

Background

- Nearly 300,000 American children are affected by arthritis or other rheumatic diseases most of which require lifelong care (National Institute of Arthritis and Musculoskeletal Disorders, 2019, para. 1)
- Unmet health needs during adolescence and in the transition to adulthood predict not only poor health outcomes as adults but also lower quality of life in adulthood (Hargreaves et al., 2015)
- Those without successful HCT may forego adult care resulting in serious health consequences (Peter et al., 2009)
- The current standard of transition support for the rheumatology population is inadequate (Lawson et al., 2011)
- Interventions to improve self-management should be standard in transition readiness procedures (Lawson et al., 2011)

Methods

Setting: Outpatient Pediatric Rheumatology clinic in northern NJ

- Adolescents aged 12-22
- Survey was emailed to patients and included in discharge summaries

Domains Assessed Included:

- Managing Medications
- Appointment keeping
- Tracking Health Issues
- Talking with Providers
- Managing Daily Activities

Objectives

Primary Objective:

- Collect patient feedback in order to identify knowledge gaps in order to develop a formal transition program within the division of pediatric rheumatology.

Secondary Objectives:

- Increase awareness of transition and skills required.
- Collect self-reported patient feedback about their own personal readiness and comfort in readiness to transition.
- Collect patient feedback to evaluate readiness in each domain of the TRAQ tool
- Propose recommendations for the development of a targeted transition program for this practice that will be uniquely tailored to the needs of the population

Results

12 patients participated in the survey

- 9 fully completed the survey: 2 males, 7 females

Mean Readiness Score: 4.12 out of 5 = 82.4%

Score Range: Low of 47 High of 96

Gender Scores:

- Mean for Males: 82%
- Mean for Females: 76.57%

Correlations with Transition Readiness TRAQ Score:

- Age: $p=0.0069$**
- Age at diagnosis: $p=0.857$
- Disease impact: $p=0.616$
- Self-reported readiness to transition $p=.007$**



| TRAQ Tool Domains Ranked Lowest score to Highest | Average Score | Percentage |
|--|---------------|-------------------------------|
| Appointment Keeping | 3.2 | 64% |
| Managing Medications | 3.9 | 78% |
| Tracking Health Issues | 4 | 80% |
| Managing Daily Activities | 4.6 | 92% |
| Talking with Providers | 4.9 | 98% |
| OVERALL AVERAGE | 4.12 | 82.4% READY ON AVERAGE |

Implications

- The results of the project reflect the literature: adolescents are lacking basic skills needed to transition to an adult medical home.
- Identification of knowledge gaps allowed for educational materials directed at the weakest domains including appointment keeping (insurance information), managing medications, and tracking health issues.
- A Poster including a QR code that leads to resources and informational infographics will be provided to the project site.
- A presentation as well as various resources will be provided to the project site as well in order to guide future quality improvement initiatives regarding Transition Readiness.
- Future research should focus on the effectiveness of this education as well as the suggested implementations to practice.

Conclusion

- Lack of disease knowledge and self-management skills have been identified as one of many barriers to a successful transition of care. Education focused on current gaps in knowledge may assist in developing the groundwork of disease knowledge and management which will aid in a successful transfer to an adult medical home
- Resources will aid in quality improvement efforts to improve disease knowledge and self-management of rheumatic conditions which will lead to more seamless transitions of patients
- The future goals of effective transitioning include enhanced payment for transition services, identifying those in need of services, achieving insurance coverage in those transitioning, training for primary care physicians and medical subspecialists to promote transitions within the medical home. (AAP & AAFP, 2011)

