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Multidisciplinary Team Approach Effect On Pediatric Severe Asthma

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Abstract

Problem. Children with severe asthma are more likely to be non-adherent with their prescribed medications, often related to barriers. A holistic assessment of these patients has been suggested, but is not typically performed in most pediatric asthma clinics. The purpose of this project was to evaluate the effects of severe pediatric asthma clinic services designed to perform holistic assessments and provide comprehensive care.

Methods. An observational, descriptive design was used to evaluate the Severe Asthma Clinic for Kids (SACK) created in 2013 using a retrospective database review. A convenience sample of data collected on all children treated in the clinic from January 2014 through January 2020 was evaluated.

Results. A total of 144 SACK patients (N=144) revealed 121 (84%) had more than one visit to the clinic. During their initial visit, 94 (65.28%) reported at least one barrier to care; however, the number of barriers steadily decreased to zero for those experiencing at least six clinic visits. Caregiver's quality of life scores increased 31% per visit (p=0.0009), asthma control test scores increased 89% per visit (p<0.0001), and medication refills increased to 5.98 refills per visit (p<0.0001). While lung function studies had essentially no change (p=0.1157), the number of emergency (ED) visits and hospitalizations was essentially zero.

Implications for Practice. The SACK clinic for children provided a multidisciplinary approach to the evaluation and management of children with asthma. A multidisciplinary team approach allowed for removal of barriers to care and improved the control of asthma and quality of life for children.

Multidisciplinary Team Approach Effect On Pediatric Severe Asthma

Asthma is a significant chronic condition in the U.S. affecting more than 25 million Americans, of whom six million (nearly 25%) are less than 18-years of age (National Heart, Lung, and Blood Institute [NHLBI], 2007). In fact, asthma is the most common chronic lung disease of childhood, characterized by variable and recurring airflow obstruction, airway inflammation, and bronchial hyperresponsiveness. The interaction between airway obstruction, inflammation and bronchial responsiveness determines the clinical manifestations (i.e., cough, wheeze, shortness of breath, and/or chest tightness), as well as the severity of the asthma (NHLBI, 2007). African American or Puerto Rican male children, and those living below the Federal Poverty Level (FPL) are at highest risk for developing asthma (American Academy of Asthma, Allergy, and Immunology [AAAAI], 2019). Additionally, asthma is a leading cause of school absenteeism in the U.S., accounting for almost 14 million missed days of school per year (U.S. Department of Health & Human Services [HHS], 2018). Further, asthma has a significant economic impact on the U.S. with direct and indirect costs of almost $82 billion annually (Nurmagambetov, Kuwahara, & Garbe, 2018). Almost half of costs related to asthma are associated with patients with severe asthma due to the high healthcare resource utilization needed by these patients (Nunes, Pereira, & Morais-Almedia, 2017).

In the U.S., pediatric severe asthma affects 300,000-600,000 (5-10%) of the six million children with asthma (Chung et al., 2014). While this population represents a small portion of childhood asthma, associated burdens such as increased risk for adverse events from medication use, life-threatening exacerbations, and decreased quality of life are higher in severe asthmatic children than in those children with less severe disease (Nunes et al., 2017). Severe asthma is defined by the European Respiratory Society (ERS) and the American Thoracic Society (ATS) as asthma in persons older than six-years of age “which requires treatment with high dose inhaled corticosteroids (ICS) plus a second controlled (and/or systemic corticosteroids) to prevent it from becoming uncontrolled or which remains uncontrolled despite this therapy” (cited in Chung et al., 2014, p. 349). While the ERS/ATS severe asthma definition does not include children under the age of six-years, asthma management for young children remains personalized, using a step-wise approach (Global Initiative for Asthma [GINA], 2019). Younger children can be considered to have severe disease when attempts at lowering maintenance asthma therapy develop into loss of asthma control (Marko & Ross, 2019).

Recent asthma practice recommendations stressed the importance of referral for the patient with severe asthma to an asthma specialist for evaluation and management of the disease (Scottish Intercollegiate Guidelines Network (SIGN) and British Thoracic Society (BTS), 2019; GINA, 2019; NHLBI, 2007). Referral should be made to help confirm the diagnosis of asthma, evaluate for co-morbid conditions, assess for barriers to care, and for expertise in new asthma controller therapies. In addition, providing coordinated care, including education about asthma management, could contribute to decreased rates of asthma exacerbations requiring hospital admission (Kelly et al., 2015).

Despite the presence of pediatric severe asthma outpatient centers and clinics throughout the U.S., there is paucity in the literature regarding the effect such clinics have on the evaluation and management of children with severe asthma. The purpose of this program evaluation was to better understand how a consistent, multidisciplinary approach to management of severe asthma in the pediatric patient impacted control of the disease in a Midwestern, urban pediatric medical center with the highest rates of asthma in the U.S. (Harris, 2019). The aim of this project was to determine the effectiveness of asthma control and quality of life in pediatric patients with severe asthma whose asthma is managed by a multidisciplinary team. The outcome measures of interest were: 1) demographic variables, 2) Asthma Control Test (ACT) scores, 3) spirometry measurements (first second of forced expiratory volume [FEV1] and fractional exhaled nitric oxide level [FENO]), 4) oral corticosteroid use, 5) emergency department (ED) visits, 5) hospitalizations, 6) Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ) scores, and other screening instruments (e.g. Beck's Depression Youth Inventory or PHQ9-Modified, Health and Treatment Beliefs, Barrier Review, Social History). The question for study was: What is the effect on asthma control and quality of life from a multidisciplinary team approach for the treatment of the child with severe asthma?

Literature Review

A literature search in PubMed, CINAHL Plus, and Medline Plus for publications pertaining to the effects of pediatric multidisciplinary severe/refractory outpatient asthma clinics on children with severe asthma produced no studies. The search was expanded to national organizations associated with asthma and asthma practice guidelines, including the AAAAI, SIGN and BTS, ERS and ATS, GINA, and the NHLBI. The search was refined using the key search terms: *multidisciplinary, severe, asthma*, and *pediatric* using the Boolean operators AND and OR. This resulted in 33 publications published between the years 1995 through 2019. Inclusion criteria were studies on children with severe asthma and multidisciplinary teams or approaches. Thirty of the publications were eliminated, since they did not pertain to care of the child with severe asthma or a multi-disciplinary approach. One publication was a one-page abstract, not a detailed publication, but was selected for review. The remaining two publications retrieved were related to the intended information sought; therefore, an ancestry approach was used from publications. Ultimately, 19 publications, four practice guidelines, and a book were selected for this literature review.

Severe asthma in children is a heterogeneous disease consisting of multiple phenotypes with a range of clinical, molecular, and cellular inflammatory attributes (Ramratnam, Bacharier, & Guilbert, 2017). For instance, Liu et al. (2016) summarized eight essential factors correlating asthma severity among inner city children with severe asthma: sensitization, allergic inflammation, pulmonary physiology, stress, obesity, vitamin D, environmental tobacco smoke (ETS) exposure, and rhinitis severity, including pulmonary physiology, rhinitis severity, ETS exposure and allergic inflammation. Similarly, the Severe Asthma Research Program (SARP) identified four clusters of shared clinical, physiological, and biological characteristics of children with asthma based on lung function, atopy, comorbidities, number of symptoms and medication use (Fitzpatrick et al., 2011). Children with severe asthma were found in all clusters (Fitzpatrick et al., 2011). Having an understanding of childhood-asthma phenotypes may allow for more personalized asthma care and an increased likelihood of better asthma outcomes (Ramratnamet al., 2017).

The ERS/ATS recommended comorbidities be addressed, inhaler technique reviewed, and the diagnosis of asthma be confirmed before asthma is determined to be severe. In addition, adherence to prescribed asthma therapy should be assessed (Chung et al., 2014). Past studies of asthma medication compliance have found adherence rates in children with asthma to be approximately 55% (HHS, 2018); however, adherence in children with severe asthma ranged from 28-67% (Boutopoulou, Koumpagioti, Matziou, Priftis, & Douros, 2018). Moreover, there is an increased risk for poor adherence in ethnic minorities and in persons of lower socioeconomic status (McQuaid, 2018).

Because of the potential confounding complexities and effects of the social determinants of health on severe asthma, especially with the pediatric population, several academic centers in the U.S. with experts in asthma care have created specialty clinics or centers dedicated to the care of the children with severe asthma. The Severe Pediatric Asthma Consortium is a group of pediatric allergists and pulmonologists from the U.S. who collaborate efforts to develop standards of care for the child with severe asthma (E. Forno, personal communication, June 10, 2019). The primary objective of the Consortium is to standardize care of children with severe asthma. The Consortium is currently comprised of seven academic sites and a combined clinical, translational, and research approach is used by the Consortium to help to improve asthma outcomes in this high-risk population. However, there are no publications from the Consortium regarding clinical care of the child with severe asthma.

Three publications specific to a multidisciplinary approach to caring for the child with severe asthma were found and reviewed. Capucilli, Amos, and DaVeiga (2018) published an abstract reviewing asthma outcomes of 42 subjects who were cared for in the Pulmonary Problematic Asthma (PAPA) clinic in Philadelphia, Pennsylvania. This abstract concluded improved asthma outcomes were more likely to occur when multidisciplinary care was used to help the following: (a) decrease barriers to clinic visits, and (b) address compliance with prescribed asthma therapy. The second publication, a retrospective chart review of 141 high-risk asthma patients being cared for by the Asthma Action Team (AAT) within a primary care setting in Boston, Massachusetts was performed by Holder-Niles, et al. (2017). The authors found the use of a coordinated asthma care program was associated with decreased urgent and emergency department visits, as well as hospital admissions. The final study was a prospective study of 89 subjects who were electively hospitalized to receive care from an inpatient multi-disciplinary asthma team in Europe (Verkleij, Beelen, van Ewikj, & Geenen, 2017). These authors concluded asthma control was improved in the vast majority of patients who were recipients of care provided by a multidisciplinary inpatient team. While all three publications found coordinated asthma care was an effective approach to asthma management for the child with severe asthma, there were no major trends or patterns, nor relationships among studies of clinical outcomes to relate the multidisciplinary team approach with the management of asthma in this population.

The NHLBI Asthma Guidelines (2007) do not provide recommendations for a multidisciplinary approach specific to management of the pediatric patient with severe asthma. However, general guidelines are provided to help assess asthma control in pediatric patients with asthma. Asthma is considered to be well controlled if symptoms of asthma (i.e., cough, wheeze, and/or shortness of breath) occur $\leq$2 days/week, and/or there is need for 0-1 course of oral corticosteroids/year (NHLBI, 2007). Asthma is classified as not well controlled if symptoms occur >2 days/week, and/or there is a need for oral corticosteroids $\geq$2 times for year (NHLBI, 2007). Asthma is classified as being very poorly controlled if symptoms occur throughout the day, and/or there is a need for oral corticosteroids >3 times/year (NHLBI, 2007). Finally, the NHLBI (2007) stated in children aged 5-11 years, the FEV1 >80% predicted or FEV1/Forced Vital Capacity (FEV1/FVC) >80% was a reflection of well controlled asthma; FEV1 60-80% predicted or FEV1/FVC 75-80% was not well controlled asthma; and FEV1<60% predicted or FEV1/FVC <75% was very poorly controlled asthma. Hence, monitoring for the occurrence of symptoms, corticosteroid use, and FEV1 are indicated as objective measures of asthma control.

Alternatively, the ACT is a validated patient-based subjective instrument used to measure asthma control in the clinical setting (Schatz et al., 2006). The ACT is a reflection of perceived asthma control over the previous month (Schatz et al., 2006). A score greater than 19 is a reflection of well controlled asthma; 16-19 reflects asthma is not well controlled; and a score less_than16 reflects poorly controlled asthma (Schatz et al., 2006). While objective measures are helpful, subjective measures may also be of value when evaluating asthma control.

Likewise, the PACQLQ is a validated health-related quality of life, self-administered screening instrument and is also a subjective measurement of a perceived quality of life, but for the caregiver (Juniper et al., 1996). The PACQLQ measures two problems encountered by primary caregivers of children with asthma: activity limitation and emotional distress (Juniper et al., 1996). The PACQLQ is a reflection of the perceived quality of life experienced by the caregiver within the past seven days in relation to their child's asthma condition (Juniper et al., 1996). When completed at regular intervals, the PACQLQ screens for a clinically significant change in quality of life over time (Juniper et al., 1996). Including an assessment of the caregiver offers an opportunity for a holistic assessment in the overall control of a child's asthma condition and its impact on the family.

In summary, asthma is a common chronic condition, but those with severe asthma are at increased risk for poor asthma control and quality of life. While there are practice guidelines to support the monitoring and maintenance of asthma control, there is a gap in the literature on the effects of an outpatient, multidisciplinary team approach when caring for children with severe asthma. In addition, little is known about pediatric severe asthma (i.e., the role of phenotyping, risk for co-morbid conditions, adverse events such as hospitalizations, and quality of life). A better understanding on the impact of a multidisciplinary team care approach in an outpatient severe asthma clinic for children is needed.

Finally, in a large, Midwestern, urban pediatric medical center with a Severe Asthma Clinic for Kids (SACK), a program evaluation on its effect with this population was needed and had never been done. The framework selected for the evaluation of this program was the Johns Hopkins Nursing Evidence-Based Practice (JHNEBP) model due to its problem-solving approach in clinical decision-making. This model uses a three-step process: creating a practice question, gathering the evidence, and translation of the evidence into practice (The Johns Hopkins Hospital/Johns Hopkins University School of Nursing, 2017). The goal of the JHNEBP is to incorporate research and best practices into patient care (The Johns Hopkins Hospital/Johns Hopkins University School of Nursing, 2017). The JHNEBP model has guided this project practice question and the selection of outcome measures (data). Analysis of the data is expected to provide recommendations for improving practice, i.e., asthma control in children with severe asthma.

Method

Design

This study was performed via an observational, descriptive design utilizing a retrospective database review over a six-year period. Current practice has been to complete a SACK Patient Assessment before and during each severe pediatric asthma clinic visit, using multiple screening instruments by various multidisciplinary team members (Appendix A). Screening instruments included ACT, Beck's Depression Inventory, the Patient Health Questionnaire Modified for Adolescents (PHQ-9), a Health Belief Survey, a Treatment Regimen Survey, a (potential) Barrier Review, a Social History, and PACQLQ. The database was created in 2014 and contains the SACK Patient Assessment, including screening data. Data has been used for individual patient evaluation of asthma control, however, evaluation of the data as a whole has never been done. The period for data analysis was January 14, 2014 through January 14, 2020.

Setting

An outpatient clinic specifically designed for children with severe asthma (SACK) at an urban, Midwestern pediatric medical center serving a metropolitan population of over three million residents. The area has the highest rates of asthma in the state (Harris, 2019). There are three pediatric hospitals within the metropolitan area, each offering pediatric asthma, allergy, and pulmonology services. There are 144 patients currently enrolled in SACK with a maximum of 12 patients (a combination of new evaluation and return SACK visits) evaluated each month. The multidisciplinary team caring for the child included two pediatric pulmonologists, two pediatric allergists, a certified pediatric nurse practitioner (CPNP) who was also a Certified Asthma Educator (AE-C), a clinical nurse coordinator, a social worker, two asthma coaches, and respiratory therapists employed in the pediatric pulmonary function lab. The average time for the initial evaluation by the multidisciplinary team members is two-hours with follow-up visits lasting approximately one-hour.

Sample

A convenience sample of children aged 3-18 years who were referred to the SACK for evaluation and management of severe persistent uncontrolled asthma. Inclusion criteria were age 3-18 years and patients who had been evaluated in the SACK between January 14, 2014 and January 14, 2020. Exclusion criteria were patients under three-years or older than 18-years of age, or who had not been evaluated in the SACK between January 14, 2014 and January 14, 2020.

Approval Processes

Administrative approval from the medical center’s SACK was obtained. In addition, the medical center’s institutional review board (IRB) approval was obtained to perform data review and analysis of previously collected data associated with severe asthma. Additional approvals from the doctor of nursing practice (DNP) committee and university IRB was obtained. The greatest risk in this study was confidential information accidentally revealed. To minimize this risk, all data was retrospective and was de-identified. Benefits of this study include enhanced knowledge of outcomes for asthma control using a multidisciplinary team approach.

Data Collection/Analysis

Data collected included demographic information: age, gender, race/ethnicity, zip code, and payor status. Additional data collected were ACT scores, FEV1 and fractional exhaled nitric oxide (FENO), oral corticosteroid use, ED visits, hospitalizations, PACQLQ scores, Beck's Depression Youth Inventory or PHQ9-Modified results, health and treatment beliefs, reported barriers, and social history. All data was de-identified a coded as 14-1, 14-2, 14-3 and so on for 2014 data and 15-1, 15-2, 15-3 and so on for 2015 data, and likewise for subsequent years. All data was stored on a password-protected computer and removable drive.

Study group subjects' characteristics were presented as mean +/- standard deviation for quantitative variables, and number with percentage for qualitative variables. Random coefficient regression models were performed to detect change of medication refill rate, FEV1, PACQLQ, and ACT over time. Individual SACK clinic visits were treated as a categorical covariate to assess the change between each two visits, and also treated as a continuous variable to obtain overall trend during study period. Medication refill rate was determined by using the calculation of refills obtained/twelve months X 100%. Data was analyzed by SAS® (SAS Institute Inc., Cary, NC, USA) 9.4 version. For all analyses, values of $p < 0.05$ were considered statistically significant.

Procedures

Current practice is to complete a SACK Patient Assessment before and during each clinic visit (Appendix A). The assessment was designed to facilitate comprehensive decision-making of the differential diagnoses for cough and wheeze, and to assess for co-morbid conditions (e.g., depression, obesity, etc.) and barriers to care (e.g., social history, treatment regimens, etc.). Parental or guardian asthma literacy is also screened via Health and Treatment Beliefs questionnaires during the initial evaluation. Finally, the objective measurements of FEV1 and FENO is obtained at every clinic visit. Subjective asthma control is measured via the ACT and the PACQLQ is used to monitor caregiver quality of life in relation to their child's asthma. Interventions are individualized, based on the objective and subjective findings of each patient during a SACK visit. Changes to medications, additional ancillary testing, referral to subspecialties, social work involvement, and enrollment in an asthma coach program are all potential interventions.

Results

A total of 144 children (*N*=144) were evaluated in SACK during the study period and 121 (84%) of them had more than one SACK visit. Mean age of patients was 10.43 (*SD*= 3.91) years; three years (*n*=2, 1%), four years (*n*=3, 2%), five years (*n*=11, 7%), six years (*n*=9, 6%), seven years (*n*=14, 10%), eight years (*n*= 13, 9%), nine years (*n*=16, 11%), 10 years (*n*=11, 8%), 11 years (*n*=11, 8%), 12 years (*n*=7, 5%), 13 years (*n*=12, 8%), 14 years (*n*=7, 5%), 15 years (*n*=8, 6%), 16 years (*n*=11, 8%), 17 years (*n*=6, 4%), 18 years (*n*=3, 2%). The majority of the children were male (*n*=79, 55%) but there were 65 (45%) females. There were non-Hispanic (*n*=138, 96%), African Americans (*n*=87, 60%), Caucasians (*n*=42, 29%), mixed (*n*=15, 11%). Payor status included 103 (72%) insured by Medicaid, 41(28%) had private insurance. Finally, 62 (43%) reported living in an urban area, 51 (35%) live in a suburban area, 23 (16%) live in a rural area, 8 (6%) live in a small town. Most reported living in one household (*n*=123, 85%), 21 (15%) lived in multiple households. Most children were receiving combination therapy (inhaled corticosteroid and long acting beta agonist) (*n*=137, 95%), but 11 (8%) of the children were on monotherapy. Thirty-one children (22%) entered SACK with asthma biologic therapy previously prescribed. During initial evaluation, 65% (*n*=94) of SACK patients reported at least barrier to care, with 82 (57%) reporting an economic barrier, 78 (54%) reporting a social barrier. The mean medication refill rate was 48% ± 28, The mean FeNO level=36 ppb $\pm$ 35, mean FEV1=89% of predicted $\pm$ 20%, mean ACT score=16 $\pm$ 5, mean PACQLQ score=4 ± 1. The range for lifetime ED visits was 0-43, hospitalizations 0-28, PICU admissions 0-12, and need for mechanical ventilation 0-3 occasions (Appendix C).

The majority of families who reported one or more barrier to care had a significant decrease in barriers with subsequent SACK visits (Appendix D). There was a decrease (60%) in reported barriers from the initial SACK visit to the first follow-up SACK visit; all visits had $\geq$50% decrease in reported barriers to care. The highest drop (62%) was noted at the third SACK follow-up visit.

Increase in medication refill rate was found to be statistically significant, with an average increasing of 5.98 per visit ($p<0.0001$) (Appendix E). The rate of refills rose from visit one (initial visit) to visit two from 41.7 to 83.3; from visit two to visit three from 83.3 to 91.7. There was a decrease in refill rate from visit three to visit four from 91.7 to 50.0; all subsequent visits demonstrated an increase in rate of refills (with visits five and seven at a rate of 100%).

PACQLQ score over time significantly increased by an average of 0.31 per visit ($p=0.0009$) (Appendix F). The change in ACT score over time had an average increase of 0.89 per visit ($p<0.0001$) (Appendix G).

Trend of FEV1 over time was not found to be significant (Appendix H). Although, the trend suggests a slight decrease in FEV1 over time.

When compared to baseline number of OCS courses, ED visits, and hospitalizations (events in the twelve months prior to initial evaluation in SACK), the weighted moving average of OCS courses, ED visits, and hospitalizations twelve months after a patient's initial visit in SACK remained unchanged (around zero) (Appendices I, J, and K).

Discussion

The Severe Asthma Clinic for Kids protocol includes screening for barriers to care (economic and social) at each visit. Barriers reported by caregivers are addressed by the SACK team (primarily by the social worker) during the visit, as well post-visit via follow-up phone calls. Barriers related to both economic and social restraints were largely resolved, leading to the number of barriers reported by families significantly decreasing over time (without evidence of recurrence.). This decrease in barriers may account for our additional findings. As barriers were removed, there appeared to be a concurrent increase in caregiver quality of life in relation to their child's asthma as demonstrated by the statistically significant increase in PACQLQ score. While we cannot be certain why there is a consistent increase in quality life (as seen on the PACQLQ), we theorize that such change is likely a result of the detailed attention given to families who are a part of SACK. Families in SACK are given the opportunity to have social work involvement, as well as support from our asthma coaches—services not readily available in routine asthma clinic. The multidisciplinary team approach provided to children and their families during a SACK visit not only allows for thorough education related to asthma, and, as previously mentioned, addressing potential healthcare barriers, but is part of SACK standard of care. The unique attention provided to patients and their families could lead to better quality of life related to asthma. An increase in PACQLQ has been shown to correlate with caregivers whose children obtained asthma control (Stelmach, et al., 2012). This control may be evidenced by our finding that children who's asthma is managed in SACK experience an increase in ACT score over time. The ACT has been validated as a clinical practice screening tool that is an accurate measure of controlled and not-well controlled asthma (Jia, et al., 2013). While it is a self-administered questionnaire, it is a tool that allows clinicians to assess how effectively asthma has been controlled. The change from the majority of SACK patients reporting poorly controlled asthma (score of ≤15) during their initial evaluation, to not-well controlled asthma (score of 16-19) with subsequent visits, and, as time progressed, to well controlled asthma (score of ≥20), could be a result of the multi-disciplinary care provided at each SACK visit. In addition, this increase in asthma control correlates with the demonstrated overall increase in medication refill rate. While consistently obtaining medications as prescribed does not guarantee adherence with these medications, the increase in reported asthma control may be a direct result of more consistent use of maintenance asthma medication. This increase in medication refills could be related to the SACK families having a new-found ability to obtain medications—another possible result of our team addressing reported healthcare barriers.

We did not find that FEVI was preserved in the SACK patients. The decrease in FEVI could be explained by selection bias, i.e., the likelihood of a return SACK visit is reflective of disease severity. In addition, as the number of return visits increased, the sample size decreased, leading to a decrease in power. Another potential reason for no overall improvement in FEV1 could be due to the nature of asthma in the pediatric patient, as it has been established that children with a history of persistent asthma and impairment of lung function are at risk for a reduced growth pattern of lung function (McGeachie, et al., 2016).

We did not demonstrate a decrease in oral corticosteroid courses, nor asthma-related ED visits or hospitalizations. This could be due to the relatively low numbers of each of these variables at baseline, the need for a higher number of subjects, our study was observational and descriptive using a clinic population (i.e., this was not a clinical trial), and/or not enough follow-up visits to demonstrate such changes.

The relationship between barriers to healthcare, caregiver's quality of life in relation to their child's asthma, medication refill history/adherence, and asthma control is potentially complex, but seem to have direct influence on one another. Our multi-disciplinary approach to caring for children with severe asthma has demonstrated the importance of identifying, then addressing barriers to care. Although we cannot definitively say that removing barriers to care leads to better asthma control, our findings indicate that by doing so, such an approach leads to better outcomes for the pediatric patient with severe asthma. Further study involving a higher number of subjects, perhaps via a collaboration between severe asthma clinics that comprise The Severe Pediatric Asthma Consortium, is needed to better understand how to continue to improve clinical care, as well as decrease the morbidity and mortality associated with severe asthma in the pediatric patient.

Conclusion

Our multidisciplinary approach to care of the child with severe asthma demonstrated the importance of identifying and addressing barriers to care, as it appears that attention to social and economic barriers leads to better outcomes in this population. Removing barriers likely correlates with an increase in caregiver quality of life as it relates to their child's asthma, increase in medication refills, and increase in asthma control. Continued attention to health care barriers as reported by caregivers of children with severe asthma has the potential to increase and sustain asthma control in this group of high-risk patients.

References

American Academy of Asthma, Allergy, and Immunology (AAAAI). (n.d.). *Asthma statistics: United States.* Retrieved on 9/12/19 from https://www.aaaai.org/about-aaaai/newsroom/asthma-statistics

Boutopoulou, B., Koumpagioti, D., Priftis, K., & Douros, K. (2018). Interventions on adherence to treatment in children with severe asthma: A systematic review. *Frontiers in Pediatrics, 6*, 1-8. doi: 10.3389/fped.2018.00232

Capucilli, P., Amos, B., Ewig, J., & DaVeiga, S. (2018). A multidisciplinary severe asthma clinic for pediatric patients: review of the first 12 months experience. *Annals of Allergy,Asthma, & Immunology, 121(5),* S7. doi: 10.1016/j.anai.2018.09.019

Chung, K., Wenzel, S., Brozek, J., Bush, A., Castro, M., Sterk, P., .. Teague, W. (2014). International ERS/ATS guidelines on definition, evaluation, and treatment of severe asthma. *European Respiratory Journal, 43*, 343-373. doi: 10.1183/09031936.00202013

Fitzpatrick, A., Teague, W., Meyers, D., Peters, S., Li, X., Wenzel, S., … More, W. (2011). Heterogeneity of severe asthma in childhood: confirmation by cluster analysis of children in the National Institutes of Health/National Heart, Lung, and Blood Institute, Severe Asthma Research Program. *Journal of Allergy and Clinical Immunology, 126*, 382-389. doi:10.1016/j.jaci.2010.11.015

Global Initiative for Asthma (GINA), (2019). *Global Strategy for Asthma Management and Prevention.* Retrieved on 9/12/19 from https://ginasthma.org/wp-content/uploads/2019/06/GINA-2019-main-report-June-2019-wms.pdf

Harris, K. (2019). Mapping inequality: Childhood asthma and environmental injustice, a Case study of St. Louis, Missouri. *Social Science & Medicine, 230,* 91-110.

Holder-Niles, F., Haynes, L., D'Couto, H., Hehn, R., Graham, D., Chen Wu, A., & Cox, J. (2017). Coordinated asthma program improves asthma outcomes in high-risk children. *Clinical Pediatrics, 56*(10), 934-941. doi: 10.1177/0009922817705186

Jia, C., Zhange, H., Liang, R., Jiang, Y., Powell, H., Fu, J.,…Wang, G. (2013). The asthma control test and asthma control questionnaire for assessing asthma control: Systematic review and meta-analysis. *Journal of Allergy and Clinical Immunology, 131(3),* 695-703. doi: 10.1016/j.jaci.2012.08.023

Johns Hopkins Hospital/Johns Hopkins University School of Nursing. (2017). *Johns Hopkins Nursing Evidenced-Based Practice Model.* Retrieved on 11/26/19 from file:///Users/kertz_l/Desktop/JHNEBP%20Model%20and%20Tools-%20Permission%20%7C%20IJHN%20Learning%20System.webarchive

Juniper, E., Guyatt, G., Feeny, D., Ferrie, P., Griffth, L., & Townsend, M. (1996). Measuring quality of life in the parents of children with asthma. *Quality of Life Research, 5,* 27-34.

Kelly, R., Stoll, S., Bryant-Stephens, T., Janevic, M., Lara, M., Ohadike, Y., … Malveaux, F. (2015). The influence of setting on care coordination for childhood asthma. *Health Promotion Practice, 16*, 867-877. doi: 10.1177/1524839915598499

Liu, A., Babineau, D., Krouse, R., Zoratti, E., Pongracic, J., O'Connor, G., … Busse, W.

(2016). Pathways through which asthma risk factors contribute to asthma severity in inner-city children. *Journal of Allergy and Clinical Immunology, 138*, 1042-1050. doi: 10.1016/j.jaci.2016.06.060

Marko, A., & Ross, K. (2019). Severe asthma in childhood. In Bacharier, L, & Guilbert, T. (Eds.), *Asthma in childhood* (pp. 243-258). Philadelphia, Pennsylvania: Elsevier.

McGeachie, M., Yates, K., Zhou, X., Stemberg, A., Van Natta, M., Wise, R.,…Strunk, R. (2016). Patterns of growth and decline in lung function in persistent childhood asthma. *New England Journal of Medicine, 374(19),* 1842-1852. doi: 10.1056/NEJMoa1513737

McQuaid, E. (2018). Barriers to medication adherence in asthma: The importance of culture and context. *Annals of Allergy, Asthma, and Immunology, 121*(1), 37-42. doi: 10.1016/j.anai.2018.03.024

Nunes, C., Pereira, A., & Morais-Almeida, M. (2017). Asthma costs and social impact. *Asthma Research and Practice, 3*(1), 1-22. doi: 10.1186/s40733-016-0029-3

Nurmagambetov, T., Kuwahara, R., Garbe, P. (2018). The economic burden of asthma in the United States, 2008-2013. *Annals of the American Thoracic Society, 15*(3), 348-356. doi: https://www.atsjournals.org/doi/full/10.1513/AnnalsATS.201703-259OC?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub%3Dpubmed#readcube-epdf

Ramratnam, S., Bacharier, L., & Guilbert, T. (2017). Severe asthma in children. *Journal of Allergy and Clinical Immunology, 5*(4), 889-898. doi: 10.1016/j.jaip.2017.04.031

Schatz, M., Sorkness, C., Li, J., Marcus, P., Murray, J., Nathan, R.,…Jhingran, P. (2006). Asthma control test: Reliability, validity, and responsiveness in patients not previously followed by asthma specialists. *Journal of Allergy and Clinical Immunology, 117(3),* 549-56. doi: 10.1016/j.jaci.2006.01.011

Scottish Intercollegiate Guidelines Network (SIGN) and British Thoracic Society (BTS). (2019). SIGN 158 British Guideline on the Management of Asthma. Retrieved on 9/11/19 from https://www.brit-thoracic.org.uk/quality-improvement/guidelines/asthma/

Stelmach, I., Podlecka, D., Smejda, S., Majak, P., Jerzynska, J., Stelmach, A…,Stelmach, W. (2012). Pediatric asthma caregiver's quality of life questionnaire is a useful tool for monitoring asthma in children. *Quality of Life Research, 21(9),* 1639-1642. doi: 10.1007/s11136-011-0070-x

Teague, W., Phillips, B., Fahy, J., Wenzel, S., Fitzpatrick, A. Moore, W., … Jarjour, N. (2017). Baseline features of the severe asthma research program (SARP III) cohort: Differences with age. *Journal of Allergy and Clinical Immunology in Practice, 6*(2), 545-54. doi.org/10.1016/j.jaip.2017.05.032

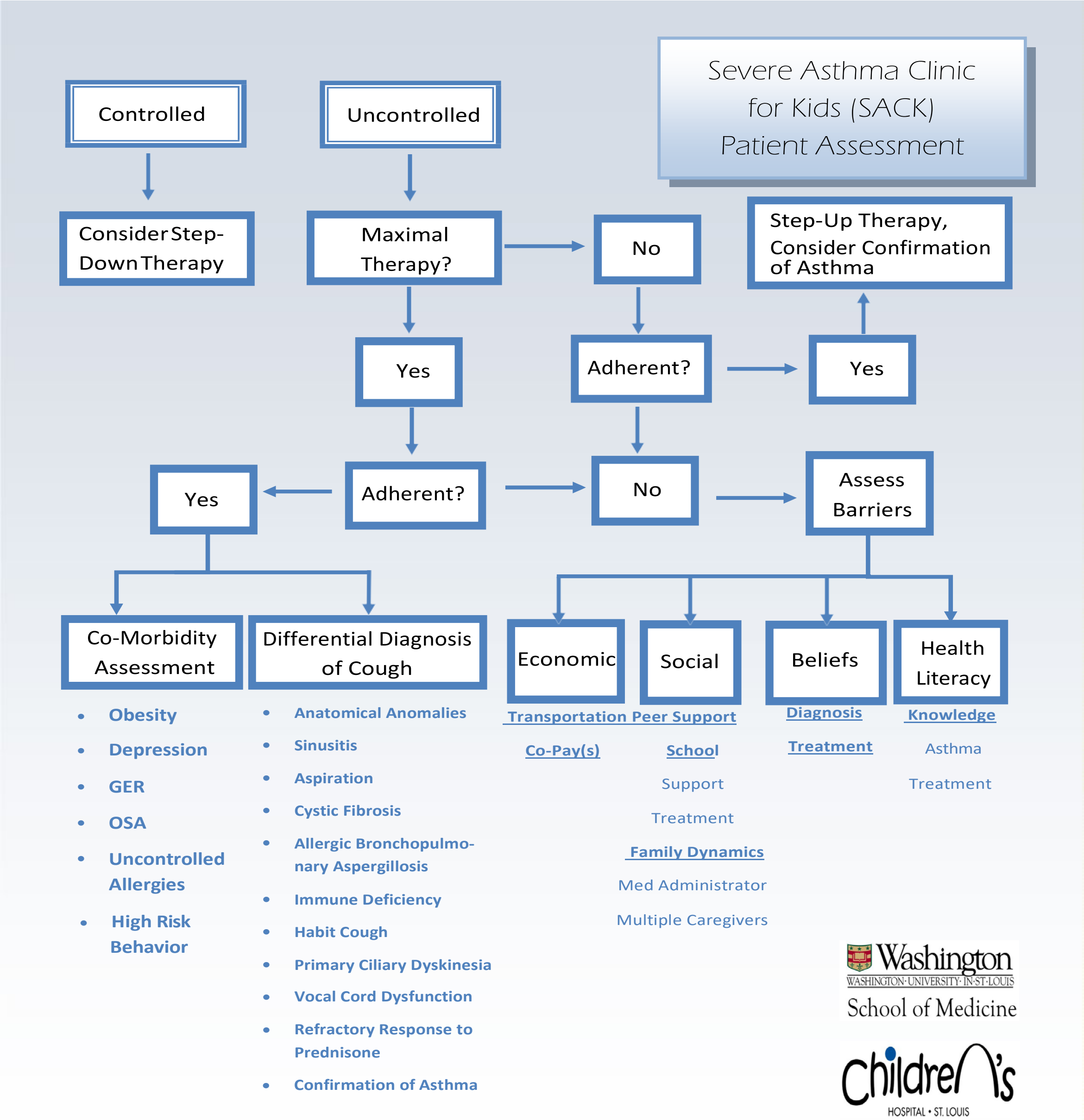
U.S. Department of Health & Human Services (HHS), Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report. (2018). *Vital signs: Asthma in children—United States, 2001-2016*. Retrieved on 9/11/19 from https://www.cdc.gov/mmwr/volumes/67/wr/mm6705e1.htm?s_cid=mm6705e1

US Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute (NHLBI). (2007). *Expert Panel Report 3: Guidelines for the Diagnosis and Management of Asthma.* (NIH Publication No. 08-5846). Retrieved on 9/11/19 from https://www.nhlbi.nih.gov/sites/default/files/media/docs/asthsumm.pdf

Verkleij, M., Beelen, A., van Ewijk, B., & Geenen, R. (2017). Multidisciplinary treatment in children with problematic severe asthma: A prospective evaluation. *Pediatric Pulmonology, 52*, 588-597. doi: 10.1002/ppul.23623

Appendix A

Severe Asthma Clinic for Kids (SACK) Patient Assessment



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Appendix B

Data Collection Instrument

Category	Detail
Inclusion Criteria	ERS/ATS definition of severe asthma and/or GINA Guidelines
Demographics	Age Sex Race Ethnicity Zip code Insurance
Medical History	Lifetime: Courses of oral corticosteroids Emergency department visits Hospital admissions Pediatric intensive care unit admissions Mechanical ventilation
Interval History	Courses of oral corticosteroids Emergency department visits Hospital admissions Pediatric intensive care unit admissions Mechanical ventilation
Co-Morbidities	Allergic rhinitis Food allergy Allergic bronchopulmonary aspergillus Eczema Sinusitis Gastroesophageal reflux Immune dysfunction Depression (PHQ-9 or Beck's Depression Inventory) Obstructive sleep apnea Obesity
Asthma Control	Asthma Control Test
Caregiver Quality of Life	Paediatric Asthma Caregiver Quality of Life Questionnaire

Diagnostics	Lung Function (FEV1, FEV1/FVC) FeNO Imaging Chest x-ray Chest CT Sinus CT Bone density scan Lab Studies Blood eosinophils IgE Serum allergy testing Percutaneous skin testing Sweat chloride Procedures Bronchoscopy Ciliary biopsy Polysomnogram
Medications	Inhaled corticosteroid Inhaled corticosteroid with long-acting bronchodilator Long-acting muscarinic Leukotriene receptor antagonist Theophylline Maintenance oral corticosteroids Anti-IgE therapy Anti-IL-5 therapy Anti-IL-4 therapy Short-acting bronchodilator Ipratropium bromide
Adherence	Medication refill history Subjective report
Health literacy	Health belief survey Treatment belief survey
Barriers to care	Subjective report

Appendix C

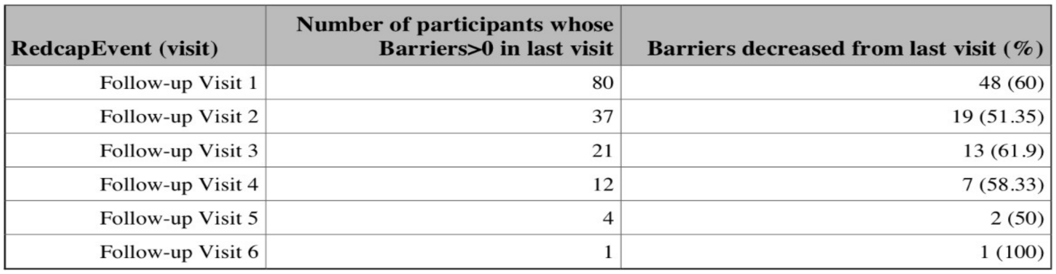
Baseline Demographics

Race			
White	42 (29.37%)		
African American	87 (60.41%)		
Mixed	15 (10.49%)		
Ethnicity			
Hispanic/Latino	6 (4.17%)		
Gender			
Male	79 (54.86%)		
Female	65 (45.14%)		
Age of Child (Years)	10.43 ± 3.91	10 (7-14)	[3 – 18]
Insurance (%Medicaid)	103 (71.53%)		
Living Area			
Urban Area	62 (43.06%)		
Suburban Area	51 (35.41%)		
Rural Area	23 (12.5%)		
Small Town	8 (5.56%)		
Household			
One Household	123 (85.42%)		
Multiple Households	21 (14.58%)		
Baseline Medications (multiple choices)			
ICS	11 (7.64%)		
ICS/LABA	137 (95.14%		
Baseline Biologic Usage	31 (21.53%)		
Barriers Assessed	94 (65.28%)		
Economic	82 (65.28%)		
Social	78 (54.17%)		
Medication Refill Rate (%)	48.42 ± 27.74	41.67 (25 – 66.7)	[0 – 116.67]
Baseline FeNO Level	35.69 ± 34.81	22 (12 – 45)	[5 – 196]
Baseline FEV1	89.22 ± 20.49	92.5 (78 – 104)	[38 – 127]
Baseline ACT Score	15.99 ± 5.09	16 (3.35 – 5.38)	[3 – 26]
Baseline PACQLQ Score	4.28 ± 1.31	4.19 (3.35 – 5.38)	[1.5 – 7]
Baseline Serum Eosinophils	433.43 ± 351.52	400 (100 – 680)	[0 – 1600]
Lifetime ED Visits	12.14 ± 9.43	10 (5 – 20)	[0 – 43]
Lifetime Hospitalizations	5.17 ± 5.15	3 (1 – 8)	[0 – 28]
Lifetime PICU	1.21 ± 1.83	1 (0 – 2)	[0 – 12]
Lifetime ETT	0.22 ± 0.55	0 (0 – 0)	[0 – 3]
Lifetime BiPAP	0.23 ± 0.65	0 (0 – 0)	[0 – 3]
Baseline ED Visits (past 12 months)	2.4 ± 2.9	2 (1 – 3)	[0 – 24]
Baseline Hospitalizations (past 12 months)	1.13 ± 1.47	1 (0 – 2)	[0 – 8]
Baseline PICU (past 12 months)	0.26 ± 0.6	0 (0 – 0)	[0 – 4]
Baseline OCS (past 12 months)	3.39 ± 2.65	3 (1 – 5)	[0 – 10]

A total of 144 subjects were included in Table 1. Quantitative data was presented as mean ± standard deviation, median with interquartile range and minimum and maximum were also presented. Qualitative data was presented as N (%). Data was analyzed by SAS® (SAS Institute Inc., Cary, NC, USA) 9.4 version.

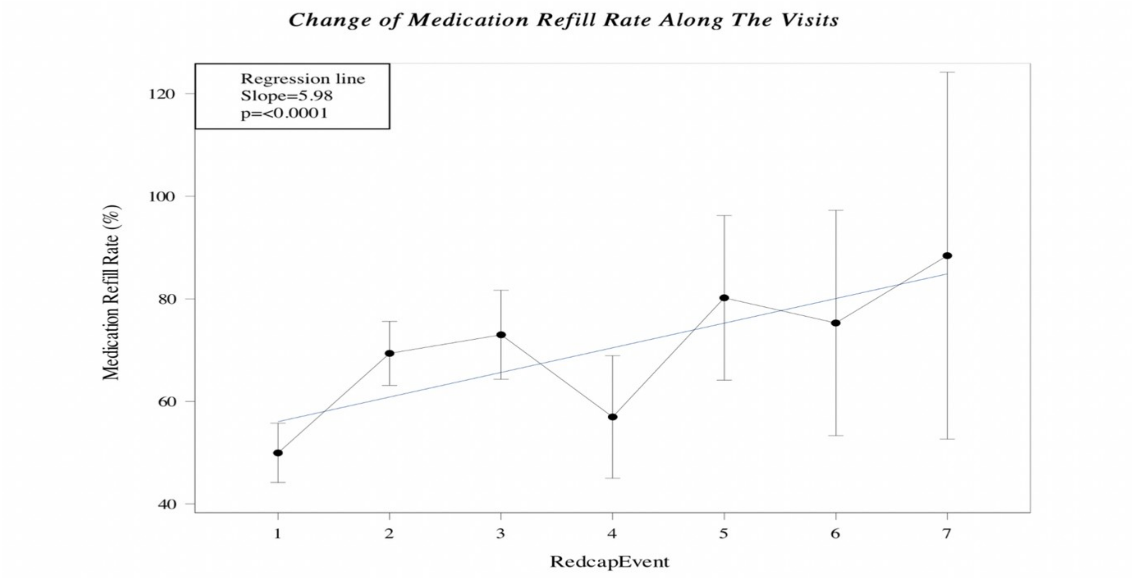
Appendix D

Barriers Decrease from Last Visit



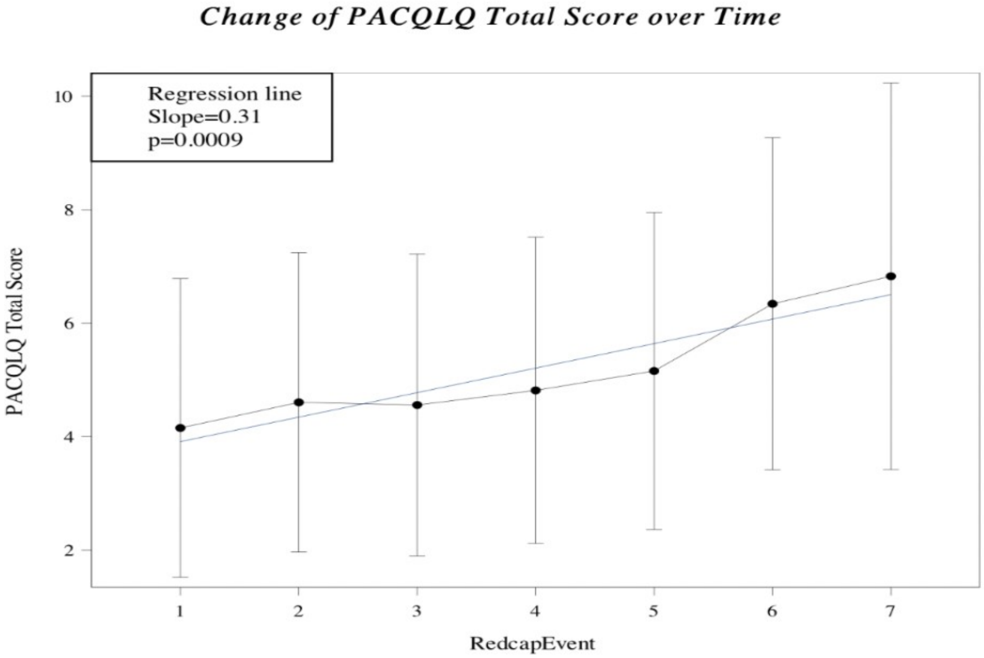
RedcapEvent (visit)	Number of participants whose Barriers>0 in last visit	Barriers decreased from last visit (%)
Follow-up Visit 1	80	48 (60)
Follow-up Visit 2	37	19 (51.35)
Follow-up Visit 3	21	13 (61.9)
Follow-up Visit 4	12	7 (58.33)
Follow-up Visit 5	4	2 (50)
Follow-up Visit 6	1	1 (100)

Appendix E



The plot above shows the change of medication refill rate estimated values over time. The estimated values (black dots) and 95% confidence intervals (black bars) were obtained from the model (visit was treated as categorical covariate). Also, a regression line was added in the plot. The slope and P-value were obtained from another random coefficient model (visit was treated as a continuous covariate). The regression line indicates the estimated medication refill rate had an average increasing of 5.98 per visit (p<0.0001).

Appendix F



Change of PACQLQ Total Score over Time

The plot above shows the change of PACQLQ total score over time. The estimated values (black dots) and 95% confidence intervals (black bars) were obtained from the model (visit was treated as categorical covariate). Also, a regression line was added in the plot. The slope and P-value were obtained from another random coefficient model (visit was treated as a continuous covariate). The regression line indicates the PACQLQ score had an average increasing of 0.31 per visit (p=0.0009).

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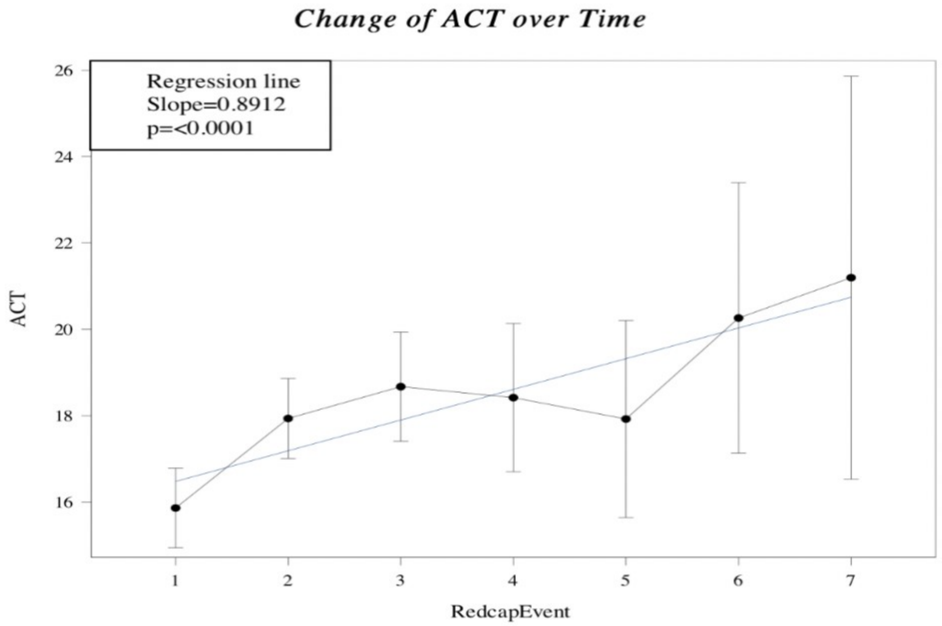
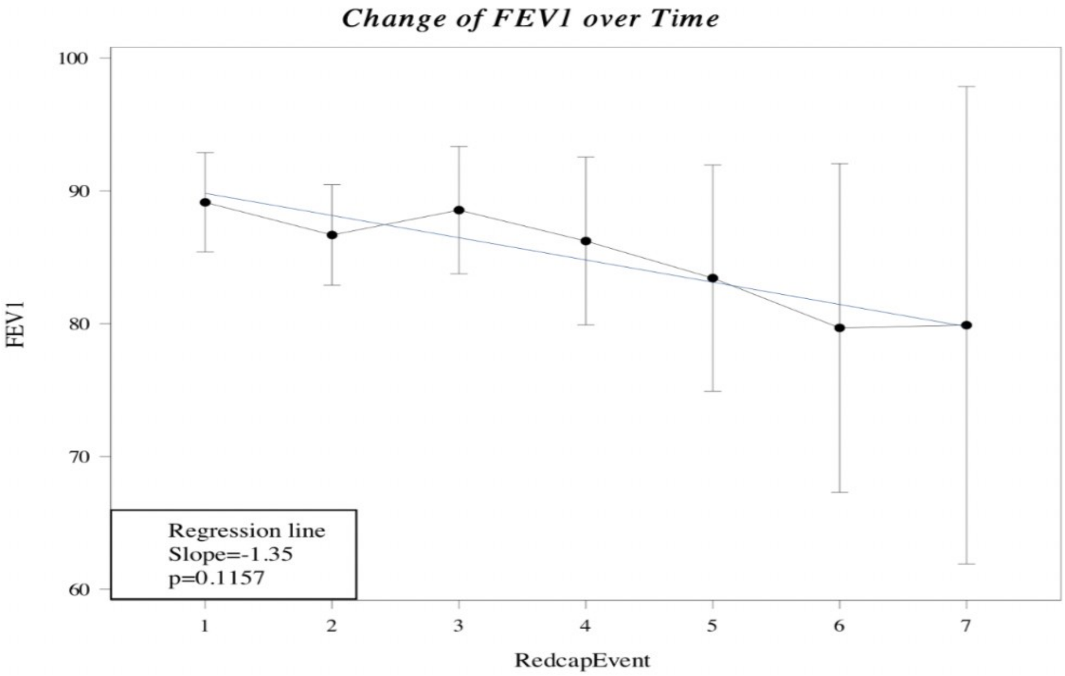
Appendix G



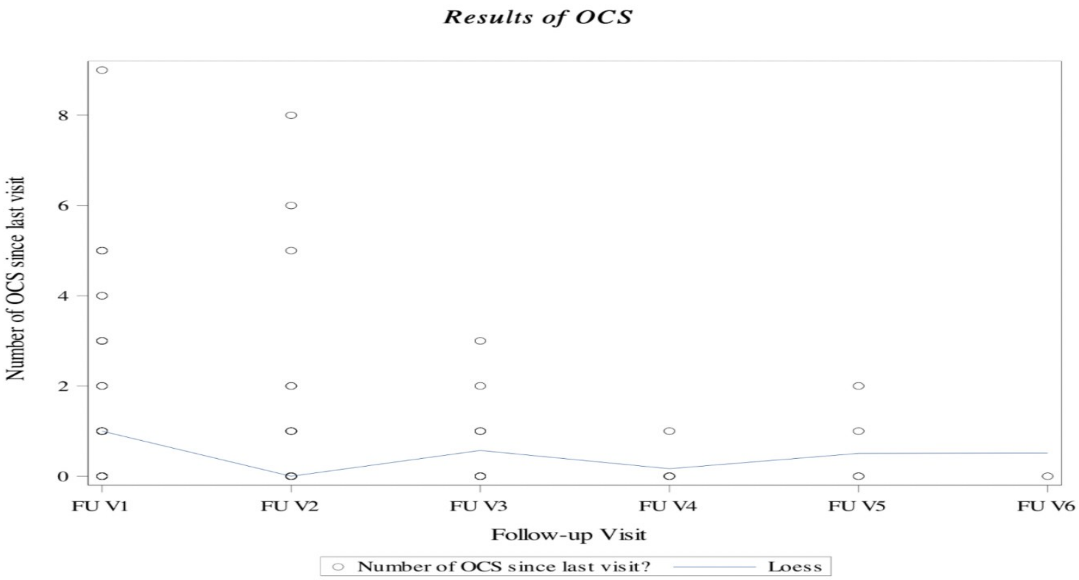
The plot above shows the change of ACT score over time. The estimated values (black dots(and 95% confidence intervals (black bars) were obtained from the model (visit was treated as categorical covariate). Also, a regression line was added in the plot. The slop and P-value were obtained from another random coefficient model (visit was treated as a continuous covariate). The regression line indicated AC score had an average increasing of 0.89 per visit (p<0.0001).

Appendix H



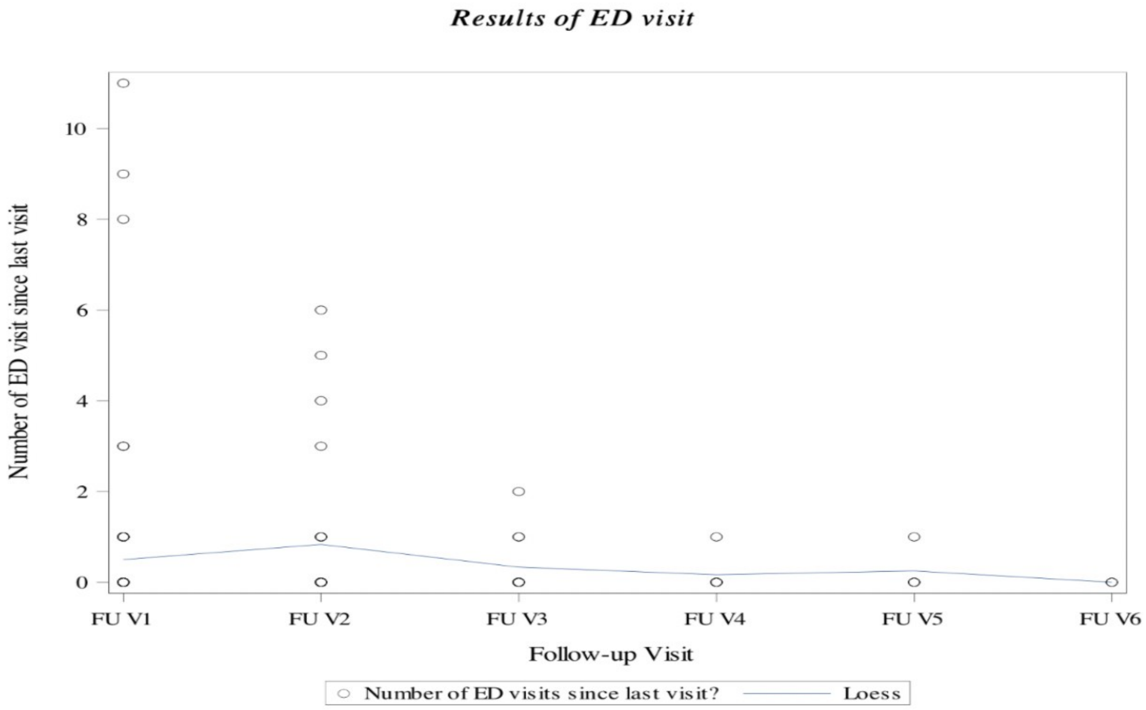
The plot above shows the change of FEV1 over time. The estimated values (black dots) and 95% confidence intervals (black bars) were obtained from the model (visit was treated as categorical covariate). Also, a regression line was added in the plot. The slope and P-values were obtained from another random coefficient model (visit was treated as a continuous covariate). There is not a significant change of FEV1 over time (p=0.1157)

Appendix I



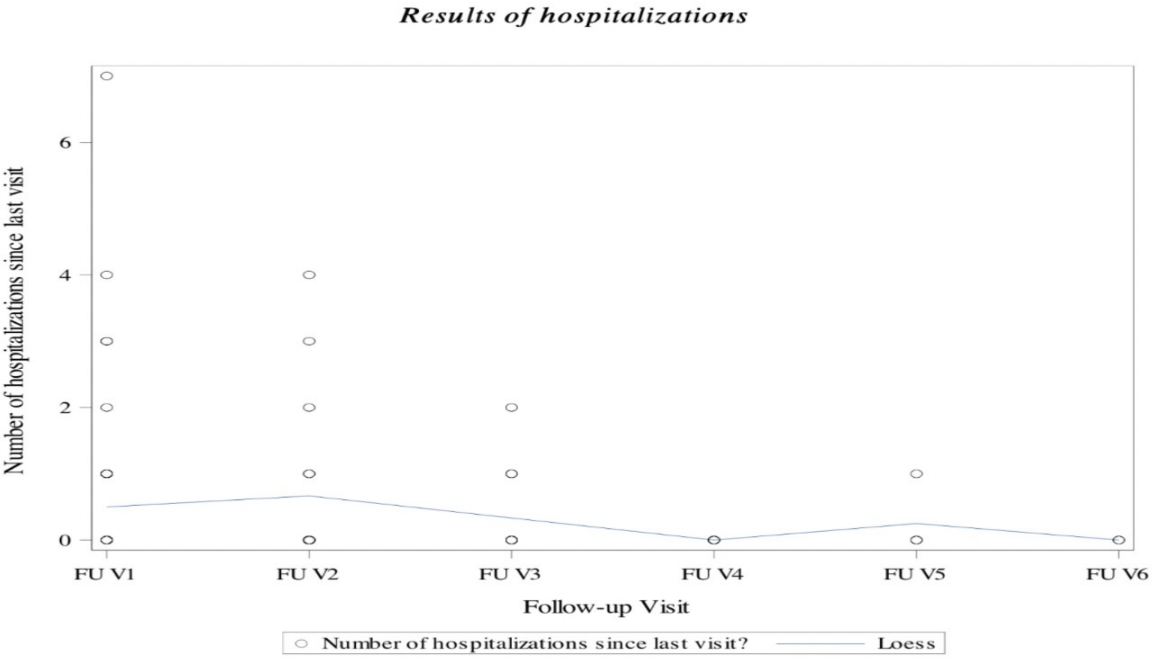
The loess line displays moving average over time and the line is very flat around 0 visit over time.

Appendix J



The loess line displays moving average over time and the line is very flat around 0 visit over time.

Appendix K



The loess line displays moving average over time and the line is very flat around 0 visit over time.