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"Looking out for Each Other" A Qualitative Study on the Role of Social Network Interactions in Asthma Management among Adult Latino Patients Presenting to an Emergency Department

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Abstract

The **objective** of this study was to identify the types of interactions between asthma patients and their social networks such as close family and friends that influence the management of asthma.

Methods—Participants were Latino adults presenting for a repeat visit to the emergency department for asthma treatment. Qualitative interviews were conducted with 76 participants. They were asked to describe the experiences of their social networks that have asthma and how interactions with these individuals influenced their own asthma management. Responses were transcribed and analyzed using Grounded Theory as a qualitative analytic approach. Responses were assigned codes; similar codes were grouped into concepts and then categorized to form overarching themes.

Results—Four themes emerged: 1) Perceptions of severity of asthma may be based on the experiences of social networks; 2) Economic factors may contribute to the sharing and borrowing of asthma medications between patients and their social networks; 3) Economic factors may contribute to using home remedies instead of prescribed medications; 4) Social network members may be unaware of the factors that trigger asthma and therefore, contribute to asthma exacerbations.

Conclusion—This study identified important social network interactions that may impact asthma management in Latino adults. These results can be used to broaden the current focus of asthma self-management programs to incorporate discussions on the role of social networks. A focus on social network interactions addresses the social epidemiology of asthma and advances our understanding of root causes that may underlie the high prevalence of asthma in many Latino communities.

Keywords

Asthma; Latino; social networks; access; culture

Declaration of interest

We have no financial or personal disclosures that would bias this study.

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INTRODUCTION

Asthma affects approximately 18 million adults [1, 2]. Adults with asthma are more likely to be unemployed, have a greater number of sick days, and are more likely to report limitations in work related activities [1, 3]. Adults with asthma also experience a greater burden of comorbid mental illness [4, 5]. Total medical expenditures attributed to adult asthma are approximately $18 billion, of which $10 billion are attributed to direct medical cost [1, 6]. Hospitalizations and emergency department (ED) visits are significant contributors to the cost of asthma. Among adults with asthma, the number of emergency department visits is estimated at 1.1 million and the number of hospitalizations at almost 300,000 [7]. Therefore, asthma is a costly condition that exerts a significant toll on the economy and a personal toll in terms of productivity and quality of life.

Racial and ethnic minorities and those residing in low income communities have a higher prevalence of asthma and have more visits to the ED for asthma [8, 9]. In particular, Latinos have one of the highest rates of asthma. Latinos are 30 percent more likely to visit the hospital for asthma as compared to non-Latino or non-Hispanic Whites. Latinos are also more likely to present to the ED with asthma as a first listed diagnosis yet, less likely to be taking preventative medications for asthma [10, 11]. Latinos are the fastest growing and youngest ethnic group in the US. By 2050, approximately 25% of the US population is expected to be comprised of Latinos [12]. As the number of Latinos continues to increase in the U.S., understanding the factors that contribute to higher patterns of utilization for asthma will become an even greater public health imperative. These factors provide a backdrop and compelling rationale for focusing on Latinos in this study.

The prevalence, morbidity, and mortality for asthma differ among Latinos by country of origin. The prevalence is highest in Puerto Ricans, followed by Dominicans and Cubans, and lowest in Mexicans and Central Americans [13]. The variable rates of asthma observed among different Latinos groups may reflect differences in acculturation, early life exposures, or genetic-environmental and social interactions [14, 15].

When caring for Latino adults with asthma, an important social context to consider is the role of the family and social network interactions. Studies have documented the beneficial impact of supportive social ties and social network interactions on health [16, 17]. However, the health benefits may only be evident within specific social network contexts or attributed to only certain interactions. In fact, some interactions between patients and members of their family or social networks may prove to be detrimental despite noble intentions [18–21] [22]. The importance of family and social network interactions in the Latino culture is highlighted by the commonly used word '*familismo*' a term used to emphasize the importance placed on family. Familismo defines the interdependent relationship among social networks, nuclear and extended family members for support [23]. This study will contribute to the existing literature on asthma by advancing our understanding of mechanisms by which social interactions may contribute to asthma in Latino adults. The objective of this study was to identify the types of interactions between asthma patients and their social networks that may influence asthma self-management and that may in part, contribute to the higher healthcare utilization observed in some Latino communities.

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METHODS

This qualitative portion was nested within a larger quantitative study that was focused on identifying characteristics of patients with asthma who had frequent visits to an emergency department (ED) in the South Bronx, New York. A total of 192 patients met eligibility criteria, were consented, and recruited for the larger study. The analyses that are described in this paper focus on Latino adults because they were the predominant ethnic group presenting to this emergency department with asthma. For this qualitative portion, participants identified themselves as either Latino or Hispanic; were adults over 18; and were seen for a repeat visit to the ED during the past 12 months. A total of 192 participants were enrolled in the parent study and 103 (54%) were Latino adults. Of the 103 Latino adults, 76 completed qualitative interviews on their social networks' experiences with asthma and were included in these analyses.

Prospective participants were approached, consented, and interviewed while they were receiving treatment for asthma in the emergency department or after they were admitted to the inpatient service for the treatment of asthma. A semi-structured interview format was used. Participants were guided using specific probes. They were asked to describe their personal experiences with asthma, whether they had family members or friends with asthma, and the role of their family and friends in the management of their own asthma. Participants respond in an open-ended format. On average, the duration of the qualitative portion of the study was 30 to 40 minutes.

Grounded theory is the methodological framework that was used for the collection and analysis of qualitative data. Grounded theory is an inductive analytic approach that involves constant comparison of data through a series of iterative steps that lead to the development of an inductively derived theory from the data [24, 25]. These steps include the identification of codes, concepts, categories and then finally to theories that describe the social phenomena of interest [26]. This process continues until no new findings emerge a point known as data saturation. Codes are descriptive labels or tags representing key concepts that are being conveyed in the data. Codes can be actual responses or select words from the transcripts. In this study, similar codes were grouped into categories. Categories were then analyzed to identify recurring and dominant themes. Interviews were conducted by one individual who was trained in qualitative research techniques. However, the analysis of data was done by multiple corroborators. When there were discordant views regarding the final analysis and interpretation of findings, the raw data was reviewed by an additional corroborator until consensus was reached. This study was approved by the Institutional Review Board (IRB) of Lincoln Medical and Mental health center; and the Health and Hospitals Corporation (HHC), New York.

RESULTS

As shown in table 1, 76 participants were included in these analyses. Of these, 68% were women and their mean age was 43(±13) years; 74% were unemployed, 71% were on Medicaid and 38% had lost their health insurance in the past 12 months. Four themes emerged: 1) The perceptions of severity of asthma may be based on the experiences of social

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networks; 2) Economic factors may contribute to the sharing and borrowing of asthma medications between patients and their social networks; 3) Economic factors may contribute to using home remedies instead of prescribed medications; 4) Social network members may be unaware of the factors that trigger asthma and therefore, contribute to asthma exacerbations. These themes are further described below.

The perceptions of severity of asthma may be based on the experiences of social networks

Among participants in this study, a diagnosis of asthma was often present in one or more family members; 64% of the participants had first degree relatives with a history of asthma, most commonly the family member was a parent, a sibling, or a child. As one participant recalled her family history she discussed how asthma affected many family members across multiple generations. *"My mother, sister, brothers and all of my 3 children have asthma."* Another participant stated, "*Everyone in my family had asthma, my mother, 2 of my sisters, my daughter, aunt and cousins, yes, they all had asthma in the family."*

The perceptions of asthma severity were shaped by the experiences of their family members. Participants described how they were affected by the asthma-related death of a close relative; 3 participants stated that they had one close family member die as a result of asthma. The following is an account from a participant of how her mother died of asthma a year ago. *"About a year ago, my mother had an asthma attack; she called 911, but died before reaching the door for the emergency units to enter her home, this changed my life."* Another patient also described the impact of her mother's death on her views on asthma. "*My mother died from asthma, her first attack was at 17, she was pregnant with me."* This patient went on to describe that as a result of her mother's experience with asthma, she is fearful that she will also die of asthma. She continues by saying *"I have fear; the same thing will happen to me."* Other participants with similar experiences of losing a family member to asthma said that it had a tremendous impact on her asthma management. Examples of responses under this theme include "*I take it seriously now after what happened*." Other participants said, *"As a result of her experience, now, I see my primary provider, yes, I have an asthma (action) plan." "I know what to do; I know it is caused by stress, allergies, so now I don't wait."*

Economic factors may contribute to the sharing and borrowing of asthma medications between patients and their social networks

Many of the responses focused on the impact of the economy. The majority of participants in this study were unemployed; approximately one-fourth reported that they could not buy medications due to medication cost and a lack of money nor could they see a physician due to the cost of visits. Participants described that as a result of the recent economic downturn, they were laid off from work. As a consequence of losing their jobs, several participants said that they also lost their insurance coverage. As a result, they said they were not able to return to see their primary care physicians. "*I had no insurance for past 12 months, so no meds. I used to visit the doctor, but since no insurance, I don't go."* For some participants, the lapse in health insurance was a major factor which prompted a visit to the ED for treatment. *"My Medicaid expired this time I could not get medications so I came to emergency room and*

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then got admitted." "I had no coverage for the past 1 year and used to come here for refills."

An interesting social dynamic that was described by participants was the practice of sharing and borrowing asthma medications. Participants reported borrowing medications from family, friends, and neighbors or buying them at a lower cost from "the street". There was a sense of reciprocity between family and friends who shared a common diagnosis of asthma. Lending and borrowing asthma medications as one participant said was "*a way of looking out for each other.*" One participant stated *"I have no insurance, means no meds, so I borrow meds." Every time, if lose my breath, I take his (a friend's) medications.* One participant stated that his current insurance will not pay for nebulizer*s* and he is unable to afford his medications, therefore he relied on his brother, "*My brother, who has 2 nebulizers, and when I need it, he lends one to me.*" Another practice was buying asthma medications in their community from local stores or *"off the market",* as one participant stated." Participants said that in their community, it was quite common for people to acquire asthma medications from local stores which provided them without a prescription.

The current study is focused on adults however; some participants also resorted to using their children or grandchildren's medications. Two participants who were grandparents described how they would obtain refills from pediatricians to provide sufficient medications for their grandchildren and for themselves. One participant described how her mother was taking care of her 2 year old son who was diagnosed with asthma. Her mother who also had asthma did not have sufficient funds for her own medications and relied on a grandson's inhalers. "*My mother used my son's medications and would then ask 'his' provider for more refills for her to use when she ran out."*

Economic factors may contribute to using home remedies instead of prescribed medications

Participants also described the practice of using home remedies when they had insufficient money to purchase prescribed medications. These home remedies were described as being shared between family members with asthma. Knowledge of these remedies was often acquired from parents or grandparents. These remedies included hot tea, black coffee, relaxation, and running hot water that creates steam. In regard to these remedies, one participant stated "*when I can't buy medicines, this makes me feel better*." Another participant stated, "*I had an attack, I just took warm showers to calm my asthma attack. I have to use these other things if I cannot afford to buy meds."* This participant said that this remedy was acquired from her mother's bout with asthma. When asked how did they come to hear about these strategies, other participants stated it was *"religious"* or *"in our culture."*

Social network members may be unaware of the factors that trigger asthma and therefore, contribute to asthma exacerbations

Most participants said that their family and other social networks were helpful in the management of asthma and provided them with needed access to medications. However, a few participants did describe that family members sometimes inadvertently exposed them to

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environmental factors that triggered their asthma. These behaviors were described as being unintentional and may have reflected a lack of awareness by family and other social networks of the environmental factors that triggered asthma. For example, one participant stated "*my asthma is bad, my husband smokes at home*." Another participant said, "*Several family members I lived with were owners of pets and that triggered my asthma*." Others described how social networks smoked in their presence. As one example, "*My neighbor smokes, he made my asthma worse*." Of interest, participants did not always disclose this fact to their family or friends.

DISCUSSION

In order to successfully intervene on racial and ethnic disparities in asthma, providers must have an understanding of the range of factors that are at play. Several studies have documented the impact of family interactions on health behaviors in Latino communities. These studies have demonstrated the impact of family interactions on chronic disease management, eating behaviors, and attitudes toward illness [27, 28] [29]. Studies have also shown that the reliance on information from family and friends who were considered as being more knowledgeable was associated with delayed seeking of help for warning symptoms of chronic conditions such as diabetes, cardiovascular disease, or cancer [30]. This qualitative study advances our understanding of the dynamic social interactions that exist between patients with asthma and their social networks and provides further insight into the potential role of social networks on the management of asthma.

All of the participants in this qualitative study had prior experiences with asthma through interactions with close family members such as parents, siblings, or children who had asthma. These interactions may have influenced their perceptions of the severity of asthma, beliefs about treatments, and outcomes. The nature of these experiences spanned many generations which facilitated a practice of sharing and borrowing of asthma medications within the family unit. The study also highlighted the important contribution of socioeconomic status to asthma management and healthcare utilization. Sharing and borrowing of asthma medications was often done in the context of not having health insurance or not having enough money to purchase asthma medications. Socioeconomic factors may have also contributed to some participants resorting to using home remedies that were handed down from generations. Another finding was that social interactions may have contributed to asthma exacerbations and that family members were often unaware of their contribution to triggering asthma symptoms. These findings have several implications for expanding asthma self-management and for future research.

The National Asthma Education and Prevention Program Expert Panel Report advocates for the delivery of asthma education by clinicians during patient care visits [31]. The existing literature on asthma self management focuses on patient education, on modifying the physical environment, and on developing an individual action plan [32, 33]. An important lesson from this study is the importance of engaging both patients and their family in asthma management. Engaging patients who have asthma in discussions on the role of social networks on their health as part of the routine medical visit may provide additional insight into factors that influence asthma management. This is particularly relevant for Latino

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patients given the importance placed on the family. For example, asking patients in a respectful and non-judgmental way about their sources of information about asthma and alternate means of obtaining medications may provide opportunities for teaching. Conducting an extended family history that delves into the experiences of other family members with asthma may help to engage patients in discussions about their perceptions and attitudes toward asthma treatment and reveal underlying root causes of patients' beliefs about asthma. These discussions may uncover patterns of behaviors of social networks that may exacerbate asthma symptoms. This provides opportunities to educate both the patient as well as their family about asthma triggers. Research interventions that test the efficacy of self-management interventions may wish to explore the added value of community level interventions that involve the entire family on asthma outcomes. [34]. Another potential research area is a comparison of the impact of a shared asthma action plan between adult patients and close family members versus a traditional asthma action plan focusing on the patient only.

This study also highlights other possible mechanisms by which socioeconomic status contributes to high healthcare utilization in some Latino communities. Adults with asthma make approximately 1 million visits to the ED annually [7]. Latino ethnicity, high severity of illness, low health literacy, and low education have all been implicated as variables contributing to high ED utilization in adult asthmatics [35]. Adults living at or below the federal poverty level have a higher prevalence of asthma than adults who were living above the federal poverty level. This may be due to a higher concentration of environmental triggers in low socioeconomic urban communities or a lack of education[36]. Economic context may also impact access to medications. The study was conducted in the South Bronx a community with the highest rates of asthma [37]. The South Bronx, which constitutes Congressional District 16, is one the poorest congressional districts in the nation [38]. Approximately 40% of residents in the South Bronx live in poverty compared to 21 % in New York City as a whole. One-half of residents in the South Bronx have less than a high school degree, 26% have no personal physician, and 20% resort to using the ED for health care [39]. This social context may facilitate the practice of sharing and borrowing medications described in this study.

Previous studies have identified up to 25% of patients engage in borrowing of medications and 20% have shared medications. These studies were done in young adults, with fewer conducted among older adults [40–43]. Medication sharing and borrowing was found to be more common in low income households with multiple dwellers and among patients with low English proficiency. [44]. The practice of sharing and borrowing medications creates a community safety-net for accessing medications. When this safety-net is not available, patients may resort to using the ED to refill their medications. When patients share medications and do not alert their providers, the opportunity for instruction on proper use of medications and for addressing a lack of medications is missed. In this study, one respondent reported that asthma medications were borrowed only during emergencies. It is not clear whether patients shared inhaled corticosteroids or beta-agonist. Patients may be using incorrect medications for rescue or maintenance. Patients may also use medications that have expired. If physicians are not aware of this practice, there is missed opportunity to

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provide education on proper utilization of medications and to work with their patients to develop solutions.

One important caveat to consider is that during an acute asthma exacerbation, having immediate access to appropriate medications can be lifesaving. Therefore, sharing medications in some instances may be critical for patients who have no alternatives. Recognizing this reality must be balanced with encouraging patients to acquire their own medications. Therefore, engaging patients in discussions about practice or sharing medications is important to addressing adherence and is an important aspect of patient safety. Relative to the number of studies focused on sharing of opioids and antibiotics, to the best of our knowledge, there are no studies that focus specifically on sharing of asthma medications [42, 44]. A potential area of future research is the determination of the prevalence of sharing and borrowing specifically as it relates to asthma medications.

This study has certain limitations that should be considered in interpreting these data. While most participants were of Puerto Rican descent, the data were collected in aggregate form so that no one person was identified therefore, the responses could not be matched to specific patient characteristics including country of origin. The study was also limited by a female preponderance. Therefore, the views and observations from male asthma patients are limited. This study could be enhanced with a more formal analysis of social networks in order to determine how specific interactions influence health patterns and to elucidate other factors such as the role of social network density and composition on asthma management.

Conclusions and key findings

The current study provides a glimpse into the social context of asthma management among Latinos adults, an area that has received little attention in the asthma literature. These findings point to modifiable factors that may contribute to increased healthcare utilization among adult Latino asthmatic patients. These results are also timely as the discussion on access to care and the Affordable Care Act unfolds. Ensuring that patients have access to medications is an important component of overall access to care. This study also reinforces the important role that family and social network interactions hold in the Latino culture. Engaging patients in discussions of the roles that their social networks play in asthma management can provide important levers for education. Understanding the nuances of social network interactions between Latino patients and their family and friends may enable the development of more targeted interventions. These interactions have the potential to be harnessed into effective culturally tailored interventions that reduce the epidemic of asthma in Latino communities.

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Table 1

Demographic characteristics of Latino participants (N= 76)

Characteristics	Values
Age, years (mean± SD)	43±13
Gender	
Female	68%
Employment status	
Full time	21%
Part time	5%
Unemployed	74%
Insurance	
Medicaid/Medicare	71%
Private	8%
Self-pay	12%
Unknown	9%
In past 12 months	
Lost insurance	38%
Could not see a physician due to cost	28%
Could not see a pulmonologist due to cost	20%
Could not buy medications due to cost	22%