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Article

Running Head: Parental Quality of Life and Self-Efficacy

Title: Parental Quality of Life and Self-Efficacy in Pediatric Asthma

Kristin Kan MD MPH MSc¹, Jamie Fierstein PhD², Kathy Boon MPH², Madeleine Kanaley BA², Patricia Zavos MPH³, Anna Volerman MD⁴, Deneen Vojta MD⁵, Ruchi S. Gupta MD MPH^{6,7}

¹Division of Academic General Pediatrics and Mary Ann & J. Milburn Smith Child Health Research, Outreach, and Advocacy Center, Stanley Manne Children's Research Institute, Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, Illinois

²Institute for Public Health and Medicine, Feinberg School of Medicine, Northwestern University, Chicago, Illinois

³Mary Ann & J. Milburn Smith Child Health Research, Outreach, and Advocacy Center, Stanley Manne Children's Research Institute, Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, Illinois

⁴Department of Medicine and Pediatrics, University of Chicago Medicine, Chicago, IL

⁵Global Research & Development, UnitedHealth Group

⁶Departments of Pediatrics, Medicine, and Medical Social Sciences and Preventive Medicine, and Institute for Public Health and Medicine, Feinberg School of Medicine, Northwestern University, Chicago, Illinois;

⁷MaryAnn & J. Milburn Smith Child Health Research, Outreach, and Advocacy Center, Ann & Robert H. Lurie Children's Hospital, Chicago, Illinois

Corresponding Author: Kristin Kan, MD MPH MSc, 225 E. Chicago Ave, Box 157, Chicago IL 60611, 312 227 6785, kkan@luriechildrens.org

Objective: Self-efficacy is the personal belief that a behavior can produce a desired result; and in asthma, self-efficacy in asthma care has been related to improvements in asthma outcomes and children's quality of

life. To appreciate the full burden of asthma on families, the relationship between parental self-efficacy and quality of life also needs further study. We aim to characterize this relationship.

Methods: Secondary analysis of measurements of parents of children with persistent asthma (n=252; ages 4-17 years) from a large urban area were identified from a randomized trial; the association between baseline assessments of parental quality of life, measured by the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ), and parental self-efficacy, measured through the Parental Asthma Management Self-Efficacy Scale (PAMSES), were examined through multivariable linear regression.

Results: Parental self-efficacy in asthma was positively associated with quality of life among parents of racially and ethnically diverse children ($p=0.01$). Confidence in using medications correctly ($p=0.03$), having inhalers during a child's serious breathing problem ($p=0.02$), and knowing which medications to use during a child's serious breathing problem ($p=0.04$) were associated with a clinically meaningful difference in parental quality of life. Other significant factors associated with parental quality of life included Hispanic/Latino ethnicity ($p<0.01$) of the child and Asthma Control Test scores ($p<0.01$).

Conclusion: The findings suggest that improving parental confidence on when and how to use their child's asthma medications, particularly during an asthma attack, might be clinically meaningful in enhancing parent's quality of life.

Introduction

Quality of life in pediatric asthma remains a critical health outcome that shapes engagement of parents and children around asthma care and is routinely used to evaluate the effectiveness of asthma interventions (1-4). Evaluating both parents' and children's quality of life can broaden the clinician's understanding of the comprehensive impact of disease (5), beyond asthma symptoms and activity limitations.

Previous studies have shown that parental quality of life is associated with multiple contributing factors, including parental stress (6), health beliefs (7, 8), health literacy (9, 10), and asthma symptom control (1). Decreased parental quality of life has been associated with poor asthma control, but it can also be associated with using daily preventive medications, which is a needed therapy to attain control of asthma

symptoms (1). The authors reported that the perceived burden of asthma management (i.e., giving daily medications) was also associated with decreased parental quality of life even among parents of children with few asthma symptoms and likely well-controlled asthma (6, 11). This is concerning as parents might be experiencing a poor quality of life in trying to maintain the recommended therapies for their child's asthma. Thus, further research on the modifiable factors associated with parental quality of life is essential to clarify these relationships.

Previous studies have described self-efficacy as one of many modifiable factors to improve asthma-related management, health outcomes, and the child's quality of life (9, 10, 12-14). Self-efficacy is the confidence in one's personal ability to perform health behaviors that will achieve a desired health outcome (15) and is an important facilitator of successful pediatric asthma management (16, 17). Prior research has shown that parental self-efficacy in pediatric asthma management is positively associated with a child's health status and the child's perceived self-efficacy (16), but the association between parental self-efficacy and parental quality of life is understudied and warrants further investigation in pediatric asthma (13, 18).

We aim to describe the association between parental self-efficacy, as measured by the Parental Asthma Management Self-Efficacy Scale (PAMSES), and parental quality of life in the context of asthma care, using an existing sample of racially and socioeconomically diverse parent-child dyads of children with persistent asthma. We hypothesize that higher parental self-efficacy scores are associated with better parental quality of life while caring for children with persistent asthma. Secondly, we examine which specific components of self-efficacy (i.e., PAMSES item) are most strongly associated with parental quality of life. Individual items of the PAMSES were studied as they represent questions about specific asthma management tasks (e.g., use the medication correctly) or scenarios (e.g., when to take your child to the emergency room) that health providers are clinically concerned about in the care of a child with asthma.

Methods

Study Information

This study is a secondary, cross-sectional analysis of baseline data collected from Improving Technology-Assisted Recording of Asthma Control in Children (iTRACC), a randomized controlled trial conducted from 2016-2018 in large urban center. This trial enrolled and randomized 252 parent-child dyads of children with persistent asthma to either standard care or a Bluetooth-enabled inhaler sensor (Propeller; Madison, WI) that tracked albuterol and inhaled corticosteroid (ICS) use through a cellphone app for parents and a web portal for clinicians. Dyads were eligible for the trial if the child met the following criteria: 1) ages 4-17 years old, 2) had at least one asthma exacerbation requiring oral corticosteroids the year prior to enrollment documented by electronic health record and parent report, and 3) had an active daily ICS prescription for at least one year prior to enrollment per parent report. Recruitment occurred in five pediatric clinics, including 3 primary care clinics, 1 pulmonary clinic, and 1 allergy clinic. Children were excluded from the study if they were non-English speaking, had a co-morbid condition that might interfere with asthma symptom assessment (e.g., chronic lung disease, cystic fibrosis), or if they were participating in other research that could limit the use of inhaler sensor technology. The hospital's Institutional Review Board approved the study protocol, and the trial is registered with NIH (NCT02994238).

Parental Quality of Life

The primary outcome was asthma-related quality of life measured with the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ). Parents completed the validated 13-item scale that included questions about the experience of negative feelings with their child's asthma symptoms (9 items) and their level of concern about their child because of their asthma (4 items). For each item, responses were measured on an ordinal scale, where 7=*none of the time or not worried/concerned* and 1=*all of the time or extremely worried/concerned*. The score for the PACQLQ was calculated by summing all items and dividing by the number of items, with possible mean scores ranging from 1 to 7 (19). There were no missing data for any of the individual PACQLQ scale items. As demonstrated in past studies, a clinically minimal important difference (MID) for PACQLQ was represented by a change in mean score of 0.5 (19, 20). Cronbach's alpha for the PACQLQ in this sample was 0.93.

Parental Asthma Management Self-Efficacy Scale

The primary independent variable was asthma self-efficacy measured with the Parental Asthma Management Self-Efficacy Scale (PAMSES), a 13-item validated scale used in prior studies to reflect the confidence of parents in preventing their child's asthma symptoms and managing exacerbations (2, 14, 21). Parents rated their responses on a 5-point ordinal scale from 1= *not at all sure* to 5=*completely sure*. Scores were calculated by summing all individual items and dividing by the number of items; respondents with missing item information were excluded. We also examined two PAMSES subscales (i.e., asthma attack prevention and management), as well as each items' association with the primary outcome; subscales were specified by Bursch *et al* (16) in the first study of construction and validation of the PAMSES. Cronbach's alpha for the PAMSES in this sample was 0.89.

Covariates

Model covariates were selected *a priori* based on previous studies that have demonstrated their independent association with both asthma-related parental quality of life and parental-self-efficacy (1, 8, 10, 22, 23). Child's age, race and ethnicity, and insurance status were extracted from electronic health records. Baseline asthma symptom control was assessed using the Asthma Control Test (ACT) or childhood Asthma Control Test (c-ACT) based on age.

Analysis

De-identified data from the ACT, PAMSES, and PACQLQ were analyzed using Stata SE Version 15.1 statistical software (StataCorp LP, 2013, College Station, TX). Medians and interquartile ranges (IQR) described the ACT, PAMSES, and PACQLQ. Spearman's correlation coefficients assessed the relationship between PACQLQ and PAMSES (Spearman's rho= 0.08, p=0.2). Given the *a priori* hypothesis that PACQLQ and PAMSES were linearly related, we employed multiple linear regression to model their adjusted relationship; post estimation testing indicated the assumptions of multiple linear regression were upheld.(24, 25) In addition, separate models were fitted using each item of the PAMSES as a binary outcome (i.e., "Completely sure" or "Quite sure" versus "Fairly sure", "A little bit sure", and "Not at all sure") to determine adjusted differences in mean PACQLQ score according to individual PAMSES items. All analyses accounted for potential clustering within households and significance testing was two-tailed with an alpha level of 0.05.

Results

Study Sample

Of the 252 parent-child dyads enrolled, most children were school-aged (Table 1). Non-Hispanic White, Non-Hispanic Black, and Hispanic/Latino racial-ethnic groups were represented at approximately 20-30% each. Two-thirds of children were male, and more than half of the sample had public insurance. Parents reported a median PAMSES score of 4.4 out of 5 (IQR: 4.0 – 4.8), and median PACQLQ score of 6.2 out of 7 (IQR: 5.2 – 6.8). Median asthma control scores indicated that children had well-controlled asthma at intake.

Parental Asthma Self-Efficacy Scale

On the PAMSES (Table 2), parents reported the highest self-efficacy scores for being sure about: getting their child with asthma to a doctor's appointment, following directions for giving a medication, getting the child to take his/her medications, having inhalers if the child has a serious breathing problem, knowing which medications to use during a breathing problem, using medication correctly, and knowing when to take the child to the emergency room. Parents had higher median scores on the asthma attack prevention subscale than the management subscale.

Parental Quality of Life

Median PACQLQ scores on individual quality of life items ranged from 6.0 to 7.0 (Table 3), with parents indicating that they were least bothered that their child's asthma would interfere with family relationships.

Relationship between Parental Self-Efficacy and Quality of Life

After adjustment, parental self-efficacy and quality of life had a significantly positive relationship whereby the mean PACQLQ score differed by 0.41 for every point difference in mean PAMSES score ($p=0.01$) (Table 4). Hispanic/Latino ethnicity ($p=0.001$) and asthma control test score ($p<0.001$) were also significantly associated with mean parental quality of life (data not shown). Both subscales of parental self-efficacy were significantly related to quality of life scores; parental quality of life score differed by 0.41 for every point difference in asthma attack prevention score ($p=0.019$; data not shown) and 0.35 for every point difference

in asthma attack management score ($p=0.009$; data not shown). Standardized results are presented in the Appendix Table.

Individual PAMSES items that were significantly associated with the PACQLQ score include (Table 4): using medications correctly ($p=0.03$), helping the child avoid allergens ($p=0.02$), having the inhalers during a child's breathing problem ($p=0.02$), helping the child stay calm during a breathing problem ($p=0.02$), and knowing which medications to use during a child's breathing problem ($p=0.04$).

Discussion

Parental self-efficacy in asthma had a significantly positive association with quality of life among parents of a racially and ethnically diverse group of children. Although this positive association was not a clinically meaningful change (i.e., of the MID) of the PACQLQ (19), three individual items of the self-efficacy scale were significantly associated with a clinically relevant difference in quality of life: using medications correctly, having the inhaler with the parent when the child is having a serious breathing problem, and knowing which medications to use during a child's serious breathing problem. The significant findings point to the continued need among parents for specific support around which medications and when to use them during their child's asthma exacerbation. Thus while existing literature has shown the positive relationship between parental self-efficacy in asthma care with the quality of life of children (12, 13), our study additionally finds that building parental confidence in key areas in the asthma care of their child might enhance the quality of life of parents themselves. Thus, pediatric asthma interventions could have the benefit of improving the quality of life of both the parent and the child.

Previous qualitative studies have described the parental distress, lack of knowledge or skill of administering medications to young children, and lack of preparedness that surrounds asthma medication management (26-28). A key way that clinicians can continue to improve parent's knowledge and judgement around asthma medication use is by following the National Asthma Education and Prevention Program (NAEPP) recommendations on regular asthma education, including review of inhaler technique and roles of medications (29). Reinforcing NAEPP-recommended education routinely with families could improve parental self-efficacy and potentially parent's quality of life in asthma care.

Overall, our sample of parents reported high confidence on the PAMSES. The ceiling effect observed on the overall PAMSES scores are similar to the scores found among parents of school-aged children in Sydney, Australia (10), the original sample used for PAMSES scale validation (16), and a sample of U.S. parents with mixed English-language proficiency (2). Among these past study samples, parents score above the mid-range and mostly near the top 10-15% of the scale. The iTRACC sample may have performed slightly better on the PAMSES than some of these previous study samples because our study's parent-child dyads were recruited from pediatric primary care and specialty clinics, where supports may have already bolstered their self-efficacy, or parents exhibited social desirability bias in answering the PAMSES. Although parents scored high overall on self-efficacy, examining individual items of the PAMSES suggested some areas for focus. For example, parents were "completely sure" of simple, discrete skills, such as getting their child to a doctor's appointment or medication administration. In contrast, parents indicated lower median self-efficacy for questions that involved more judgement and decision-making. Interventions that provide enhanced, real-time clinical support during asthma attacks are much more difficult to design and implement. In most clinical scenarios, help for managing an asthma attack is parent-initiated, such as calling a clinician's office, scheduling an acute office visit, or going to the emergency room. Our results suggest that helping parents gain confidence in scenarios that require clinical judgement about their child's asthma attack and how to respond to it seem to be opportunities for targeted intervention.

Existing asthma interventions have aimed to support parents through trigger identification, daily management, and other asthma education. The examination of self-efficacy in asthma intervention studies derives from an existing theoretical model of asthma management in which asthma knowledge supports self-efficacy, that develops over time, leading to outcome factors, such as quality of life. (12, 15, 30) Measuring self-efficacy thus remains an important part of understanding the effectiveness of asthma management programs, although how to measure self-efficacy may need continued refinement; this may be the particular case with how well parents measured on the PAMSES in our study. Results are also mixed among asthma interventions in different populations to improve parental self-efficacy. For example, an intensive parent mentor intervention among African-American and Latino parent-child dyads improved

parental self-efficacy and decreased emergency department visits (2). However, a rural asthma education program with parent and child workshops and material resources showed no difference between treatment and intervention groups (3). As such, self-efficacy is one of many measured factors in asthma management and should be treated as a secondary outcome to clinical improvement in the child's asthma.

In the modeled relationship between parental self-efficacy and quality of life, higher asthma symptom control was positively associated with parental quality of life scores. The relationships between asthma symptom control and parental and child quality of life are well-established (9, 17), as the stress of uncontrolled symptoms can understandably deter from a positive quality of life. Helping children achieve well-controlled asthma remains a critical goal of asthma management and potentially strengthens quality of life for parents (29). Further in the modeled relationship, children of Hispanic/Latino origin had lower quality of life scores compared with non-Hispanic/Latino white children. The negative association between Hispanic/Latino ethnicity and parental quality of life, especially when compared with non-Hispanic, white children, is concerning. Previous studies have shown that Hispanic/Latino parents reported worse quality of life, when compared with non-Hispanic, white peers (1, 8, 31-33). Together, the findings among Hispanic/Latino parents warrant careful attention to how designing and tailoring of asthma support interventions can disparately affect quality of life of parents from minority backgrounds (7, 34-37).

We recognize several limitations of our study. Parental quality of life measures in pediatric asthma are essential but imperfect for detecting the impact of the disease on parents and children. The PACQLQ specifically focuses on two domains of quality of life—emotional impacts and activity limitations, and we recognize that other quality of life domains are worth examining but not included in the PACQLQ items. Despite its imperfections, the PACQLQ instrument represents a potential supplement to other outcomes in asthma-related studies (5). For the PAMSES, the ceiling effect might also indicate the scale's ability to discriminate parents with a wider variation in self-efficacy with asthma management as our sample and other study samples typically score above the mid-point of the scale. As with self-report measures, like the PACQLQ, PAMSES, and ACT or c-ACT, we cannot rule out common method bias in our findings. Further, we cannot make any inferences of causation given the cross-sectional data examined in this study. There were

also potential confounders that were not available in our dataset, including parent education, household income, or parent age. Life stress and parental depressive symptoms, that are found to be related to caregiver quality of life (6, 7), were also not measured in our study. Based on the original iTRACC trial design, parent-child dyads were recruited from a large urban area, from outpatient clinics, and only if they were English-speaking; generalizability is thus limited in populations that are not in urban centers, have difficulty in access to outpatient care, or are non-English speaking.

Conclusions

Our findings affirm that improving parental self-efficacy in specific asthma care areas could clinically be meaningful in parental quality of life. Improving self-efficacy among parents has the added benefit of helping this group develop enduring health-promoting behaviors to sustain long-term asthma outcomes (15). Given the gaps identified by parents in needing to improve their self-efficacy in decision-making during asthma attacks, future programs should identify ways to incorporate real-time support, especially as asthma can be a life-threatening and complex health condition for parents to manage alone. Asthma interventions should continue to evaluate how self-efficacy might change in populations with varying characteristics, such as by income or ethnic background, to understand how programs can be tailored to fit the needs of different families.

Declaration of Interest:

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Appendix Table. Adjusted Model of Standardized Parental Quality of Life with the Parental Asthma Management Self-Efficacy Scale (PAMSES)^a

	β (95% CI)	SE	p-value
PAMSES	0.19 (0.04-0.34)	0.2	0.01
Asthma attack prevention subscale	0.18 (0.03-.033)	0.1	0.02
Asthma attack management subscale	0.19 (0.05-0.33)	0.1	0.01

^aModels adjusted for child's age, race/ethnicity, insurance type (public/private), asthma control test

Table 1. Characteristics of Parent-Child Dyads (n=252)

Child Age, mean (standard deviation)	9.3 (3.4)
Child Gender, % male	66.3
Child Race/Ethnicity ^a	
Non-Hispanic White	23.8
Non-Hispanic Black	28.2
Hispanic/Latino	34.1
Other race/ethnicity	7.5
Child's Insurance	
Public	57.9
Private	42.1
Asthma Control Test, median (Interquartile Range (IQR)) ^b	20 (17-22)
Parental Asthma Management Self-Efficacy Scale, median (IQR) ^c	4.4 (4.0 – 4.8)
Pediatric Asthma Caregiver's Quality of Life Questionnaire, median (IQR)	6.2 (5.2 – 6.8)

^a6.4% missing data on race/ethnicity^bExcluded 0.8% incomplete data^cExcluded 6.3% incomplete data

Table 2. Parental Asthma Management Self-Efficacy Scale by Item (n=252)^a

	Median (IQR)
Get your child to a doctor's appointment	5.0 (5.0 – 5.0)
Follow the directions for giving medication	5.0 (5.0 – 5.0)
Get your child to take his/her medications	5.0 (4.0 – 5.0) ^b
Have inhalers with you if your child has a serious breathing problem	5.0 (4.0 – 5.0)
Know which medications to use when your child is having a serious breathing problem	5.0 (4.0 – 5.0) ^b
Know when to take your child to the emergency room during a serious breathing problem	5.0 (4.0 – 5.0) ^b
Use the medication correctly	5.0 (4.0 – 5.0)
Help your child stay calm during a serious breathing problem	4.0 (4.0 – 5.0)
Know when your child's breathing problem can be controlled at home	4.0 (4.0 – 5.0) ^c
Help your child avoid things he/she is allergic to	4.0 (4.0 – 5.0) ^b
Help your child prevent a serious breathing problem	4.0 (3.0 – 5.0)
Control a serious breathing problem at home rather than take your child to the ER	4.0 (3.0 – 5.0)
Keep the asthma from getting worse if your child starts to wheeze or cough	4.0 (3.0 – 5.0)
Asthma attack prevention subscale	4.7 (4.2 – 4.8) ^d
Asthma attack management subscale	4.3 (3.9 – 4.7) ^b

^aAsks parents how sure they are for each scenario; 5=completely sure, and 1=not at all sure^bn=249^cn=250^dn=238

Table 3. Pediatric Asthma Caregiver's Quality of Life Questionnaire by Item^a (n=252)

	Median (IQR)
Bothered because your child's asthma interfered with family relationships	7.0 (7.0 – 7.0)
Your family need to change plans because of asthma	7.0 (6.0 – 7.0)
Feel angry that your child has asthma	7.0 (6.0 – 7.0)
Feel frustrated or impatient because your child was irritable due to asthma	7.0 (5.0 – 7.0)
Your child's asthma interfere with your job or work around the house	7.0 (5.0 – 7.0)
Have sleepless nights because of your child's asthma	7.0 (5.0 – 7.0)
Feel helpless or frightened when your child experienced cough, wheeze, or breathlessness	7.0 (5.0 – 7.0)
Awakened during the night because of your child's asthma	7.0 (5.0 – 7.0)
Feel upset because of your child's cough, wheeze, or breathlessness	7.0 (5.0 – 7.0)
Worried about your child's medication and side effects	6.0 (4.0 – 7.0)
Worried about your child's performance of normal daily activities	6.0 (4.0 – 7.0)
Worried about your child being able to lead a normal life	6.0 (4.0 – 7.0)
Worried about being overprotective of your child	6.0 (4.0 – 7.0)

^aAsks parents how often in the past week have these issues occurred; 7=none of the time or not worried, and 1=all the time or extremely worried

Table 4. Adjusted Model of Parental Quality of Life with the Parental Asthma Management Self-Efficacy Scale (PAMSES) and PAMSES Items^a

	β (95% CI)	SE	p-value
Overall PAMSES	0.41 (0.08-0.73)	0.2	0.01
Get your child to take his/her medications	0.55 (-0.02-1.12)	0.3	0.06
Use the medication correctly	0.61 (0.06-1.15)	0.3	0.03
Get your child to a doctor's appointment	0.48 (-0.29-1.24)	0.4	0.22
Follow the directions for giving medication	0.88 (-0.02-1.77)	0.5	0.06
Help your child avoid things he/she is allergic to	0.39 (0.07-0.72)	0.2	0.02
Help your child prevent a serious breathing problem	0.29 (-0.01-0.60)	0.2	0.06
Have inhalers with you if your child has a serious breathing problem	0.77 (0.10-1.44)	0.3	0.02
Control a serious breathing problem at home rather than take your child to the ER	0.16 (-0.14-0.45)	0.2	0.3
Keep the asthma from getting worse if your child starts to wheeze or cough	0.10 (-0.20-0.40)	0.2	0.5
Help your child stay calm during a serious breathing problem	0.47 (0.06-0.86)	0.2	0.02
Know which medications to use when your child is having a serious breathing problem	0.75 (0.05-1.46)	0.4	0.04
Know when your child's breathing problem can be controlled at home	0.42 (-0.02-0.85)	0.2	0.06
Know when to take your child to the emergency	0.27 (-0.22-0.77)	0.3	0.3

room during a serious breathing problem			
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^aModels adjusted for child's age, race/ethnicity, insurance type (public/private), asthma control test;

PAMSES items are dichotomous variables of "completely sure" or "quite sure" versus not.

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