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An Exploration of Medical Mistrust in Urban African American Adolescents with High-risk Asthma

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Abstract

Background

Little is known about the relationship between medical mistrust and health outcomes in adolescents, particularly minority adolescents with chronic illness. This study explored medical mistrust in African American adolescents with high-risk asthma and their caregivers. Asthma is currently the leading pediatric chronic respiratory condition in the United States, and disproportionately affects urban, disadvantaged, minority children.

Methods:

This study is a cross-sectional descriptive secondary analysis that enrolled caregiver-adolescent dyads of African American individuals with high-risk asthma.

Results:

Medical mistrust levels increased with adolescent age, and males had higher mistrust scores than females. Caregivers with lower educational achievement and lower household income had higher medical mistrust scores. Adolescent medical mistrust scores and adolescent trust in provider scores were inversely related. Adolescent trust and caregiver trust were positively correlated, with similar scores noted. A negative correlation was found between caregiver medical mistrust and adolescent trust in their provider. Medical mistrust did predict poor asthma control. A negative correlation was found between caregiver medical mistrust levels and emergency visits for asthma.

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Conclusion:

This study has provided novel findings as the first documented study of intergenerational medical mistrust among urban minority adolescents with high-risk asthma. Study findings indicate that the phenomenon of medical mistrust is complex in nature and affects health outcomes. More detailed research study approaches are required in the future.

Keywords: Medical mistrust, asthma, adolescent, caregiver, intergenerational

1. Introduction

Little is known about the relationship between medical mistrust (MM) and health outcomes in adolescents, particularly minority adolescents with chronic illness. There is also a paucity in knowledge on the relationship between caregivers' trust and mistrust in a healthcare provider and if these two concepts are similar or dissimilar in their adolescent's beliefs. To address this gap in research, this study aims to explore MM in African American (AA) adolescents with high-risk asthma and their caregivers. Asthma is currently the leading pediatric chronic respiratory condition in the United States, and disproportionately affects urban, disadvantaged, minority children. Minority adolescents with asthma are at highest risk for increased morbidity and mortality [1].

Medical mistrust (MM) in healthcare providers and the medical system has been shown to be a deterrent to patients' healthcare utilization and ability to successfully manage their illnesses long term [2-4]. Medical mistrust has been identified as a significant contributor to poor health outcomes in varied populations of patients, such as AA, Hispanic, HIV positive individuals, and sexual minorities [5-15]. It has also demonstrated correlation to higher emergency department (ED) utilization, lower rates of preventive services, and fewer health seeking behaviors [16]. Medical mistrust is more specifically defined as a "lack of confidence in medical techniques, as well as beliefs that members of certain ethnic groups do not receive accurate medical information, are treated insensitively, and receive inferior care compared to other groups" [15]. Adolescents are among the medically underserved in the United States [17] and have the lowest rates of primary health care use of any age group [18-20]. The primary objective of this study was to explore medical mistrust among AA adolescents with high-risk asthma and their primary caregivers, by comparing medical mistrust between both groups of participants, and exploring associations between MM, asthma knowledge, asthma self-management, asthma related health outcomes and adolescents' emergency department utilization for acute asthma sick visits. Three specific aims guided the study objective:

Aim 1: To explore the levels of medical mistrust and trust in providers among urban African American adolescents with high-risk asthma and their primary caregiver.

Aim 2: To examine and compare the relationships between medical mistrust, trust in providers and asthma-related knowledge, medication adherence, symptom assessment and health outcomes

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(asthma control) among urban African American adolescents with high-risk asthma and their primary caregiver.

Aim 3: To examine if the presence of trust and medical mistrust in the caregiver of the African American adolescent with high-risk asthma is associated with healthcare utilization, specifically ED visits, for asthma.

2. Methods

This study is a cross-sectional descriptive analysis of the parent study, an R01 clinical trial (registry number NCT 03317977) and was guided by the Andersen Behavioral Model for Vulnerable Populations theoretical framework. Inclusion criteria required that participants be African American adolescents aged 12 years, 0 months to 16 years 11 months, with moderate to severe persistent poorly controlled asthma and have had 2 or more ED visits or hospitalizations in the previous 12 months. All eligible patients were recruited from the emergency department of a tertiary pediatric facility in Detroit. In addition to the surveys administered as part of the parent study, several other validated self-response tools were added. These tools measure race based medical mistrust (Group Based Medical Mistrust Scale) [15] and patient trust in providers (Trust in Providers Scale) [21] and parental trust in their child's provider (Pedi-TIPS Scale) [22]. The Family Asthma Management Scale (FAMSS) evaluates asthma management in families [23] utilizing eight subscales. The specific FAMSS subscales that were examined in this study include asthma knowledge of both the adolescent and the caregiver, asthma medication adherence, environmental control and asthma symptom assessment. Adolescent asthma control was measured utilizing the Asthma Control Test [24]. Emergency department utilization for asthma visits, adolescent missed days of school and caregiver missed days of work due to asthma were measured utilizing an investigator developed self-report survey. Statistical analyses included multiple linear regression analysis, Pearson correlation analysis and independent sample t-test. This study was approved by the Wayne State University Institutional Review Board.

3. Results

The study sample represented a sub-set of participants from the R01 parent project, consisting of nineteen urban African American caregiver-adolescent dyads with high-risk asthma. In the sample of adolescents, 9 were male and 10 were female, with ages ranging from 12 years old to 16 years old and a mean age of 14 years (SD = 1.2). Results also show the socio-demographic details of the caregivers with mean caregiver age of 43.5 years (SD = 6.4 years. All caregivers in the study were female and they all identified as African American ethnicity. The majority of caregivers (73.6%) had a high school education. On average, caregivers reported missing 3.1 days (SD = 4.2) of work either completely or partially over a past 3-month period due to their child's asthma. Average reported caregiver income was noted to be $13, 268/year. Table 1 displays the demographic details of the study cohort.

On average, participants missed 3.8 school days (SD = 6.5) due to asthma-related issues, with a maximum of 27 days over a period of 3 months. The average number of asthma-related

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emergency visits was 1.8 visits (SD = 1.37), with most participants (N= 47.3%) experiencing two emergency asthma-related visits over a period of 3 months.

Adolescents demonstrated a moderate level of medical mistrust. The mean score of the group was 31.25 (SD = 6.87) with a minimum score of 12 and a maximum score of 51. Male adolescents had higher MM scores than female adolescents. Most caregiver participants were also found to have a moderate level of medical mistrust. The mean caregiver score on Group Based Medical Mistrust Scale (GBMMS) was similar to the adolescent score 31.02 (SD = 7.23) and there was no significant difference noted during a paired samples t-test analysis between groups ($t(18) = -0.304$, $p = 0.765$.) as demonstrated in Table 2. It was also found that the scale had moderate level of reliability when administered to adolescents (Cronbach $\alpha = 0.68$) and adults (Cronbach $\alpha = 0.78$). Descriptive statistics of study variables can be found in Table 3.

To determine if sociodemographic characteristics of African American adolescents with high-risk asthma and their caregivers predict medical mistrust (Table 4) and trust in their personal healthcare providers (Table 5), a multiple linear regression analysis was conducted. The sociodemographic variables examined were adolescent age and gender, as well as caregiver education and income. Results were not statistically significant due to sample size; however, as adolescents increased in age, MM scores increased as well. Caregivers with lower educational achievement and lower household income had higher MM scores than caregivers with higher education achievement and higher household incomes. An inverse relationship was noted between adolescent MM scores and adolescent trust in provider (TIPS) scores. Adolescent trust and caregiver trust were positively correlated, with similar scores noted. Caregiver MM scores in their own adult healthcare provider and adolescent MM scores in their pediatric provider were not correlated. A negative correlation was found between caregiver MM and adolescent trust in their provider.

To answer the second aim, a linear regression analysis was employed (Table 6) to test if medical mistrust significantly predicted asthma outcomes. MM did not predict asthma knowledge, medication adherence, symptom assessment or environmental control. However, the regression model of medical mistrust predicting asthma control was statistically significant, explaining 15% of the variation in the dependent variables, $R^2 = .21$, $F = 4.61$, $p = .047$. Results further showed that medical mistrust significantly predicts asthma control, $B = .52$, $\beta = .46$, $t = 2.15$, $p < .05$. The average total FAMSS scale mean was 6.26 (SD =2.30), which shows that on average family units had good asthma management. The analysis of different sub-scales of FAMSS scale showed that participants had a moderate level of asthma related knowledge 5.41 (SD = 1.81), moderate level of medication adherence 5.29 (SD = 2.14) moderate score on symptom assessment 6.21 (SD = 1.72) and poor environment control 3.76 (SD = 2.68).

To address the third aim and examine whether MM in the caregiver of the AA adolescent with high-risk asthma is associated with healthcare utilization, specifically ED visits for asthma exacerbation, a Pearson correlation was conducted. Although not statistically significant ($r = 0.04$, $p = .92$), results of the analysis revealed that a negative weak association exists between

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caregiver MM and emergency department utilization for asthma, revealing that if caregiver MM increases, the frequency of visits to hospital emergency department decreases. A positive association was found between caregiver trust in the adolescent's pediatrician and emergency department visits for asthma.

Table 1 Descriptive statistics for Adolescent and Caregiver Participants (N=19)

Sample characteristics		
Adolescent	N	%
Gender		
Male	9	47.3
Female	10	52.6
Age (Mean, S.D) [Range]	14, 1.2 [12-16]	
No of school days missed in past 3 months (Mean, S.D) [Range]	3.8, 6.5 [0-27]	
Number of years child has had asthma (Mean, S.D) [Range]	11.84, 3.9 [3-16]	
Asthma related emergency department visits in past 3 months (Mean, S.D) [Range]	1.8, 1.37 [0-5]	
Asthma related emergency visits		
0	3	4.9
1 to 3 visits	11	6.0
5	1	1.6
Number of days inhaler used in past 4 weeks (Mean, S.D) [Range]	3.2, 1.6 [1-5]	
Asthma control in past 4 weeks		
Uncontrolled	9	47.3
Controlled	10	52.6
Caregivers	N	%
Age (Mean, S.D) [Range]	43.5, 6.4 [35-54]	
Education (Mean, S.D) [Range]	12.47,1.5 [11-17]	
High school (grades 9 through 12)	14	73.6
Bachelor's degree	5	26
Ethnicity: African American	19	100
No of days missed at work completely/ partially over past 3	3.1, 4.2	

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months	
Annual Family Income (Mean)	13, 268

Table 2 Paired samples t-test results for GBMMS subscale scores between caregiver and adolescent

	Paired Differences				
	M	SD	T	p	df
Variables					
GBMMS total	31.02	7.13	-0.304	0.765	18
GBMMS_T total	31.25	6.87			
Suspicion		0.284	0.780	18	
Caregiver	13.37	5.71			
Adolescent	12.79	6.15			
Group Disparities		3.968	<0.001	18	
Caregiver	14.99	2.31			
Adolescent	11.74	3.02			
Lack of Support		0.040	0.360	18	
Caregiver	8.42	2.52			
Adolescent	7.79	1.61			

*p<0.05

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Table 3 Descriptive statistics of study variables

Scales	Mean (S.D) score Caregiver	Mean (S.D) score Adolescents
GBMSS	31.02 (7.13)	31.25 (6.87)
TIPS		36.30 (4.56)
ACT		20.21 (5.46)
SUQ		7.16 (8.85)
Pedi-TIPS	35.59 (3.57)	
FAMSS	6.26 (2.30)	
-Asthma Knowledge	5.41 (1.81)	
-Medication adherence	5.29 (2.14)	
-Symptom assessment	6.21 (1.72)	
-Environmental control	3.76 (2.68)	

GBMMS=Group Based Medical Mistrust Scale; Pedi-TIPS=Pediatric Trust in Provider Scale; ACT=Asthma Control Act; FAMSS=Family Asthma Management Scale; SUQ= Service Utilization Questionnaire; TIPS = Trust in Providers Scale; GBMMS_T = Group Based Medical Mistrust Scale completed by adolescent

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Table 4 Regression Analysis Demographic Variables Predicting Group Based Medical Mistrust

Variables	B	SE B	Beta	T	p value
Age (adolescent)	1.139	1.12	5.44	1.01	0.32
Gender (adolescent)	-0.997	2.89	-11.22	-0.34	0.73
Education (caregiver)	-1.056	1.244	-3.93	-0.84	0.41
Income (caregiver)	-1.306	0.977	-4.48	-1.33	0.20
R^2= 0.37, F = 1.53, p = 0.24					

Note: B: Unstandardized Regression Coefficient
SEB: Standard Error
Beta: Standardized Regression Coefficient

Table 5 Regression Analysis of Demographic Variables Predicting Trust in Providers

Variables	B	SE B	Beta	t	p value
Age (adolescent)	1.039	1.069	0.226	0.972	0.35
Gender (adolescent)	-4.005	2.50	-0.37	-1.60	0.13
Education (caregiver)	0.451	0.859	0.165	0.53	0.61
Income (caregiver)	-0.487	0.788	-0.193	-0.62	0.55
R^2= 0.23, F = 1.02, p = 0.43					

Note: B: Unstandardized Regression Coefficient

SEB: Standard Error

Beta: Standardized Regression Coefficient

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Table 6 Linear regression results determining the effect of medical mistrust on asthma related outcomes

Variables	Asthma knowledge		Medication Adherence		Symptom Assessment		Environmental Control		Asthma Control	
	R^2(.05) F(.94)= .35		R^2(.01), F(.14)= .71		R^2(.04) F(.54)= .47		R^2(.15) F(2.62) =.13		R^2(.21) F(4.61)=.047*	
	β	t	β	t	β	t	β	t	β	t
GBMMS_T	.84	.90	-.28	-.38	.68	.74	-.90	-1.62	.52	2.15
Gender	-.18	-.72	-.21	-.82	-.22	-.88	.34	1.53	.22	.93

*p<0.05

GBMMS_T = adolescent medical mistrust

4. Discussion

This is the first study that we are aware of to use the GBMMS with urban-dwelling, ethnic minority adolescents with severe chronic illness. This is also the first study to compare group based medical mistrust to trust in healthcare providers in both an intergenerational cohort and in African American adolescents with asthma, whereas previously only caregivers had been examined in this regard [25]. Not only does this study compare intrapersonal group based medical mistrust to trust for both the adolescent and caregiver, but also uniquely interpersonally compares both trust and group based medical mistrust in the caregiver to that of the adolescent under their care. Additionally, this study examined one participant type's (caregiver's) medical mistrust and trust for two separate healthcare providers: their personal adult provider and their child's pediatrician. These unique angles of intergenerational medical mistrust have not been previously studied.

4.1 Limitations

This study's results should be interpreted in the context of multiple limitations. The small sample size, convenience sampling technique, and narrow age range of the adolescents examined in this study (average age being 14 years old) effect the external validity and the ability to generalize the findings of this study to the broader population of adolescents who are seen for asthma care in emergency department settings. As this population was an urban African American sample, it may not be generalizable to rural or suburban African American adolescents with high-risk asthma and their caregivers. Additionally, because it is a cross-sectional sample, it limits the ability to draw any causal inferences. Another limitation is that the parent study was conducted

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during the peak COVID-19 pandemic, thus limiting contact with participants and relied heavily on participant motivation, leading to a small number of dyads recruited, with the parent study consisting of only 57 participants in total. Additionally, due to pandemic restrictions, all data was collected via electronic surveys, which may have further narrowed the pool of eligible individuals who could have participated, particularly if they lacked the technology at home required to complete study questionnaires.

4.2 Implications for Health Behavior Research

This study has furthered the medical mistrust literature by examining the impact of intergenerational transmission of medical mistrust to adolescents and on chronic illness related health behaviors. As study findings indicate that medical mistrust significantly impacted asthma control in the adolescent, this is a new finding for the asthma literature, indicating that medical mistrust should be considered as a predictor of asthma control in future studies. As a result, aside from healthcare providers, these findings are pertinent to psychologists, social workers, researchers, and healthcare policy makers who are interested in improving disparate chronic disease related health behaviors.

Healthcare providers should use these results to consider the influence of intergenerational medical mistrust on asthma control in adolescents, with particular consideration given to education about asthma medication adherence. The caregiver's level of mistrust should also be considered and addressed by the healthcare provider at healthcare visits.

Future research is needed to extend the current study results, including utilizing mixed methods research, replicating findings in a larger, more diverse sample to ensure the generalizability of findings, and investigating change in MM over time, especially in developing adolescents across various adolescent ages. These future research studies should focus on qualitatively understanding how adolescents conceptualize medical mistrust and also examine adolescent medical mistrust towards non-physician healthcare providers, such as nurse practitioners. A key consideration in measuring medical mistrust is that the developmental stage of the adolescent can change the way researchers can reliably measure medical mistrust. New instruments to measure medical mistrust may need to be developed that are unique to adolescents.

Future studies should be inclusive of participants dwelling in non-urban areas, as well as those in urban areas, with uncontrolled asthma. The role of different mediating and moderating factors have not been explored, such as poor asthma control, on the relationship between medical mistrust and hospital emergency visits. As there was no comparator group in this study, the experiences of African American adolescents with asthma and their caregivers cannot be compared with other racial ethnic minorities. The inclusion of participants from multiple racial and ethnic backgrounds in future studies will allow for a broader overview and reflect different lived experiences and health related outcomes.

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4.3 Discussion Questions

How should existing developmental theories and research frameworks be modified to include the intergenerational transmission of medical mistrust?

How should healthcare providers address medical mistrust in adolescents? Should it be solely through changing their own actions and behaviors, or should healthcare providers also start including interpersonal medical mistrust reduction interventions at healthcare visits during the adolescent period?

5. Conclusion

This study has provided novel findings that have the potential to contribute to the frontier of examining the development of and various aspects of medical mistrust in youth with chronic illnesses. Healthcare providers should focus on developing targeted interventions to mitigate medical mistrust, improve asthma related health outcomes, and to advance health equity in asthma care.

Abbreviations

AA: African American

GBMMS: Group Based Medical Mistrust

MM: Medical mistrust

TIPS: Trust in Providers

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Author contributions

MS: Conceptualization, Investigation, Writing-original draft, Analyses, Writing-review & editing. DE: Conceptualization, Investigation, Writing-review & editing. RB: Validation, Writing-review & editing. HY: Analyses & editing. WGS: Conceptualization, Investigation, Writing-review & editing, and Supervision. All authors read and approved the submitted version.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Ethical approval **This study was approved by the Wayne State University Institutional Review Board, #071217MP2E.**

Consent to participate

Informed consent to participate in the study was obtained from all participants.

Consent to publication **Not applicable**
Availability of data and materials Not applicable
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