	1 (25%)
College or Trade School	0 (0%)	0 (0%)	1 (7%)	0 (0%)
Age in Years Grouped				
14 -15 Years of Age	17 (100%)	4 (100%)	0 (0%)	0 (0%)
16 -18 Years of Age	0 (0%)	0 (0%)	15 (100%)	4 (100%)

Note. Due to rounding errors, column wise percentages may not equal 100%.

**Table H3**Correlations between Dependent Variables of Adolescents 14-15 Years of Age

Variable	1	2	3	4	5	6
1. Managing Medications Mean Imputed	-					
2. Appointment Keeping Mean Imputed	0.47	-				
3. Tracking Health Issues Mean Imputed	0.40	0.51	-			
4. Talking with Providers Mean	0.06	0.19	0.25	-		
5. Managing Daily Activities Mean	0.38	0.42	0.28	0.24	-	
6. Overall TRAQ Score Mean Imputed	0.74	0.84	0.73	0.33	0.63	-

**Table H4**Correlations between Dependent Variables of Adolescents 16-18 Years of Age

Variable	1	2	3	4	5	6
1. Managing Medications Mean Imputed	-					
2. Appointment Keeping Mean Imputed	0.53	-				
3. Tracking Health Issues Mean Imputed	0.77	0.68	-			
4. Talking with Providers Mean	0.31	-0.15	0.05	-		
5. Managing Daily Activities Mean	0.09	0.30	0.42	-0.12	-	
6. Overall TRAQ Score Mean Imputed	0.82	0.86	0.92	0.03	0.45	-

**Table H5** *MANOVA Results for Subgroups and Overall TRAQ Scores of Adolescents 14-15 Years of Age* 

Variable	Pillai	F	df	Residual df	p	$\eta_p^2$
14-15 Years of Age	0.32	1.08	6	14	.419	0.32

**Table H6** *MANOVA Results for Subgroups and Overall TRAQ Scores of Adolescents 16-18 Years of Age* 

Variable	Pillai	F	df	Residual df	p	$\eta_p^2$
16-18 Years of Age	0.57	2.61	6	12	.074	0.57

**Table H7**Analysis of Variance Table for Talking with Providers Subgroup of Adolescents 16-18 Years of Age

Term	SS	df	F	p	$\eta_{\mathtt{p}}^{2}$
Group	0.05	1	4.47	.049	0.21
Residuals	0.19	17			

**Table H8**Mean, Standard Deviation, and Sample Size for Talking with Providers Subgroup of Adolescents 16-18 Years of Age

Combination	M	SD	n
A	5.00	0.00	15
В	4.88	0.25	4

**Table H9**Frequency Table for Nominal and Ordinal Variables of Intervention Groups Combined

Variable	n	%
Gender		
Male	5	62.50
Female	3	37.50
Not Answered	0	0.00
School Grade Level		
8	0	0.00
9	3	37.50
10	1	12.50
11	3	37.50
12	1	12.50
College or Trade School	0	0.00

Did\_the\_video\_help\_you\_understand\_the\_process\_of\_transition\_to\_adult\_care

	0.00
Disagree	
Neutral 2	25.00
Agree 5	62.50
Strongly Agree 1	12.50
Did the video describe your role in the transition process	
Strong Disagree 0	0.00
Disagree 0	0.00
Neutral 3	37.50
Agree 4	50.00
Strongly Agree 1	12.50

*Note.* Due to rounding errors, percentages may not equal 100%.

# Appendix I

# **Results Figures**

Figure I1

Chi-square Q-Q Plot for Squared Mahalanobis Distances of Model Residuals to Test

Multivariate Normality for Adolescents 14-15 Years of Age

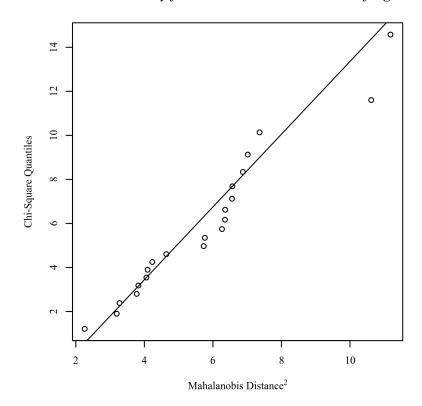
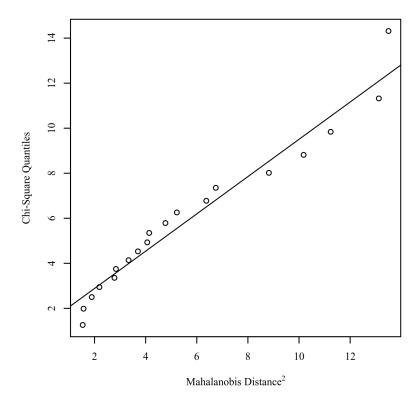


Figure 12

Chi-square Q-Q Plot for Squared Mahalanobis Distances of Model Residuals to Test

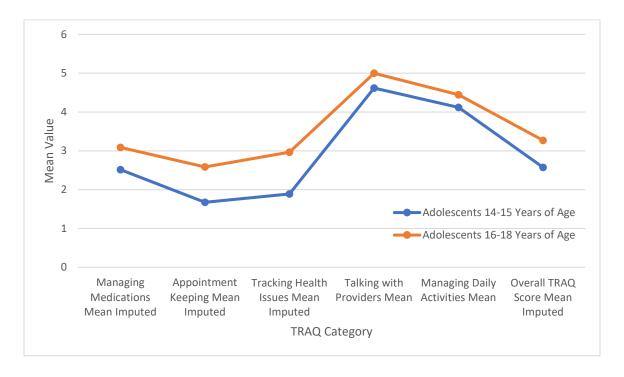
Multivariate Normality for Adolescents 16-18 Years of Age



Appendix J

Mean Transition Scores by Age

Profile Plot of Mean Subgroups and Overall TRAQ Scores by Adolescent Age Group



Appendix K

# **Correlation of Age with Average TRAQ Scores**

Scatterplot between Age in Years and Average Overall TRAQ Scores in the Baseline Group

