Asthma Management and Education

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INTRODUCTION

Approximately 25 million people in the United States suffer from asthma of various intensities; that's 8% of the country, or one in 12.[i] The asthma supplement to the 2008 National Health Interview Survey reported that less than half of people with asthma received education regarding avoiding specific asthma triggers, and of those who *were* educated, 48% of them did not follow the given advice correctly-- while reasons were not given, it can be postulated that it was due to education being insufficient or unclear rather than patients deliberately choosing to avoid medical advice. Over the period of 2001 - 2009, primary care visits for asthma management declined while emergency room and hospitalization use rates remained the same. In that same time period, the rate of asthma diagnoses in black children increased by 50%.[i]

Asthma is a much bigger killer than most people believe; it is often regarded as an annoyance of childhood by the wealthier and healthier of the US population, rather than the serious condition it can be. In 2007, 3,447 asthma deaths in the US were reported--185 children and 3,262 adults.[ii] The CDC believes the true number to be higher due to underreporting. The majority of these deaths are avoidable if proper personalized care management plans are followed, including the potential use of daily corticosteroids, quick-relief rescue inhalers and patient understanding of when their condition has worsened such that they need to go to a physician's office or hospital. These plans cannot be constructed by emergency or urgent care clinicians due to their not following patients outside the urgent setting.

Research has been done to establish that adult asthma patients often choose to use emergency or urgent care rather than making appointments with their own physicians even for non-urgent reasons such as inhaler refills[i], no published literature exists to indicate *why* patients may make these choices.

RESEARCH QUESTION

What non-economic reasons do asthmatic adults in New York City have to forego primary care management in favor of using urgent care and/or emergency rooms for month-to-month prescription and disease management?

METHODS

A series of semi-structured interviews were performed to address the question at hand. These participants were recruited from a pool of patients attending a specific urgent care practice who came in for refills on their asthma medications with no other complaints between the period of October 26, 2017 and November 8, 2017. Other eligibility criteria included being an adult (defined as between the ages of 18-65 inclusive), use of a rescue inhaler in the past year, living or working in New York City, and having health insurance. Exclusion criteria included seeing primary care for asthma management and having diagnosed mental illness.

The interviews took place at the Westway Diner around the corner from the urgent care practice cited above. The average length of the interview was thirty minutes after exclusion of time spent primarily eating rather than talking. While participants were offered compensation for their time by way of having their meal at the diner paid for, neither took advantage of this offer.

Semi-structured qualitative interview was chosen as the method of study as it allows for the participant to take the lead in conversation without eliminating the researcher's ability to ensure the coverage of specific information. The interview is somewhat freeform and letting the participant say what they need to say, but also allows the researcher to maintain some control. Open-ended questions encouraged the participants to more carefully consider the situations presented.

RESULTS

The interviews began with a disclaimer that we would be discussing non-economic reasons for using urgent rather than primary care for asthma management, and yet despite that expense of care remained a theme throughout both discussions. Another frequently cited reason was that of difficulty making appointments, indicating problems with access to primary care and/or pulmonology. Those patients who are in relatively good health without frequent exacerbation of their symptoms believe they do not need to see primary care. "I think I'm healthy and young enough to not have to go [to a primary care doctor]," said one subject, while the other was more specific about his situation: "Usually the doctors are all, 'follow up with this or that if it gets any worse,' and it never gets any worse. It just stays the same. So I don't go."

Another common theme was that of purchasing rescue inhalers—albuterol sulfate, sold as Ventolin and ProAir HFA—over the counter. Often, visits to emergency or urgent care are brought on for a need to refill one of these inhalers, whether or not the inhaler has been recently needed. Many European patients are surprised they can't just purchase generic albuterol in a pharmacy as they can back at home, and the two American patients interviewed felt the same way.

"If they can do it in the UK, what's different about here?"

It is not that the patients in question are unaware of the need for preventive care in medicine. On the contrary, all subjects were aware of the need for seeing primary care in regard to conditions such as cancer. One participant cited that he knew he would need a primary care provider eventually, and intended to get one in order to get "things like prostate and colonoscopy covered." The other, despite being many years younger than the first, agreed: when asked if anything could make her choose to see primary care, her response was a simple "turning 50." At

that point, would she get her inhalers from primary care? “Yes?” Then what was keeping her from doing it now? “Well, now it’s inconvenient. Getting here [to urgent care] is a lot easier.”

The issue of asthma education was another topic that interested the researcher, who hypothesized that lack of education may be part of the reason for these patients’ choices to not be followed by a specific person. Neither participant, as it turned out, had been given quality or even halfway decent asthma education as an adult. One was diagnosed at age five, and her parents may have received good education—she couldn’t recall—but once she aged out of seeing a pediatrician, she was on her own with no resources. The second, who was diagnosed in an emergency department and has to this day not seen primary care or pulmonology, never received any education outside of discharge paperwork. “There were handouts [at the ER], and urgent care gives me paperwork when I leave with the visit summary,” he said. Upon being asked if he would be interested in receiving more comprehensive asthma education, his response circled back to economy: “I’d definitely want that if I didn’t have to pay for it. Like, I care, but I don’t fifty dollars care.” Education seems to be more available to parents than it is to adults, and lack of education was a common thread across interviews.

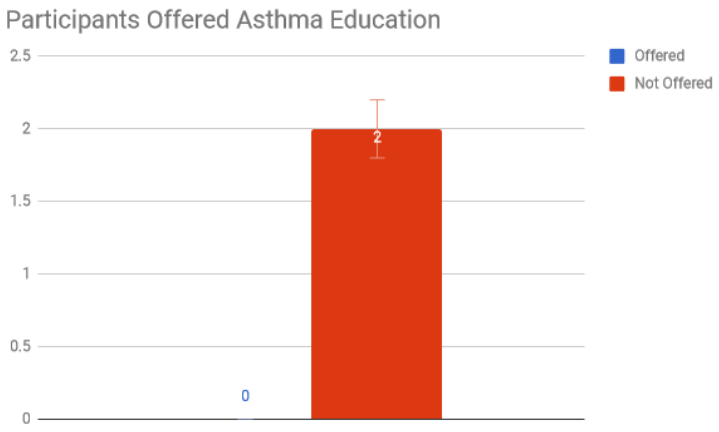

Fig. 1: Participants offered asthma education vs not offered in adulthood.

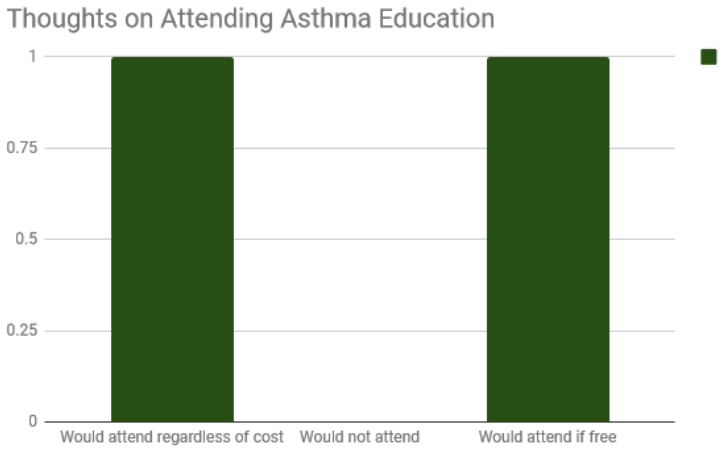

Fig 2. A comparison of those participants who would attend adult asthma education if it were free vs. those who would attend regardless of cost vs. those who would not attend.

Wait times and cost came up in both interviews, in a fashion that analysts found confusing: the patients seemed frustrated to have to wait at primary care offices and have to pay for primary care appointments, but never mentioned the long waits in the emergency department or urgent care, nor did they mention the fact that copays for either or both of those are more expensive. Patients did not seem concerned, despite their choice of attending emergency departments for some care, about asthma being a true *emergency*; in their experience, the disease was not a "big deal" and played no significant risk to their health.

The cost of care was also mentioned in a different context, one that has little to do with the question at hand but provided some context to why patients may be concerned about asthma care costs in general—even those with insurance are being priced out of their medications, and the emergency department or urgent care may be able to hand over samples or discount cards. "I'm not sure I'd trust Mexico," said the male participant, "but I have another friend with asthma, he buys Advair things, the round things, disks, gets those for $250 a pop in Mexico because they're even more expensive here." When he said they were more expensive here, he

meant *with insurance*: the price of Advair Diskus without any insurance coverage comes to $473.

DISCUSSION

Study Limitations

Due to this study's limited sample size, the analysis was not as robust as it could be; when results are either 100%, 50% or 0% of participants it is harder to really see trends. The sampling pool was also small, with patients only pulled from one specific clinic during one short time period. All participants were the same race, and came from different socioeconomic backgrounds; environmental influences that did not come up during interviews could be influencing results. Participants were also not stratified for seriousness of condition or asthma type—the two chosen to be interviewed actually had two different variants of asthma. As a result, these findings are not transferable to the general asthmatic population.

Implications

If access to primary care doctors were easier, and ease of referral to pulmonology were improved, these results indicate more asthmatics would see one, the other or both. Difficulties with getting same-day appointments and coordination of care are primary barriers for seeing PCP and specialists.

While asthmatics seem not to realize how serious their own chronic disease is, at least as far as these two participants go they are not completely clueless about preventive medicine—they seem to be more concerned about the development of cancer in the future than the management of asthma now. While cancer prevention and early detection are very important, the downplaying of the risks of asthma itself indicates that these patients may not be aware of how

dangerous asthma can be. Several studies(cite) also indicate that improperly managed asthma has been linked to lung cancer.

Available asthma education for adult patients, either diagnosed as children or in adulthood, seems to be lacking. Even with a simple Google search, it is easier to find sites and programming focused on adults *parenting* asthmatics or for children and teens themselves. Children are not just little adults, and pediatric and adult management are different—therefore even those who *were* well educated in youth and who had well trained parents are in need of more learning about their conditions *as adults*.

Next Steps: Possible Interventions

With the success of urgent care, or "doc in a box" offices that do not require appointments for asthmatics, the idea of suggesting drop-in asthma clinic hours for primary care offices is one that carries some weight. An endocrinology office associated with Albany Medical Center (Albany, NY) has an afternoon set aside for diabetic patients to drop in, and Mount Sinai Hospital (New York, NY) has the same with one morning for its dermatology clinic. While spaces are limited in both models, designing something similar for pulmonology for asthma management may carry weight.

Asthma education is an entire industry, complete with a National Asthma Educator Certification Board, and could do well to expand its focus. Public education campaigns from TV spots to billboards teaching the long-term risks and dangers of asthma, as well as the seriousness of asthma attacks and those unsettling initial attacks of chest tightness have the potential to make a difference. Do for asthma what we have done for heart disease and stroke, and even HIV and cancer: not a scare campaign, but education carrying weight and allowing people to realize that asthma isn't just something children get during gym class and grow out of.

Continuity of care for young adults "graduating" from pediatrics could also be improved, between pediatricians having networks set up to help patients move to adult primary care practices that are able to handle their asthma cases to university health systems being trained to better manage cases of asthma.

Lastly, there is some merit to making the albuterol sulfate rescue inhaler available over the counter, though it may still carry considerable cost. This has been successful in many other countries, most recently the UK, where it was implemented in 2012. Unfortunately, the possibility of many economic improvements is tied inexorably in with the US political climate and have little hope of improving with current trends.

Next Steps: Further Research

This brief study suggests possible expansion of research in several places. Further study into urgent care/emergency department usage vs. primary care or specialist use is needed with larger sample sizes and other modifications to sampling and study design in order to create transferability. Closer cost-benefit analysis specifically of making albuterol sulfate HFA available over the counter in the United States pharmaceutical market and medical climate could bring some forward motion to this frequent request by patients—it also carries risks such as patients *never* seeing doctors outside acute attacks. Lastly, studies into available education and assistance resources for asthmatic adults and ways to expand upon and improve these resources can be driving forces toward decreasing some of these problems.

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