RESEARCH ARTICLE

Evaluating the Quality of Life and Transition of Adolescents and Young Adults with Asthma in an Inner City

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Abstract

Purpose
This study examines the correlation of the Mini Pediatric Asthma Quality of Life Questionnaire (miniPAQLQ) with the Got Transitions Readiness Assessment Survey (GTRAS) of inner-city adolescents and young adults with asthma in Newark, New Jersey.

Methods
One hundred six patients with asthma, aged 12-21 years old, were assessed at University Hospital in Newark, NJ while receiving typical care. In this cross-sectional study, patients were assessed using the miniPAQLQ and GTRAS tools. General demographics were captured. MiniPAQLQ sections on activity, symptom, and emotional function, were compared to the GTRAS questions on perceived transition readiness and ability to complete healthcare tasks.

Results
Fifty-three percent of the patients were female, 57% were African American, 37% were Latino/a, and 97% had insurance. The overall median quality of life (QOL) score was 6. Specific activity, symptom and emotional function QOL scores did not correlate with overall perceived transition readiness. However, QOL scores >5 did correlate with patients' abilities to complete specific health-related tasks of transition, especially when comparing emotional function and "knowing" their health.

Conclusions
Our results demonstrate that the emotional function of adolescents and young adults with asthma is significantly linked to their ability to complete healthcare tasks independently, indicating that a psychological-based approach to transition may be necessary. Low emotional QOL scores may help identify patients at risk of poor transition who would benefit from additional intervention. Further research is needed to assess quality of life and its effects on development of these patients.

Keywords: asthma, adolescent, young adult, transition, independence, quality of life

1. Introduction

Transition, the "purposeful, planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented healthcare systems", is a critical period in the lives of adolescent and young adult (AYA) patients[1]. Transition encourages the development of autonomous health decision making in these formative years, but in doing so, creates many barriers to care[2]. During adolescence, patients experience several changes, including new financial responsibilities, increased commitments, and social pressure to fit in[2-3]. The risks associated with improper preparation to manage these changes while transitioning to adult care settings include lower rates of compliance with treatment, lack of follow up, and the establishment of poor health behaviors that can have long-term consequences[4]. Furthermore, failure of AYA patients with chronic disease to successfully navigate these challenges is historically linked to poor health outcomes in adulthood and diminished quality of life[5]. This relationship between transition and quality of life has been well-described in the literature for chronic diseases such as diabetes, hemophilia, and HIV[6-8]. However, the link between readiness for independent care and its implications on quality of life for AYA asthmatics has not yet been investigated.

Asthma, a complex "chronic disorder of the airways…characterized by variable and recurring symptoms, airflow obstruction, bronchial hyperresponsiveness, and an underlying inflammation", is the most common chronic disease among pediatric patients[9-10]. As of 2017, over 6.1 million children are affected by asthma and the prevalence continues to increase as asthma remains highly underdiagnosed and undertreated[11]. The increasing prevalence means an increasing number of young patients with asthma graduating to adult health care. This is especially true of Newark, New Jersey. A broadly underserved and undereducated urban population, Newark has one of the highest rates of asthma incidence in New Jersey, greater than 1.5 times the state average[12]. Pediatric asthma in Newark is a product of air pollutants, chronic stress, poverty, lack of health insurance, and decreased health literacy[13]. Studies have shown that low income, urban adolescents tend to exhibit poor self-management in the setting of uncontrolled asthma[14-15]. This is particularly concerning since asthma presents a lifelong burden to patients should it extend into adulthood uncontrolled. For example, in AYA asthmatics, low FEV1 predicts a decline in quality of life over five years and is associated with physiological and psychological hindrance on activities of daily life[16-17]. Reduced quality of life can lead to additional chronic comorbidities such as diabetes mellitus, arthritis, cardiovascular disease, stroke, and osteoporosis in adulthood that were otherwise preventable[18]. As such, the development of independence with regard to healthcare is becoming increasingly important. It is essential that AYA asthmatics attain the skills to successfully manage their disease and thus, quality of life during this crucial period.

While preparedness for transition and quality of life in AYA asthmatics have been explored independently, the relationship between the two have not been assessed together. Our study aims to investigate the correlation of perceived readiness of transition with quality of life of inner city AYA patients with asthma in Newark, New Jersey.

2. Methods

One hundred six AYA, asthmatic patients (n=56 female) completed a transitional care and quality of life assessment during routine care and results were reviewed. The study received exempt status and approval by the onsite Institutional Review Board. Patients between the ages 12-21 years old (mean age of 15.6, median age of 16 years) were being assessed for transition readiness and quality of life in the outpatient pediatric pulmonary clinic (50%) at an inner city hospital in Newark, New Jersey while receiving typical care. Other participants who completed the assessments were in the hospital's pediatric emergency room (36.8%), pediatric inpatient floor and pediatric intensive care unit (9.4%), and outpatient pediatric and internal medicine/pediatric primary care clinics (3.8%). Approximately 91.5% of patients had public insurance which included Medicaid, Medicare and HMO plans, while 5.7% had private insurance and 2.8% patients did not have insurance. The majority of patients identified as African American (57%; 34.6% Latino/a, 8.4% other) (Table 1).

Each participant independently completed two assessment tools, the Got Transitions Readiness Assessment Survey (GTRAS)[19] (Appendix A) and the Mini Pediatric Asthma Quality of Life Questionnaire (miniPAQLQ)[20] (Appendix B). The GTRAS is a 25-item, self-report questionnaire that assesses pediatric patients' perceived readiness to transition to adult health care (Appendix A). The GTRAS is divided into three subsections focusing on transition importance and confidence (items 1-2), personal health knowledge (items 3-11), and ability to navigate the healthcare system (items 12-25). Items 1 and 2 represent the patient's overall self-perceived readiness to transition. These items receive a score ranging from 0 (not) to 10 (very), with higher scores indicating greater importance of confidence in transition ability. Patients then had to select one of the following statements, "Yes, I know this," "I need to learn this," or "Someone needs to do this…Who?" for specified transition tasks (items 3-25). The miniPAQLQ is a 13-item, self-reported questionnaire that assesses quality of life in pediatric asthmatics that is further divided into symptoms, emotional function, and activity (Appendix B). MiniPAQLQ symptoms are investigated by items 1 through 6, emotional function by items 7 through 10, and activity limitation by items 11 through 13. Items 1-3 and 11-13 are rated on a 7-point Likert-type scale with 1= extremely bothered and 7=not bothered, while items 4-10 are rated on the following: 1= all of the time and 7= none of the time.

Univariate and multivariate analyses were done to assess patient characteristics using

Excel. Mean and median values for demographic data (Table 1) and miniPAQLQ scores were generated. Wilcoxon ranked-sum test and McNemar's test was used to calculate P values. Spearman's Rho was used to calculate the correlation coefficient.

Table 1: Demographics

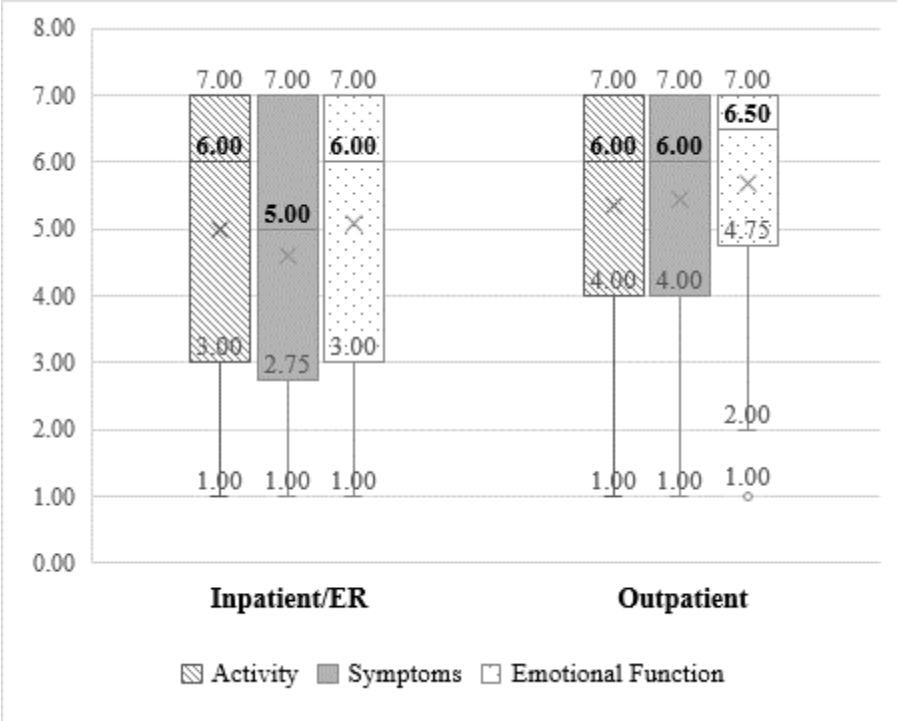
		n=106	%
Gender	Female	56	52.8%
	Male	50	47.2%
Age (years)	12 to 17	87	82.1%
	18 to 21	19	17.9%
Race	African American	61	57.0%
	Latino/a	37	34.6%
	Other	9	8.4%
Insurance	Public	97	91.5%
	Private	6	5.7%
	None	3	2.8%
Location	ER	39	36.8%
	Inpatient	10	9.4%
	Outpatient	57	53.8%

3. Results

The median miniPAQLQ score for the sample is 6, with an interquartile range of 4-7. The median for activity, symptoms, and emotional function are 6 (IQ range 4-7), 5.5 (IQ range 3-7), and 6.25 (IQ range 4-7) respectively. Differences among miniPAQLQ scores were also assessed based on location of care (Fig 1). The median miniPAQLQ activity, symptom and emotional function scores in the inpatient setting were 6 (IQ range 3-7), 5 (IQ range 2.75-7), and 6 (IQ range 3-7) respectively. In outpatient participants, the median miniPAQLQ activity, symptom and emotional function scores were 6 (IQ range 4-7), 6 (IQ range 4-7), and 6.5 (IQ range 4.75-7) respectively. Using Wilcoxon ranked-sum test, there was no significant difference found in any of the miniPAQLQ scores comparing the inpatient setting versus outpatient setting, but symptom scores were noted to be approaching significance (activity, symptom, and emotional function p-values = 0.44, 0.06, 0.19 respectively).

The data were then analyzed to compare perceived readiness to transition among participants who reported miniPAQLQ scores of >5 or ≤5. An affirmative response to GTRAS items of "Yes, I know this" indicates perceived readiness to transition in that capacity. However, there is no known "acceptable miniPAQLQ score" designated in the literature. As a result, the threshold for acceptable miniPAQLQ was set at >5. Thus, a patient selecting a score of 6 in the emotional function items corresponds to experiencing negative emotions "hardly any of the time" and in symptom and activity items, corresponds to being "hardly bothered at all."

Figure 1: Median miniPAQLQ Scores by Location



Using Spearman's rank correlation coefficient, there was no correlation between miniPAQLQ activity, symptom and emotional function scores and patients' overall self-perceived readiness to transition (GTRAS item 2) (r_s= 0.15743, 0.07824, and 0.0466 respectively). A patient's perceived importance to transition (GTRAS item 1) also did not correlate with their miniPAQLQ scores (r_s= 0.02467, 0.04706, and 0.06835 respectively). However, McNemar's test revealed a statistically significant difference in perceived readiness for specific transition competencies among participants who responded >5 versus ≤5 for most of the miniPAQLQ areas (Figs 2-4). Specifically, patients' emotional function scores correlated with whether or not they "knew" how to do more GTRAS tasks than based on their activity or symptom scores (17 total GTRAS items versus 15 and 16 respectively). Three tasks consistently did not correlate with any of the quality of life areas, including "thinking about questions to ask before a doctor's visit," "knowing where to get medical care when the doctor's office is closed," and "having a file at home for medical information." The number of participants who indicated perceived readiness to transition on the GTRAS and scored >5 versus ≤5 for miniPAQLQ activity, symptom, and emotional function scores is summarized in Figures 2-4.

Figure 2: GTRAS Answers and QOL Activity Score

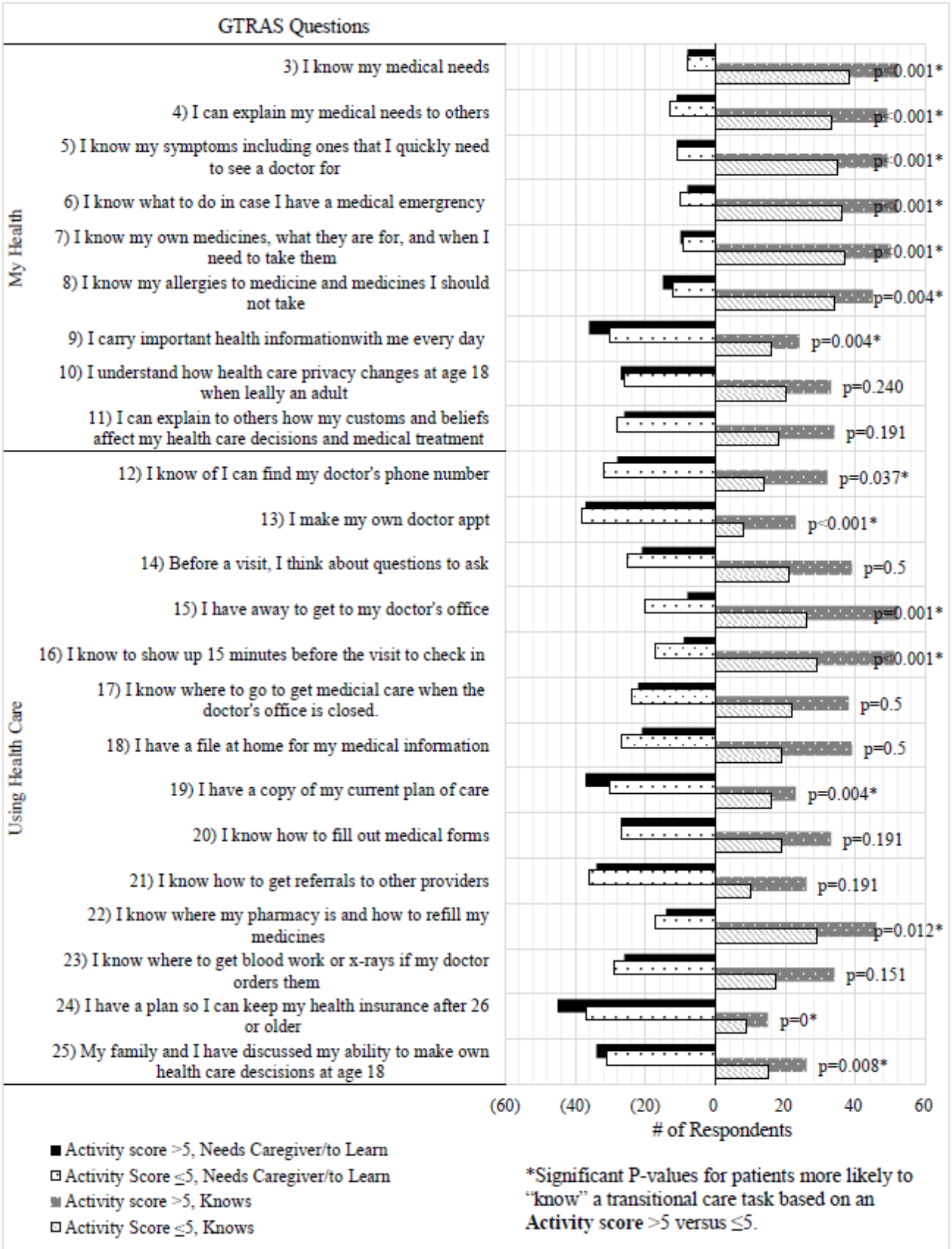


Figure 3: GTRAS Answers and QOL Symptom Score

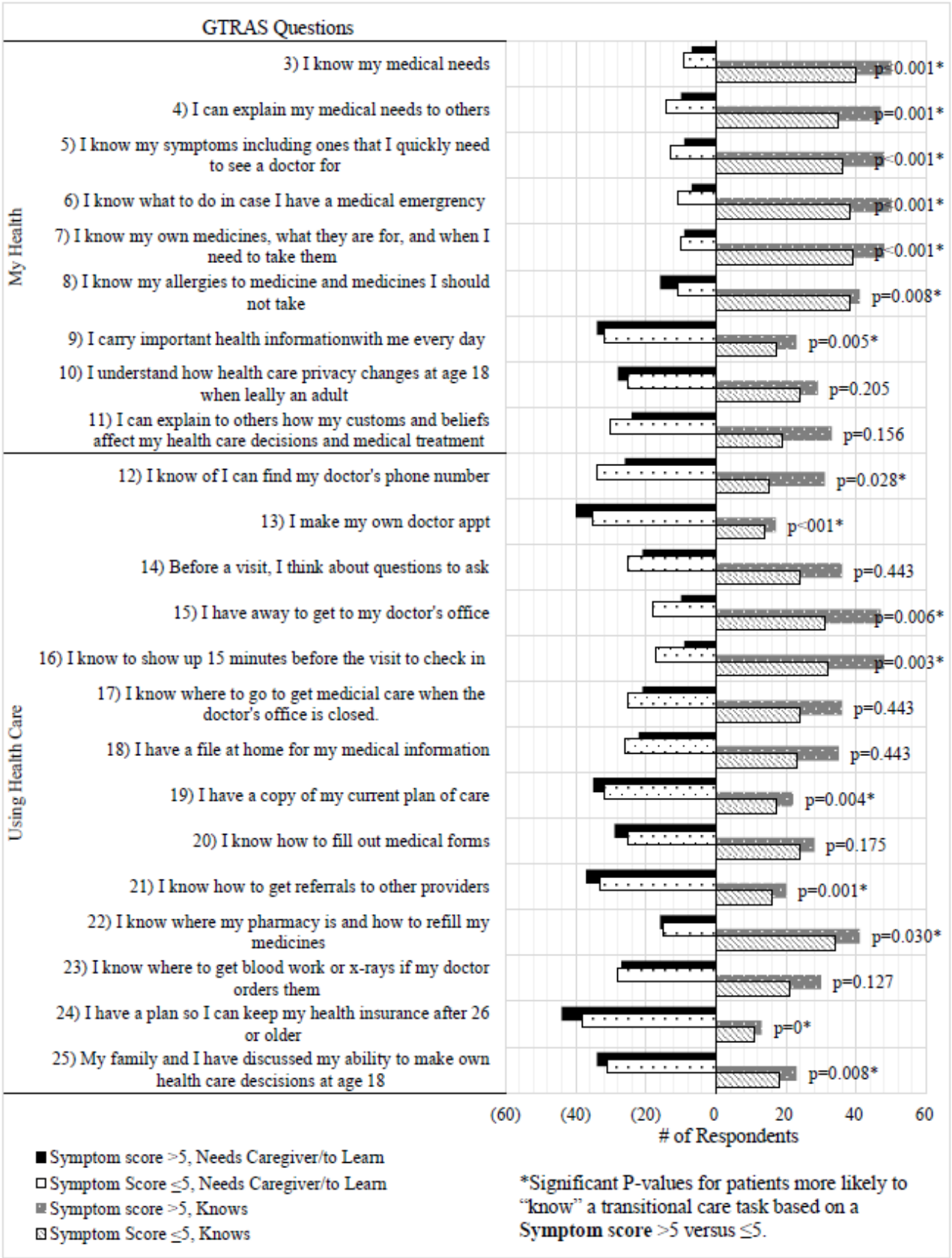
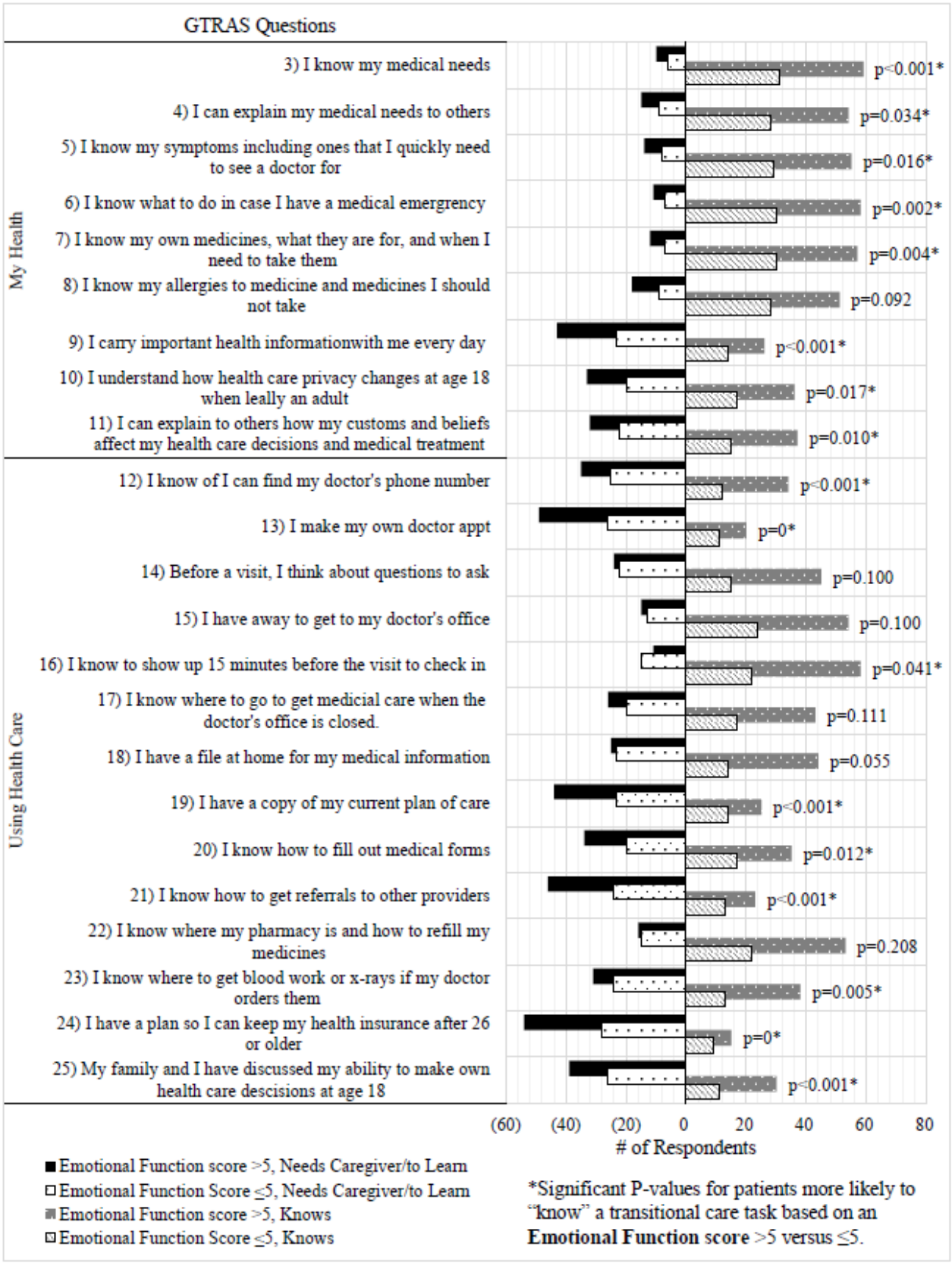


Figure 4: GTRAS Answers and QOL Emotional Function Score



4. Discussion

While it is well documented that adolescents struggle to manage their asthma during and after the progression from pediatric to adult providers, there is limited information regarding patients' quality of life and readiness for independent care. This is the first study in the United States to quantify the relationship between quality of life and self-perceived transition readiness in AYA asthmatics in the urban, underserved setting.

The overall median miniPAQLQ score of 6 among this urban AYA asthmatic population is surprisingly reassuring. When analyzing the individual elements of miniPAQLQ, participants also demonstrated fewer negative emotions, such as frustration, anger, etc., (median 6.25) and activity limitation (median 6) than symptom control (median 5.5). This finding assumes that patients in our population tend to have slightly better quality of life emotionally than with their activities or symptoms, but overall, largely positive. Our results also showed no statistically significant increase in miniPAQLQ scores in an outpatient setting versus inpatient/ER setting, showing some consistency in patient responses despite being acutely treated for an exacerbation but noting that the difference in their symptom score was approaching significance.

When comparing a patient's quality of life scores with their overall self-perceived readiness to transition, there was no correlation. However, miniPAQLQ scores seemed to correlate with a patient's perceived ability to complete specific healthcare tasks. Specifically, a high miniPAQLQ score correlated with tasks that assessed a patients' understanding of their health (GTRAS items 3-11). There was also a correlation in the ability to complete certain healthcare utilization tasks (GTRAS items 12-13, 16, 19, 24-25) based on high miniPAQLQ scores in all 3 areas. High miniPAQLQ emotional function scores seemed to correlate with the self-perceived knowledge of slightly more GTRAS items than activity or symptom scores. Of note, the emotional function score questions are also more easily generalizable to other disease assessments than the activity or symptom questions. This finding echoes the previously mentioned notion that emotional state may play a more consistent role in transition readiness when compared with their disease state. As such, further investigation into the role of emotional function in developing AYA's independence in healthcare is needed.

As stated previously, the data was gathered via a self-administered survey and therefore, subject to response bias. Discrepancies in the reporting of behaviors due to the Hawthorne effect may mask the true relationship between GTRAS and miniPAQLQ variables. Our study also only compared GTRAS and miniPAQLQ scores at one point in time. It is possible that when followed prospectively, the two surveys may show some convergence. Similarly, a larger sample size may reveal additional findings as several p-values in the comparison between GTRAS and miniPAQLQ seemed to be approaching significance. Thus, further research should be done to assess quality of life in these patients at different points between ages 12

to 21. By doing so, we can monitor progression and development of self-sufficient healthcare behaviors as patients approach the transition to adult care settings.

Currently, there is no known acceptable miniPAQLQ score that defines the "appropriate" level of quality of life. As such, the acceptable miniPAQLQ score was set to >5 for this study to include responses of hardly or not bothered/experiencing specific activity limitations, disease symptoms or emotional function. Furthermore, the GTRAS is not a validated questionnaire. However, it is a recommended assessment tool of transition readiness in adolescent and young adult patients. The GTRAS directly evaluates the patient's overall thoughts on the transition to adult providers, in addition to specific developmental behaviors and therefore, is a useful questionnaire when assessing along with self-perceived quality of life.

Despite these limitations, the clinical significance of our findings is impactful. While the importance of proper transition is well-known, there is no standardized method for how to accomplish a successful development of a young adult. The fact that overall self-perceived transition readiness (GTRAS item 2) did not significantly correlate with quality of life prompts the question of whether this is due to the way this development is currently structured, the specific nuances of this urban, underserved and impoverished community, and the efficacy of the GTRAS as a measurement tool. Furthermore, this lack of correlation between self-perceived readiness and quality of life suggests a deficit of knowledge about the behaviors and priorities of AYA asthmatics. Our data suggests that AYA patients may benefit from stepwise transition benchmarks surrounding their emotional states and/or milestones. The transformative period between ages 12 to 21 serves as the timeframe to track the AYA patient's progress, similar to monitoring pediatric developmental milestones across several visits in the first years of life. Provider-driven guidance of this process is key. By understanding observer bias and its relationship to the transitional care process, we can better identify patients at risk of not developing crucial skills and lead to early intervention. Additionally, this process actively encourages AYA patients to provide insight into their own care and subsequently take ownership of their health. Our findings indicate that these milestones should correlate emotional and psychosocial tasks rather than exclusively focusing on disease symptoms or activities. This early training aims to empower the patient and will therefore encourage better health behaviors in adulthood. It would be interesting to see if this relationship between emotional quality of life and ability to complete independent health behaviors holds true among AYA with other chronic diseases, such as diabetes, HIV, and sickle cell anemia etc. Future studies assessing these AYA populations would add further insight regarding how best to structure transition milestones or training, as well as how to establish an interdisciplinary team to assist patients with this process.

5. Conclusions

Currently an unaccounted factor, the transition period presents additional challenges to the management of chronic illness and as a result, may contribute to poor outcomes in young adult and adolescent patients. Our results demonstrate the need to pay more attention to the psychological and emotional components associated with the development of independent health practices in adolescent and young adult patients. Low emotional quality of life scores may assist providers in identifying patients at risk of poor transition and in need of more focused preparation. Additionally, stepwise emotional benchmarks throughout ages 12 to 21 may help promote transition success for AYA patients. Further research is needed to assess the emotional quality of life and validated transitional care surveys and their outcomes, as this may provide key insights on how to best manage these patients throughout the period of transition.

6.References

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Appendix A: Got Transitions Readiness Assessment Tool[19]

got transition

Sample Transition Readiness Assessment for Youth/Young Adults

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health, using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

Date:

Name: Date of Birth:

Transition and Self-Care Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it to you to manage your own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

How confident do you feel about your ability to manage your own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

My Health *Please check the box that applies to you right now.*	*Yes, I know this*	*I need to learn*	*Someone needs to do this… Who?*
I know my medical needs.	☐	☐	☐
I can explain my medical needs to others.	☐	☐	☐
I know my symptoms including ones that I quickly need to see a doctor for.	☐	☐	☐
I know what to do in case I have a medical emergency.	☐	☐	☐
I know my own medicines, what they are for, and when I need to take them.	☐	☐	☐
I know my allergies to medicines and the medicines I should not take.	☐	☐	☐
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	☐	☐	☐
Using Health Care			
I know or I can find my doctor's phone number.	☐	☐	☐
I make my own doctor appointments.	☐	☐	☐
Before a visit, I think about questions to ask.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know to show up 15 minutes before the visit to check in.	☐	☐	☐
I know where to go to get medical care when the doctor's office is closed.	☐	☐	☐
I have a file at home for my medical information.	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get referrals to other providers.	☐	☐	☐
I know where my pharmacy is and how to refill my medicines.	☐	☐	☐
I know where to get blood work or x-rays done if my doctor orders them.	☐	☐	☐
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	☐	☐	☐
I understand how health care privacy changes at age 18 when legally an adult.	☐	☐	☐
I have a plan so I can keep my health insurance after 18 or older.	☐	☐	☐
My family and I have discussed my ability to make my own health care decisions at age 18.	☐	☐	☐

Appendix B: Mini Pediatric Asthma Quality of Life Questionnaire20"

Please complete all questions by circling the number that best describes how you have been during the last week as a result of your asthma.

HOW BOTHERED HAVE YOU BEEN DURING THE LAST WEEK BY:

	Extremely Bothered	Very Bothered	Quite Bothered	Somewhat Bothered	Bothered A Bit	Hardly Bothered At All	Not Bothered
1. COUGHING	1	2	3	4	5	6	7
2. WHEEZING	1	2	3	4	5	6	7
3. TIGHTNESS IN YOUR CHEST	1	2	3	4	5	6	7

IN GENERAL, **HOW OFTEN** DURING THE LAST WEEK DID YOU:

	All of the Time	Most of the Time	Quite Often	Some of the Time	Once in a While	Hardly Any of the Time	None of the Time
4. Feel OUT OF BREATH because of your asthma?	1	2	3	4	5	6	7
5. Feel TIRED because of your asthma?	1	2	3	4	5	6	7
6. Have trouble SLEEPING AT NIGHT because of your asthma?	1	2	3	4	5	6	7
7. Feel FRUSTRATED because of your asthma?	1	2	3	4	5	6	7
8. Feel FRIGHTENED OR WORRIED because of your asthma?	1	2	3	4	5	6	7
9. Feel IRRITABLE (cranky/grouchy) because of your asthma?	1	2	3	4	5	6	7
10. Feel DIFFERENT OR LEFT OUT because of your asthma?	1	2	3	4	5	6	7

HOW **BOTHERED** HAVE YOU BEEN DURING THE LAST WEEK DOING:

	Extremely Bothered	Very Bothered	Quite Bothered	Somewhat Bothered	Bothered A Bit	Hardly Bothered At All	Not Bothered
11. PHYSICAL ACTIVITIES (such as running, swimming, sports, walking uphill/upstairs and bicycling)?	1	2	3	4	5	6	7
12. BEING WITH ANIMALS (such as playing with pets and looking after animals)?	1	2	3	4	5	6	7
13. ACTIVITIES WITH FRIENDS AND FAMILY (such as playing at recess and doing things with your friends and family)?	1	2	3	4	5	6	7

DOMAIN CODE:

Symptoms: 1, 2, 3, 4, 5, 6
Emotional Function: 7, 8, 9, 10
Activity Limitation: 11, 12, 13

