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Understanding Autonomy in Patients with Moderate to Severe Asthma

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ABSTRACT

Background: Autonomy is the ability of patients to make informed medical decisions.

Autonomy is rooted in disease state understanding. Medical ethics, especially the principle of autonomy, plays an important role in healthcare delivery when caring for diverse populations.

Objective: We sought to identify patient characteristics that influence autonomy.

Methods: 295 adults with moderate to severe asthma completed two surveys at the beginning of a one year randomized clinical trial. The Navigating Ability and Inhaled Corticosteroids Knowledge questionnaires were combined to create a 21-question assessment of autonomy with possible scores ranging from 10-105. Linear regression was performed on the derived autonomy score predicted by patient baseline characteristics.

Results: Comparison revealed statistically significant differences in baseline autonomy scores in patients who reported Spanish as their primary language ($p=0.01$), patients with diabetes ($p=0.01$), and those with depressive symptoms ($p=0.03$) at -11.4 (95% CI, -20.5, -2.3), -4.8 (95% CI, -8.3, -1.3), and -3.1 (95% CI, -5.9, -0.3) points respectively. Non-Hispanic White participants on average were found to have 8.2 (95% CI, 4.5, 12.0) points higher autonomy scores compared to non-Hispanic Black participants (Bonferroni adjusted $p<0.01$). Patients with higher functional health literacy had higher autonomy scores (coefficient=0.24, 95% CI, 0.1, 0.4, $p<0.01$)

Conclusions: Autonomy is associated with comorbidities, demographics, and literacy. These results may reflect differences in social, educational, and economic opportunities encountered by patients. Further investigation is needed to assess and understand how socioeconomic and educational factors influence autonomy. By identifying differences in autonomy based on baseline patient characteristics, this project serves as an initial step in adjusting current and developing new treatment guidelines and interventions to improve patient autonomy.

HIGHLIGHT BOX**What is already known about this topic? (35 word limit)**

There is a scarcity of research highlighting the essential role of medical ethics, particularly autonomy, in the clinical practice of Allergy and Immunology.

What does this article add to our knowledge? (35 word limit)

In a population of patients with moderate to severe asthma, baseline differences in autonomy were associated with comorbidities, demographics and health literacy. These differences may reflect variability in economic, educational, and social opportunities.

How does this study impact current management guidelines? (35 word limit)

The identification of differences in autonomy based on patient characteristics is an initial step in modifying treatment guidelines to improve patient autonomy and subsequently healthcare equity.

Key Words: Asthma; Autonomy; Healthcare delivery; Health disparities; Health literacy;
Inhaled corticosteroids; Medical ethics; Patient-centered care

Abbreviations:

CI	Confidence Interval
CES-D	Center for Epidemiological Studies-Depression
HAP2	Helping Asthma Patients 2
ICSK	Inhaled Corticosteroids Knowledge
ICS	Inhaled Corticosteroids
IQR	Interquartile Range
NAV2	Navigating Ability
S-TOFHLA	Short Test of Functional Health Literacy in Adults

INTRODUCTION

A fundamental principle of medical ethics is autonomy.¹ Autonomy is the ability of patients to make decisions that are informed and free of coercion regarding their own medical care. In order to make such choices, patients must understand the pertinent pathophysiology and management of their medical condition, which includes knowledge of the available treatment options.² Without this understanding, patients are unable to make informed decisions regarding the management of their health and how they could adapt their treatment plan so it is in accordance with their personal values. Autonomy underlies nearly all office visits, treatment plans, and interactions patients have with the healthcare system. Hence, obtaining a more comprehensive understanding of autonomy is a step to an increasingly equitable healthcare system in which all individuals have the ability to participate in and access to comprehensive medical care.

In 2001, the Institute of Medicine, now the National Academy of Medicine, included patient-centered care as one of the six goals for healthcare.³ The National Academy of Medicine defined patient-centered care as “Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”³ In a healthcare system that strives to improve patient-centered care, understanding autonomy is fundamental as patients with greater autonomy are better able to participate in their treatment plans and make medical decisions that align with their values.

Autonomy, as all aspects of medical ethics, plays an important role in healthcare delivery. This is particularly true when caring for patients from diverse backgrounds whose values and weighing of their relative significance differ from that of the clinician and other patients. A key component of autonomy is patients recognizing and applying their personal values when making

decisions. Numerous factors influence patients' health and medical decision-making, such as education, language, culture, socioeconomic status, sex, race, and literacy. Understanding these factors along with recognizing differences in how values are held among different populations are important concepts for clinicians to consider when discussing the delivery of medical care. Hence, clinicians recognizing these differences in values and how they influence patients' interactions with the healthcare system are steps to improving autonomy, and by extension, making medicine more equitable.

One of the unique aspects of the specialty of Allergy and Immunology is that its providers have the opportunity to care for patients of all ages and backgrounds. While this is not solely limited to the field of Allergy and Immunology, in an increasingly specialized healthcare system, this is a more unique practice. This also includes treating patients with various comorbidities, levels of health literacy, and from diverse backgrounds. Hence, a thorough understanding of patient values and autonomy is crucial in the delivery of patient-centered care by Allergists and Immunologists. Yet, even with this important role of medical ethics within the field, there is a shortage of research connecting the field of Allergy and Immunology with medical ethics.⁴ This scarcity is even more noteworthy when observing the amount of research relating ethics with other chronic diseases.⁴

Improving autonomy is a step toward building a healthcare system that is increasingly patient-centered. An initial step to improving autonomy is to better understand the practical application of this principle in healthcare. In this study, we sought to further illuminate patient characteristics that were associated with autonomy in this patient population.

METHODS

We conducted a retrospective review of baseline characteristics of patients enrolled in the HAP2 trial (Helping Asthma Patients 2), a cohort of patients recruited from low income backgrounds with moderate to severe asthma.^{5,6} HAP2 compared the effect of a patient advocate intervention with usual care in the management of asthma.^{5,6} For this study characteristics of patient autonomy were evaluated using a 21-question assessment. The questions in the assessment were related to several dimensions of autonomy. The concept of autonomy includes decision-making and health understanding.² The survey questions focused on asthma disease state understanding, medication understanding, such as their name, proper use, and function (eg, controller versus reliever inhaler), medical decision-making, and healthcare system understanding, such as how to solve potential problems encountered in the healthcare system.

HAP2 was approved by the University of Pennsylvania's Institutional Review Board. 295 adults with moderate to severe asthma completed two surveys at the beginning of a one year randomized clinical trial.^{5,6} Patients were recruited from practices serving urban low income neighborhoods and included family medicine, general internal medicine, pulmonary and allergy-immunology practices. Participants were at least 18 years old, had a diagnosis of asthma and reversible airflow obstruction, were prescribed an inhaled steroid, met criteria for moderate or severe asthma by NHLBI Guidelines and had a scheduled appointment with an asthma provider from a participating practice within the initial six months of participation in HAP2.^{5,6} Two surveys, the Navigating Ability (NAV2) and Inhaled Corticosteroids Knowledge (ICSK) questionnaires, were combined to create a face validated assessment of autonomy.⁷⁻⁹ The NAV2 consisted of 11 questions and the ICSK contained 10 questions so in combination a total 21-question assessment of autonomy was developed.

The original NAV2 questionnaire from Perez et al. consisted of 11 questions.⁷⁻⁹ The 11 questions in the original NAV2 had variable scoring of the answers. Questions could be scored by a yes (1) or no (0), some questions were scored using a range of 0-4, and others by 0-5 and the total number of correct responses were tallied for the 11 questions. As all questions in the NAV2 were determined to be related to different aspects of autonomy, the 11 questions in the NAV2 were rescored to have comparative weight for this project. Thus, the NAV2 items were rescored so all questions were rated on a scale of 0-5. The ICSK items were scored on a scale of 1-5. Thus, for this project, the NAV2 questionnaire had score range of 0-55 and ICSK questionnaire had a score range of 10-50. Total possible autonomy scores ranged from 10-105. The internal consistency was assessed using Cronbach alpha in addition to the correlation between the rescored NAV2 and ICSK subscales.

Baseline characteristics were ascertained by self-reporting at HAP2 enrollment. Functional health literacy was measured using the Short Test of Functional Health Literacy in Adults (S-TOFHLA).¹⁰ Depressive symptoms were evaluated using the Center for Epidemiological Studies-Depression (CES-D) screening assessment.¹¹ The relationship between autonomy scores and the number of comorbid conditions was assessed. There were 6 comorbidities included, namely obesity, diabetes, hypertension, hyperlipidemia, cancer, and depressive symptoms. These comorbidities were in addition to patients' asthma. Of note, patients with greater than 4 or more comorbidities were combined into one group, termed 4+, due to the fact that the patients in this study tended to have fewer comorbidities. In fact, only 6 patients reported 6 comorbidities.

A multivariable linear regression was performed on the derived autonomy score predicted by patient baseline characteristics. A positive regression coefficient denoted an increase in

autonomy score with an increase in the characteristic, whereas a negative coefficient corresponded to a decrease in autonomy score with an increase in the characteristic. Coefficients with p-value less than 0.05 were considered statistically significant. For characteristics with more than two levels, the Bonferroni correction was applied to individual pairwise comparisons when the omnibus test was statistically significant.

RESULTS

295 out of 312 HAP2 patients completed all questionnaires. Patient characteristics are enumerated in Table 1. The NAV2 and ICSK questionnaires with their scoring and associated dimensions of autonomy are depicted in Tables 2 and 3 respectively. Cronbach's alpha was calculated removing one item at a time. The alpha from these calculations ranged from 0.70-0.73 and the overall was 0.72. The closeness of these values suggests there are no inconsistent items that when removed from the scale improve the scale's internal consistency. The Pearson correlation coefficient between the revised NAV2 score and the ICSK score was 0.32. This finding was similar to that reported by Perez et al, which reported a correlation of 0.35.⁷ Thus, there was an association between higher levels of knowledge on the ICSK and higher scores on the NAV2.

As seen in Table 4, comparison found statistically significant differences in baseline autonomy scores in patients who reported Spanish as their primary language ($p=0.01$) and in those with either diabetes ($p=0.01$) or depressive symptoms ($p=0.03$) at -11.4 (95% CI, -20.5, -2.3), -4.8 (95% CI, -8.3, -1.3), and -3.1 (95% CI, -5.9, -0.3) points respectively. These values represent the difference across levels within a covariate. For example, the difference in model estimated mean autonomy scores in those without depressive symptoms (69.7) minus those with

depressive symptoms (66.6) yielded 3.1. Thus, patients with depressive symptoms had 3.1 points lower baseline autonomy scores compared to those without depressive symptoms. Non-Hispanic White participants on average had 8.2 (95% CI, 4.5, 12.0) points higher autonomy scores compared to non-Hispanic Black participants (Bonferroni adjusted $p < 0.01$). Comparison of the two additional race and ethnicity groups, namely Hispanic or Latino and Other, with non-Hispanic Black participants did not demonstrate a significant difference. Individuals with higher functional health literacy, as measured by S-TOFHLA, had higher autonomy scores (coefficient=0.24, 95% CI, 0.1, 0.4, $p < 0.01$). The Bonferroni adjusted p-value for race and ethnicity was statistically significant as described previously, however the Bonferroni adjusted p-value for education level was not. Model estimated mean autonomy scores based on patient characteristics are depicted in Figure 1. The relationships between autonomy scores and asthma related services, including hospitalizations in the past year and ER visits in the past year, were not statistically significant. Associations between autonomy scores and other characteristics were not found to be statistically significant.

DISCUSSION

We identified several notable differences in baseline autonomy based on patient characteristics in the studied population. A statistically significant increase in autonomy at baseline was noted with two characteristics, namely functional health literacy, as measured by S-TOFHLA, and non-Hispanic White participants. It is difficult to identify a single cause as to why the higher autonomy score was seen in non-Hispanic White participants compared to non-Hispanic Black participants. Socioeconomic, cultural, financial, or a combination of these factors may have contributed to this observed difference. In addition, this may be related to systemic

biases and reflect the different experiences various patient populations have when interacting with the healthcare system. Understanding why this difference was seen is crucial in the process of working towards a healthcare system that is just and equitable. The association of increased baseline autonomy with greater functional health literacy can be explained by the fact that patients who have an improved ability to understand health information are better able to process this information and make medical decisions based on their own values. Research into why there was variability in autonomy based on both health literacy and demographics and how these differences can be addressed ought to be the source of future investigations.

A statistically significant decrease in baseline autonomy was observed in patients who reported Spanish as their primary language, those with diabetes, and those with depressive symptoms. Regarding the correlation between those whose primary language was Spanish and decreased baseline autonomy, there are two notable provisions. In the study protocol, questions were read to patients in their preferred language and there were only 12 patients who reported Spanish as their primary language. Yet, we believe this association has important implications for autonomy. As questions were conveyed in each patient's preferred language, it is less likely the actual communication of the questions was the barrier. Autonomy is not defined by one or two encounters, but rather, by a lifetime of interactions with the healthcare system. This association suggests health information in other medical contexts may not be adequately conveyed to patients during their interactions with the healthcare system. The cumulative effect of these interactions may result in patients being provided with less information to use when making medical decisions. While a provider may believe he or she has explained the pertinent medical information, and thus provided patients with the information required to make an informed decision, perhaps this is not always the case. This unintended miscommunication can

have a wide-array of implications on a patient's health and autonomy. For example, it could lead to a situation in which a patient is making a decision without being fully aware of all available treatment options. This observation provides an opportunity for providers to rethink how they communicate with patients whose primary language is one other than English. Utilizing methods, such as a certified phone or video translator, connecting patients with physicians who speak their preferred language, or using a patient advocate who can communicate in real time with patients are possible ways to address this barrier. Future studies could examine if similar correlations are consistently seen in patients whose primary language was one other than English or Spanish.

There are several potential explanations as to why decreased baseline autonomy was seen in patients with diabetes and depressive symptoms. We considered the possibility that the additive effect of having more than one chronic condition, namely asthma plus diabetes and/or depressive symptoms, may have a negative impact on autonomy. Just as chronically ill patients become physically deconditioned over time, perhaps there could be a deconditioning of autonomy when a person has multiple chronic conditions. Being chronically ill can be mentally taxing, and so this could have the potential to impact on one's ability to make decisions.

We examined the relationship between autonomy scores and the number of comorbid conditions. As seen in Figure 2, there was a trend towards lower autonomy scores in patients with increasing comorbidities. Yet, analysis showed there was not a statistically significant relationship between autonomy scores and the number of comorbidities (F-statistic (4, 283)=1.33, $p=0.257$). Of note, patients in this study tended to have fewer comorbidities; only 6 patients reported having all 6 comorbidities. It is possible that different results may have been obtained if the study population included a greater proportion of patients with greater comorbidities. Further assessing the relationship between autonomy and the number of

comorbidities, particularly in a study population with a prevalence of higher comorbidities, could be a source of further investigation.

We did not identify if the patients with diabetes in this study were well or poorly controlled. If patients were poorly controlled, as mentioned above, it is possible the state of being chronically ill may have an impact on autonomy. Another possibility may be related to the interactions between patients with diabetes and their providers. While certainly not true in all clinical practices, in a healthcare system in which providers face increasing time constraints, there may be a tendency for providers to direct treatment plans. For example, the conversation may be “Your blood sugars have been high so we will increase your insulin glargine by 5 units.” rather than “Your blood sugars have been high. How do you think we can best address this problem?”. In the former conversation, patients are not provided an opportunity to engage in medical decision-making. In the second scenario, patients are given an opportunity to critically think and provide a treatment plan that is in accordance with their values. And if the proposed plan by the patient is less than ideal, it serves as an opportunity for education. While providers are seeking to avoid the harms of hyperglycemia, the former conversation may have a negative impact on autonomy. While this study and the preceding HAP2 trial focused on asthma control, rather on than diabetes management, autonomy is shaped by a lifetime of interactions that a patient has with the healthcare system and so prior conversations with medical providers about diabetes management may be able to, at least partially, explain why decreased autonomy was seen in patients with both asthma and diabetes. This relationship suggests the manner in which various comorbid conditions are managed may influence autonomy.

In the study, depressive symptoms were self-reported using a validated screening questionnaire.¹¹ Severity of these symptoms was not included as part of this study. It is possible

that severe and/or undertreated symptoms may have a negative effect on autonomy. The interplay between mental health and ethics is rapidly evolving and the relationship between mental health conditions and autonomy could be the source of future research endeavors. While the aforementioned theories are possible explanations for the association between decreased autonomy in patients with both asthma and either depressive symptoms or diabetes, additional investigation is needed to further illuminate these relationships. In addition, autonomy is a complex ethical principle and there is likely more than one explanation for the findings seen in this study.

It is notable that the relationships between autonomy and the other tested variables including age, gender, education level, history of hospitalization, history of Emergency Room visits, and other chronic conditions of obesity, hypertension, hyperlipidemia, and cancer were not found to be statistically significant. A possible explanation for this may be the sample size of 295 patients was not large enough to detect other differences. Another possibility is there is a unique aspect of the conditions of diabetes and depressive symptoms that when an individual has both asthma and diabetes or depressive symptoms the additive effect is a decrease in autonomy. It is also possible that a larger study may identify different relationships that were not seen in this study. With the goal of improving patient-centered care, studying relationships between patient characteristics and autonomy ought to be a source of future investigation.

A limitation of our study is our population was patients with moderate to severe asthma from practices serving low income neighborhoods and so our outcomes may not reflect other populations. In addition, income was not included as a covariate in this study as there was missing income data when patients self-reported their income. Thus, the direct relationship between income and autonomy was not studied in this project. An additional limitation was the

survey questions placed greater emphasis on assessing medication understanding in comparison to the other dimensions of autonomy. Yet, overall, the survey questions covered the key facets of autonomy, namely medical decision-making and health understanding.^{1,2} Additionally, these surveys assessed asthma medications and treatment protocols that were in place prior to the 2019 GINA asthma management guidelines.¹² Hence, a survey designed to reflect the treatment protocol of these new guidelines could be a source of future research. Another limitation of this study was the combination of the two questionnaires was only face validated as an assessment of autonomy. However, we feel this study was an important step in utilizing and developing techniques to understand and assess patient autonomy.

In this study, autonomy was measured using questionnaires. Using surveys to assess autonomy has been performed in other studies.^{2,13,14} Yet, autonomy is a complex principle and a more in-depth understanding of it could be obtained by utilizing multiple techniques in conjunction. This multifaceted approach could be the aim of future studies. Of note, while we focused on autonomy, further understanding of other ethical principles, especially in their relationship to Allergy and Immunology, ought to be areas of future research endeavors.

Physicians and other medical providers have done a great deal in terms of patient education and providing patients with the tools to understand and manage their health. Moreover, the emphasis on and value of shared decision-making as well as communication with patients are increasingly appreciated by providers even as they face more demanding time constraints. Highlighting the shortage of research relating the field of Allergy and Immunology with medical ethics is not a critique, but rather an opportunity for Allergists and Immunologists to consider how different ethical principles influence their clinical practice and treatment guidelines.

Understanding why there are differences in autonomy and identifying ways to address autonomy in various populations are steps to making healthcare more equitable.

By detecting differences in autonomy, we identified areas in which interventions and advocacy efforts can be developed to improve patient autonomy. Given the complexity of autonomy, more than one intervention, either simultaneously or sequentially, may be needed to improve autonomy for different populations. In addition, we hope this project encourages future research into the relationship between medical ethics and the specialty of Allergy and Immunology.

CONCLUSION

This study identified multiple patient characteristics, including comorbidities, demographics, and functional health literacy, that were associated with differences in autonomy. These associations may reflect differences in social, educational, and economic opportunities encountered by patients and ought to be the source of further investigation. With the aim of improving patient-centered care, a goal enumerated by the National Academy of Medicine, developing a comprehensive understanding of autonomy is essential. This study provided an initial step in the process of adjusting current and developing new guidelines and interventions to improve patient autonomy.

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Figure 1 Legend. Representation of the model estimated mean autonomy scores and 95% confidence intervals associated with selected patient characteristics. The mean scores were derived from responses to the 21-question autonomy assessment. The scores were derived based on predicted values from the estimated model. All categories included in this Figure had statistically significant differences in baseline autonomy based on patient characteristics.

Figure 2 Legend. Relationship between autonomy score and number of comorbidities (F-statistic (4, 283) = 1.33, $p=0.257$).

412 **Table 1.** Baseline characteristics of 295 participants^{5,6}

Characteristic	Level	Value
Age, mean (SD)	Age Range: 19-93 years old	51 (14)
Reading Comprehension Raw Score (0-36), median (IQR)*		34.0 (25.0, 35.0)
Gender	Female	207 (70.2%)
	Male	88 (29.8%)
Race and Ethnicity	1:Non-Hispanic Black/African American	196 (66.4%)
	2:Hispanic or Latino	24 (8.1%)
	3:Non-Hispanic White	64 (21.7%)
	4:Other: including American Indian/Alaskan Native, Asian, Native Hawaiian/Pacific Islander, or Declined	11 (3.7%)
Smoking Status	Never	149 (50.5%)
	Past	95 (32.2%)
	Current	51 (17.3%)
What is the LAST grade of school you completed?	Some high school or less	39 (13.2%)
	High school graduate or G.E.D.	92 (31.2%)
	Some college or trade school	77 (26.1%)
	College graduate	87 (29.5%)
What is your primary language?	English	279 (94.6%)
	Spanish	12 (4.1%)

	Other	4 (1.4%)
BMI	1:<18.5	1 (0.3%)
	2:18.5 to <30	112 (38.0%)
	3:30 to < 35	76 (25.8%)
	4:35 and 35+	106 (35.9%)
Diabetes	No	234 (79.3%)
	Yes	61 (20.7%)
Hypertension or High Blood Pressure	No	140 (47.5%)
	Yes	155 (52.5%)
Hyperlipidemia or High Cholesterol	No	193 (65.4%)
	Yes	102 (34.6%)
Cancer	No	274 (92.9%)
	Yes	21 (7.1%)
Depressive Symptoms^	No	180 (61.0%)
	Yes	115 (39.0%)
Number of comorbidities, median (IQR)		2.0 (1.0, 3.0)
	0	35 (11.9%)
	1	60 (20.3%)
	2	89 (30.2%)
	3	63 (21.4%)
	4+	48 (16.3%)
Hospitalized in last 12 months	No	207 (70.2%)

	Yes	88 (29.8%)
ER visit in last 12 months	No	165 (55.9%)
	Yes	130 (44.1%)

*Measured by Short-Test of Functional Health Literacy in Adults (S-TOFHLA)

^Measured by the Center for Epidemiological Studies-Depression (CES-D). CES-D is a screening questionnaire, scores range from 0-60 and a score greater than or equal to 16 indicates increased risk of depression. It is not diagnostic of depression. Patients with a score 16 or higher were given further questions and if concern persisted the patient's medical team was contacted.¹¹

420 **Table 2.** Navigating Ability questionnaire and associated dimension(s) of autonomy*

	Score [^]	Responses [†]	Dimension(s) of Autonomy
1. Patient lists all asthma medication names correctly.	Correct: 5	233 (79.0%)	Medication understanding
	Incorrect: 0	62 (21.0%)	
2. Patient correctly recites number of times a day required to take inhaled steroid.	Correct: 5	265 (89.8%)	Medication understanding
	Incorrect: 0	30 (10.2%)	
3. Patient correctly recites number of puffs of inhaled steroid per unit of time.	Correct: 5	255 (86.4%)	Medication understanding
	Incorrect: 0	40 (13.6%)	
4. Patient can correctly name which of their medications is a controller and which is a reliever.	Correct: 5	225 (76.3%)	Medication and disease state understanding
	Incorrect: 0	70 (23.7%)	
5. Patient can recite action plan.	Correct: 5	92 (31.2%)	Medical decision-making, medication and disease state understanding
	Incorrect: 0	203 (68.8%)	
6. Ask patient: "What is a copay" Correct answer: A copay is the portion I pay for a medical visit or medication that insurance doesn't cover. (Participant must indicate: I pay; not covered by insurance; for medical visit or	Correct: 5	173 (58.6%)	Healthcare system understanding
	Incorrect: 0	122 (41.4%)	

medication or procedure)			
7. Ask patient: “If you were unsure of the amount of your copay, what is the best way to find out how much it is?” Read choices and ask patient to choose the best response. a. Call the insurance company b. Ask the receptionist c. Ask the doctor d. Ask a friend e. Other Correct answer: a. Call the insurance company	Correct: 5	199 (67.5%)	Healthcare system understanding, medical decision-making
	Incorrect: 0	96 (32.5%)	
8. Ask patient: “If your doctor prescribes a medicine that your health insurance does not cover, what would you do?” Read choices and ask patient to choose the best response. a. Call the doctor’s office b. Wait until next visit, scheduled in a month c. Borrow from a friend or family member d. Do nothing e. Substitute another medicine Correct answer: a. Call the doctor’s office	Correct: 5	233 (79.0%)	Healthcare system understanding, medical decision-making
	Incorrect: 0	62 (21.0%)	

9. Ask patient: “You are accompanying a friend to his/her first visit to a new primary care provider. Your friend was recently hospitalized. What would he/she need to bring to that visit?” Do not read options. a. Insurance card b. ID c. Medications/list of medications d. Records and/or test results The sum of “yes” responses will be the score.	Score range: 0-4	2.0 (1.0, 3.0)	Healthcare system understanding, medical decision-making
10a. Ask patient: You were seen by the doctor for a cough. You were given a medication for the cough. The cough does not go away. You are going to a follow-up visit for the cough. What could you do to prepare for the visit? Do not read options. 1. Write down or prepare questions 2. Make a list of symptoms 3. Know medications taken 4. List problems with medications 5. Other reasonable option (eg, bring any tests or records sine you had the initial visit) The sum of “yes” responses will be the score.	Score range: 0-5	1.0 (0.0, 1.0)	Medical decision-making, medication understanding

10b. Ask patient: “What could you do to remember the details of the visit?” Do not read options 1. Take notes at the visit 2. Ask questions at the end of the visit 3. Look at the visit summary 4. Bring a family member or a friend The sum of “yes” responses will be the score.	Score range: 0-4	1.0 (1.0, 1.0)	Medical decision-making
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*Questionnaire and scoring adapted from Perez, et al.⁷

^Correct responses were scored at 5. Incorrect responses were scored at 0.

†For questions 9-10b, responses reported as median (IQR)

Table 3. Inhaled Corticosteroids Knowledge questionnaire and associated dimension(s) of autonomy*

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false	Responses [^]	Dimension(s) of Autonomy
1. Inhaled steroids make airway muscles relax.	1	2	3	4	5	2.0 (1.0, 3.0)	Medication understanding
2. Inhaled steroids work by fighting inflammation.	5	4	3	2	1	1.0 (1.0, 2.0)	Medication understanding
3. Inhaled steroids work by fighting infection.	1	2	3	4	5	4.0 (3.0, 5.0)	Medication understanding

4. The full effect of inhaled steroids depends on regular use and may take days to work.	5	4	3	2	1	2.0 (1.0, 2.0)	Medication and disease state understanding
5. Inhaled steroids make you gain weight.	1	2	3	4	5	3.0 (1.0, 4.0)	Medication understanding
6. When you use inhaled steroids, your wheeze or chest tightness gets better immediately.	1	2	3	4	5	3.0 (2.0, 5.0)	Medication and disease state understanding
7. The full effect of inhaled steroids begins immediately.	1	2	3	4	5	4.0 (2.0, 5.0)	Medication and disease state understanding
8. Even if I have no symptoms from asthma, I should take [say rescue/reliever inhaler they are prescribed]	1	2	3	4	5	4.0 (1.0, 5.0)	Medical decision-making, medication and disease state understanding

everyday so that I can stop asthma attacks from starting.							
9. Even if I have no symptoms from asthma, I should take [say ICS they are prescribed] everyday so that I can stop asthma attacks from starting.	5	4	3	2	1	1.0 (1.0, 2.0)	Medical decision-making, medication and disease state understanding
10. [Say ICS they are prescribed] should be taken only when I have asthma symptoms.	1	2	3	4	5	5.0 (4.0, 5.0)	Medical decision-making, medication and disease state understanding

*Questionnaire and scoring adapted from Perez, et al.⁷ For each question, increased knowledge results in a higher score.

^Responses reported as median (IQR)

Table 4. Outcomes of multivariable linear regression performed on the derived autonomy score predicted by patient baseline characteristics

Baseline Characteristic	Coefficient	Std. Err.	t or F test statistic	p-value	95% confidence interval		Standardized coefficients
Age	-0.02	0.06	-0.34	0.74	-0.13	0.09	-0.020
Functional health literacy*	0.24	0.07	3.24	<0.01	0.10	0.39	0.192
Gender							
Female	Ref						
Male	-0.02	1.54	-0.01	0.99	-3.05	3.01	-0.001
Race and ethnicity							
Non-Hispanic Black/African American	Ref		6.83	<0.01			
Hispanic or Latino	1.68	3.34			-4.90	8.26	0.035
Non-Hispanic White	8.22	1.90			4.49	11.96	0.256
Other	-2.28	3.49			-9.16	4.59	-0.033
Smoking status							
Never	Ref		1.57	0.21			
Past	-1.94	1.55			-4.99	1.11	-0.069
Current	1.00	1.86			-2.66	4.66	0.029
Education level							
Some high school or less	Ref		4.09	<0.01 [†]			
High school graduate or G.E.D.	1.56	2.21			-2.79	5.92	0.055
Some college or trade school	6.17	2.38			1.48	10.86	0.205
College graduate	6.43	2.47			1.56	11.29	0.221
Primary Language							
English	Ref						
Spanish	-11.42	4.62	-2.47	0.01	-20.51	-2.33	-0.170
BMI category							
<18.5	Ref		1.19	0.31			
2:18.5 to <30	-15.30	11.26			-37.48	6.87	-0.561
3:30 to < 35	-15.94	11.26			-38.11	6.24	-0.526
4:35 and 35+	-13.65	11.24			-35.77	8.48	-0.494
Comorbidity							
Diabetes	-4.83	1.78	-2.72	0.01	-8.32	-1.33	-0.148
Hypertension	-0.94	1.47	-0.63	0.53	-3.84	1.97	-0.035
Hyperlipidemia	1.88	1.54	1.22	0.22	-1.15	4.90	0.067
Cancer	-2.15	2.59	-0.83	0.41	-7.24	2.94	-0.042

Depressive Symptoms [^]	-3.10	1.40	-2.22	0.03	-5.85	-0.35	-0.114
Asthma related service use in the past year							
Hospitalization	2.67	1.72	1.56	0.12	-0.71	6.05	0.092
ER visit	0.12	1.60	0.07	0.94	-3.03	3.27	0.004

434 *Measured by Short-Test of Functional Health Literacy in Adults (S-TOFHLA)

435 [^]Measured by the Center for Epidemiological Studies-Depression (CES-D)

436 †Overall p-value for education level is significant, however the Bonferroni adjusted pairwise comparisons

437 are not

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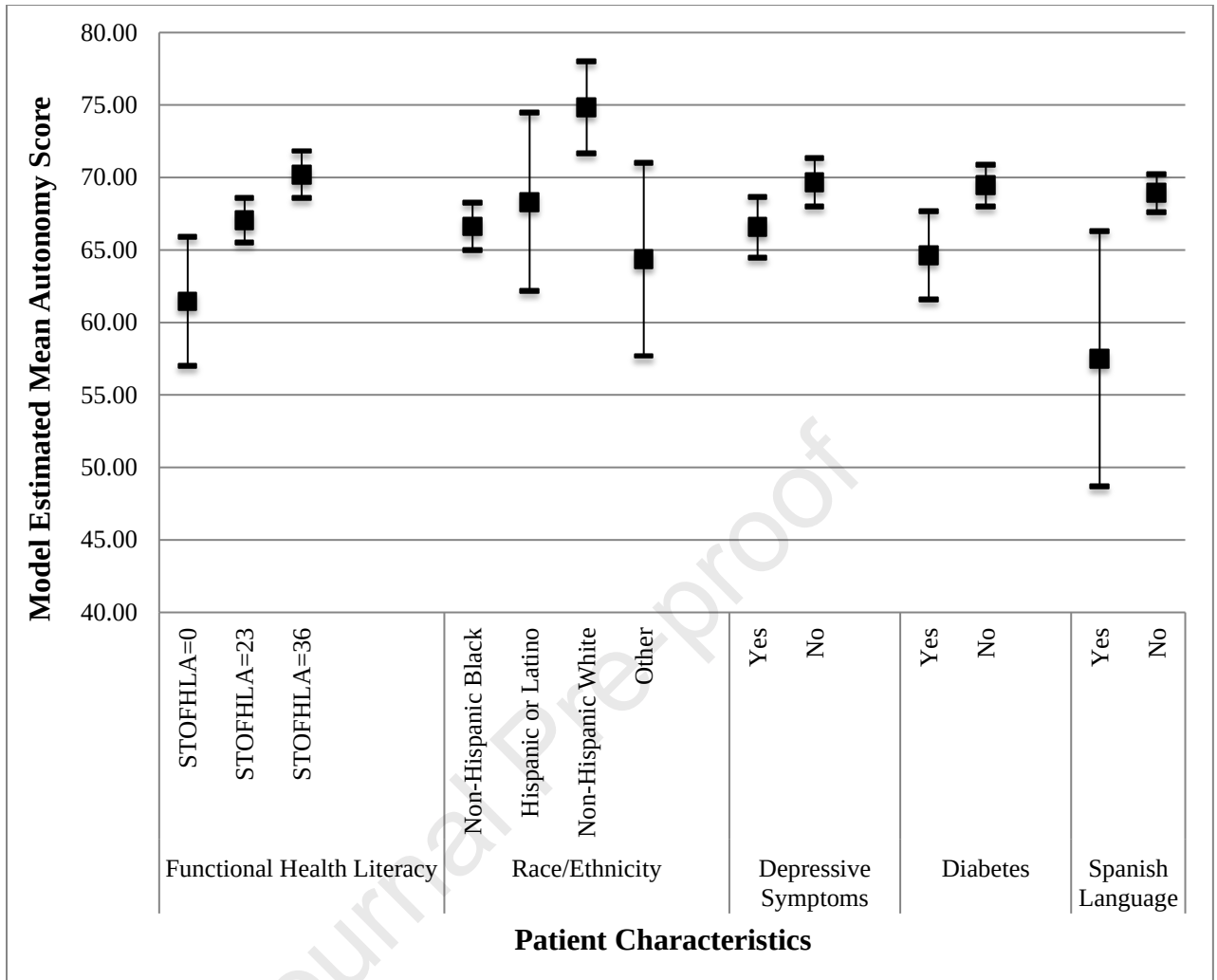


Figure 1. Representation of the model estimated mean autonomy scores and 95% confidence intervals associated with selected patient characteristics. The mean scores were derived from responses to the 21-question autonomy assessment. The scores were derived based on predicted values from the estimated model. All categories included in this Figure had statistically significant differences in baseline autonomy based on patient characteristics.

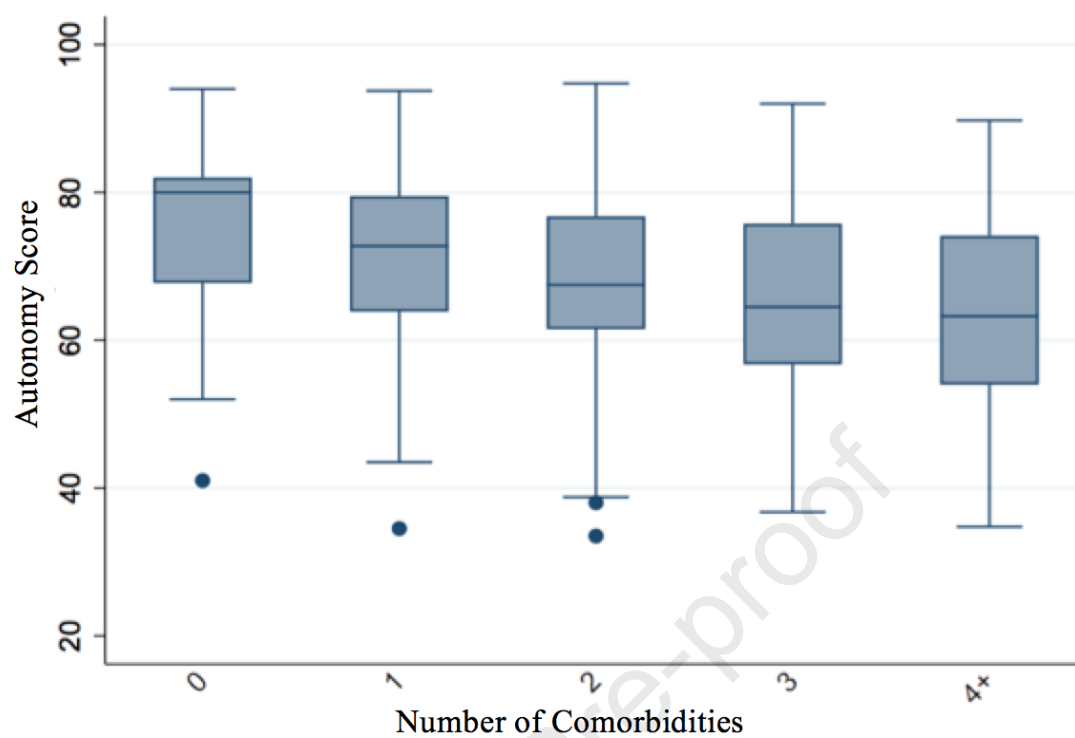


Figure 2. Relationship between autonomy score and number of comorbidities (F-statistic (4, 283)=1.33, $p=0.257$).