CLEARING CLINICAL BARRIERS: ENHANCING SOCIAL SUPPORT USING A PATIENT NAVIGATOR FOR ASTHMA CARE

Heather L. Black, PhD[1], **Chantel Priolo, BA**[1], **D'Jahna Akinyemi, MD**[1], **Rodalyn Gonzalez, BA**[1], **Danielle S. Jackson, MPH**[1], **Laura Garcia, MPH**[1], **Maureen George, PhD, RN, AE-C**[2], and **Andrea J. Apter, MD, MSc**[1]

[1] Section of Allergy & Immunology, Division of Pulmonary, Allergy, & Critical Care Medicine, University of Pennsylvania Philadelphia, Pennsylvania

[2] School of Nursing Family and Community Health Division, Center for Health Equity research, University of Pennsylvania Philadelphia, Pennsylvania

Abstract

Background—Patients with moderate or severe asthma, particularly those who are minority or poor, often encounter significant personal, clinical practice, and health system barriers to accessing care.

Objective—To explore the ideas of patients and providers for potentially feasible, individualized, cost-effective ways to reduce obstacles to care by providing social support using a patient advocate or navigator.

Methods—We conducted 4 focus groups of adults with moderate or severe asthma. Participants were recruited from clinics serving low-income and minority urban neighborhoods. Data from these patient focus groups were shared with two additional focus groups, one of nurses and one of physicians. Researchers independently coded and agreed upon themes from all focus groups which were categorized by types of social support: instrumental (physical aid), informational (educational), emotional (empathizing), validation (comparisons to others).

Results—Patients and providers agreed that a patient navigator could help patients manage asthma by giving social support. Both groups found instrumental and informational support most important. However, patients desired more instrumental help while providers focused on informational support. Physicians stressed review of medical information while patients wanted information to complete administrative tasks. Providers and patients agreed that the patient navigator's role in asthma would need to address both short-term care of exacerbations and enhance long-term chronic self-management by working with practice personnel.

Conclusions—Along with medical information, there is a need for providers to connect patients to instrumental support relevant to acute and long-term asthma-self-management.

Keywords

Asthma; control; patient navigator; self-management; barriers; communication

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Corresponding Author: Andrea J. Apter, MD, MSc, 829 Gates Building, Hospital of the University of Pennsylvania, 3600 Spruce Street, Philadelphia, PA 19104. Telephone: (215) 662-3215; FAX: (215) 615-0780; apter@mail.med.upenn.edu..

INTRODUCTION

Patients who are poor or belong to racial or ethnic minorities tend to receive lower quality health care.[1] Asthma, which affects 15 million adults, is one disease of many whose outcomes differ according to socioeconomic status and race/ethnicity.[2-5] Blacks are three times more likely to be hospitalized than whites.[4, 6-8] For low-income minority patients, a variety of personal, social, and practice factors can impede self-management and contribute to asthma morbidity.[1, 9-13] The goal of this project was to explore feasible, individualized, cost-effective ways to address these barriers using a patient advocate or navigator.

Harold P. Freedman, MD first proposed the concept of a Patient Navigator (PN) to overcome obstacles to early diagnosis and initial treatment of cancer for patients living in poverty in Harlem.[14-16] Since then, PN interventions have focused on vulnerable groups: the uninsured, minority, elderly, and low-income patients, particularly for screening or facilitating treatment for cancer.[17-19] PNs have varied from trained laypersons from the community to social workers and medical personnel. PNs have provided or arranged transportation, scheduled appointments, ensured that medical records are available, and provided social support.[20] Efficacy has been shown, but not uniformly.[17, 21-24] In recent years, PN programs have been extended to other settings,[25] although to our knowledge, not to asthma.

Asthma patients, like those undergoing screening, diagnosis, or initial treatment of cancer, may need help with tasks like making lists of questions to ask during an appointment or learning to use medications correctly. However, for a chronic disease like asthma, successful self-management may require more ongoing support to help patients understand and remember complicated and changing medical and administrative information. In an anxiety-provoking medical setting, these tasks can be difficult for patients with moderate or severe illness, whether or not there are additional barriers such as a primary language other than English or low health literacy. We used focus groups to assess whether patients and providers could agree on useful and cost-effective services a PN could provide and the characteristics that a PN should have to help moderate or severely affected asthma patients.

METHODS

Study design

Focus groups are a qualitative research technique used for gathering data where discussion and group synthesis are desired. Qualitative research is particularly useful for understanding experiences and perspectives of individuals such as patients and their health care providers. Ideas generated would be the first step in designing feasible, acceptable, and cost-effective activities a PN could perform.

While individuals' responses may be influenced by social pressures of the focus group, moderator techniques are used to limit such pressure, for example, patients, nurses, and physicians were recruited into separate groups. Likewise moderators ensure the discussion is not dominated by only a few participants or one point of view. A RIVA-trained (http://www.rivainc.com/training) moderator led six focus groups: four of patients, one of nurses, and one of physicians. The University of Pennsylvania Institutional Review Board approved the protocol.

Participants

Patient participants had completed an ongoing randomized controlled trial of a problem-solving intervention to improve adherence with inhaled corticosteroids. These participants were at least age 18 with moderate or severe asthma according to National Heart Lung and Blood Institute Expert Panel Report 3 guidelines.[3] They had a physician's diagnosis of asthma, were prescribed

an inhaled corticosteroid, and had evidence of reversible airflow obstruction: a) documented forced expiratory volume in 1 second percent predicted (FEV1) < 80%, and (b) improvement in FEV1 or FVC with bronchodilator (an increase in the percent predicted FEV1 or forced vital capacity of at least 12%, with 200 ml in absolute FEV1 after two to three puffs of inhaled albuterol or an increase of >15%, and 200 ml in absolute FEV1 with asthma treatment). For the larger study information on socio-demographics, asthma severity, and social support had been collected. Social support was assessed with the Medical Outcomes Study Social Support Survey. This 19-item survey gives a mean score scaled from 0-100.

Two focus groups of patients were recruited from the control arm (receiving standard asthma education derived by the National Heart Lung and Blood Institute Expert Panel Report 3 guidelines[3]) and two groups from the intervention arm. Patients in the intervention arm learned to define a specific individual problem to maintaining adherence to their inhaled corticosteroid regimen, consider alternative solutions, select and try one solution, and revise their solutions. We thought experience with a problem-solving protocol might facilitate patient thinking about how a PN could help them mitigate barriers to self-management.

Provider participants worked in primary care or specialty clinics participating in the same randomized controlled trial as patients. Providers and patients were invited until each focus group could be assured of having 5-8 participants.

Procedures

The focus groups began with a brief definition of a PN as someone who would help asthma patients. The rest of the discussion centered on three topics: barriers to controlling asthma; PN activities before, during, and after a medical visit that could promote patient self-management of asthma; characteristics that a PN should have. In addition, both provider groups responded to patients' ideas and discussed how PN activities could be integrated into their practices effectively. Each group was audio-recorded using standard equipment and a note-taker was present.

Analysis

Using the Grounded Theory approach,[26] our investigators independently analyzed the focus group data in two steps. In the first step, notes were put into Excel and each investigator hand-coded the PN activities discussed in each focus group into major themes derived directly from the data. Through meetings and discussion all investigators agreed that the PN activities from the groups fell into the following themes: medicine and information; administrative; communications; emergency; advocacy support; transportation and childcare support; and peer support.

As the themes were discussed and analyzed further, it was clear that they fell into categories already in existence in the social support literature. For this reason, we chose to use a well-established existing conceptual framework to discuss our findings.

Conceptual framework

We framed our analysis using four functional content categories of social support, proposed by House[27] and summarized by Wills and Shinar:[28] instrumental, informational, emotional, and validation social support. Instrumental support involves tangible direct physical assistance, (e.g. accompanying a patient to a doctor's appointment or helping patients write an asthma emergency plan). Informational support is the provision of advice, suggestions, and useful information that enhances problem-solving (e.g. information on dose and timing of medications, or how to obtain referrals for appointments). Emotional support, the provision of empathy, love, or trust, increases self-esteem, and reduces anxiety and depression (e.g.

connecting with a patient on a personal level to empathize, or providing companionship so the patient is not lonely). Validation support offers constructive feedback by aiding patients as they compare themselves to others to determine how well they are doing (e.g. patients in a support group discussing their number of trips to the emergency department, or sharing tips for medication management).[27, 28] These categories are conceptually different and provide a framework for the provision of social support, although when applied to a specific activity, the activity may involve several types of support. We categorized participant statements according to the primary element of social support provided.

RESULTS

Twenty-seven patients participated in the focus groups (Table I). They were mostly female and African American. More than half had an ED visit or hospitalization for asthma in the year before enrolling in the randomized controlled trial. The patients had significant comorbidities: 16 (59%) had hypertension, 7 (26%) diabetes, 4 (15%) coronary artery disease, and 4 (15%) cancer. Medical Outcome Study Social Support Survey scores ranged from 38.2 to 93.4, indicating good variation among the participants in their levels of perceived social support.

Patients that were in the intervention arm of the trial had increased awareness of their own asthma management strategies and had experienced working with a research coordinator. These patients were better able to spontaneously identify ways that a PN could help them. However, none of the activities that these groups mentioned were in any way performed by the research coordinators in the previous study. Interestingly all patient focus groups, regardless of their status in the previous study, ultimately agreed on activities for the PN.

Five nurses, all female, and seven physicians, of whom four were female, attended the provider groups; seven providers were from primary care practices and five from asthma specialty practices. Nine providers were white, two were Asian, and one physician was African American.

Overall, patients most emphasized their need for instrumental (physical) help and wanted the PN to ensure that providers understood their needs. Nurses agreed with patients' desire for instrumental support, but also wanted the PN to provide increased informational support through education about disease management. Physicians stressed PN roles in provision of information to the patient, facilitating medication adherence, and also supplying physicians with information.

Instrumental Social Support: physically giving aid

Patient participants valued PN instrumental social support tasks that could physically improve communication between patients and providers. For example, using their understanding of patients' environment and context, PNs could assist patients before and during their visits in preparing medication lists or questions to be addressed during the medical visit. Other instrumental tasks included support during exacerbations, assistance with obtaining medications, and help completing administrative tasks.

Communication assistance—All groups desired assistance with communication. Five patients talked about the PN helping them communicate during the visit.

"[The PN could] explain to the doctor what you are trying to say or help you ask questions."

"They may notice things you don't notice during your visit, sometimes we miss out on things too, it would be another set of ears."

"... be sure you have 'scripts for when you're gonna need it; leave with the scripts... remind you..."

Patients wanted the PNs to perform an advocacy role for them in the appointment.

"It would be unrealistic, but ideal if even during your visit someone could advocate for you if you were unsatisfied with how the visit went. If there was someone the doctor respected enough – because doctors are not always right and when you're just a layman, or whatever we are, not medical professionals,... we're not viewed as being equal... So if there were someone that could go in between... maybe it could have a better resolution."

"My husband has trouble with steps and when he gets [the shared special assistance] ride...sometimes those rides are late and you wait a long time... I say, "Tell them at the office that this is the time they're picking you up and you can't wait there for two hours." And that's something the advocate could really help with."

Three out of five nurses suggested specific communication and orientation tasks for the PN during the appointment.

"If there's a language barrier, make sure there's an interpreter there."

"To greet them [the patients] at their visits...they [the patients] know its one person they can always count on."

Physicians were in favor of PNs attending visits to enhance the patient-provider relationship by giving additional information that the physician might not have time to ask. There was little concern about the PN being present in the exam room, as long as it did not slow down the visit or impede care.

"During the visit, they just need to stay out of my way. I'm thrilled for them [PN] to be in the room and some of the best advocates might point out, "you know this person doesn't read," or is an extra pair of ears, when we run down the instructions... And if their job is navigation, they can help clarify that communication and get the plan carried out."

"They [patients] can ask questions [of the PN] that they normally wouldn't ask the doctor... like, "I don't know how to use this inhaler." It's not always easy to get me on the phone especially when its not urgent, but maybe it [the PN] could be someone they could get in touch with easier."

Emergencies—Almost all patients stressed the need for assistance with emergencies. Patients did not mention action plans. Among providers, action plans were mentioned only briefly. Patients believed that they had taken responsibility for managing their asthma and had systems in place for controlling exacerbations.

Patient: "...You have to know what you have to do, your body, your signals, the navigator is only [there to help]...you need to know how to manage your asthma..."

Despite taking personal responsibility for managing their own asthma, 15 patients desired instrumental social support at the time of an exacerbation; some nurses also identified a need, although physicians did not.

Patient: "The only time I would need someone with me is when I'm having an attack. Words can't come out and you need to let someone to know what's going on, sometimes I wheeze so bad I can't talk. You could write it down and this person could talk for you because the more you talk the more short of breath you get."

> Nurse: "Maybe if [the PN] knew what the contacts are, like family members to tell them what's happening, you know, what needs to be done..."

Four patients talked about caregivers – often children – who were trained to look for symptoms and call for help.

> Patient: "Well it would be my son, one of mine, because he looks out real well, his attitude is, "If dad's good, then I'm good." He makes sure I take my Advair... he wants to make sure I'm alright."

Medication support—Patients wanted help managing medication lists (4), reminders of medications requiring new prescriptions (5), reviews of prescriptions after the visit to ensure all is correct (5), strategies to take their medications between visits, assistance obtaining medications in an emergency, and support as they express their concerns about adverse effects of medications to their physicians.

> Patient: "They could ask the doctor about the milligrams in the medications that you're taking so you don't get chemically imbalanced with other medications you're taking... I'm also a diabetic with glaucoma."

> Physician: "Checking eligibility for free medications... It takes a lot of work to qualify patients for medical assistance programs. If the PN was trained in this and it means I don't have to do it, it is fine..."

Administrative tasks—Assistance for patients with administrative tasks was important to patients and providers.

> Patient: "Make sure you have all you're paperwork – all your referrals."

> Patient: "... make sure your insurance is in line, say after I'm in the hospital I would love to have someone to call the pharmacy and make sure my medicines are ready so I don't have to wait."

Nurses (3/5) and physicians (7/7) agreed with the need to assist with remembering to refill medications, helping to procure test results, and scheduling appointments.

> Nurse: "In our office we try to schedule, but there's lots of patients that don't have their tests done here, because they're out of network."

> Physician: "... navigating the insurance system, you know that huge gap. Getting it [the visit / medication] approved, and all that facilitating between the patient and the office would be helpful."

Informational Social Support: providing useful information

Although providers put the most emphasis on medical information, patients wanted more than just medical information. Though some patients said they wanted the PN to review medical information (3), they were more interested in the PN giving them information about available instrumental support. All groups had suggestions for what information the PN could provide.

> Patient: "Would that person [PN] be able to help you find the best insurance?"

> Nurse: "...information to help the patients, what are the available communication resources, what are the things the drug companies will give them..."

> Physician: "[PN could provide] patient instruction and uses of inhalers... I don't have time in my schedule to teach it, and it's unlikely they get this [education] when they go to the pharmacy..."

All the nurses recommended PN phone calls before and after the visit to: teach patients about asthma, discuss triggers, tell patients what to expect in their doctor's visit, gather medication information, find out if patients had any emergency department visits, and be sure patients understand physicians' recommendations. Nurses also wanted the PN to update the practice between visits, particularly for patients with frequent exacerbations (4).

> Nurse: "If there's a problem and the patient is due for an office visit, it would be nice if [the PN] could call and leave us a message before.... Some patients don't call until they're ready for the ER..."

Information for physicians—Physicians concentrated less on patients' need for information about available instrumental support, and more on their desire to give patients medical information. They wanted PNs to provide medical information in two directions: to educate patients to promote better adherence, and to give physicians data that would help them provide better care, such as peak flows, test results, lists of medications and adherence (6). They did not explore a role for PNs in asthma exacerbations.

> Physician: "Review all the medications they've been on and why they are not on them anymore and making a list with them, whether they had a reaction."

> Physician: "Follow up to see...if things were going badly and it looked like there was a need for a physician intervention then maybe, [the PN] could initiate some kind of contact for us including another appointment sooner."

Emotional Social Support: providing empathy

The need for emotional support was raised much less often. Several patients suggested that the PN accompany them during the visit with the doctor for moral support. Physicians discussed an emotional role for the PN building a relationship with the patient in order to obtain and dispense information.

> Patient: "Just sit in the room with me, because some people get really nervous just seeing doctors sometimes."

> Physician: "I feel like the thing the navigators need to do is less task-oriented and more like ...sort of figuring out what's in the patient's head. And the same navigator needs to know what's in my head when I have a visit and I only have five minutes to spend on what to do with these medications..."

Validation Social Support: peer support and constructive feedback

Participants in every patient group indicated a desire for an asthma support group (6) where they could get together with their peers to hear stories, share information, resources, and techniques that they are using to manage asthma.

> Patient: "We all can help each other, and you know I wanna talk to them. Not because they're a new person, but I wanna help them."

A few physicians preferred the idea of a "group visit" to a support group, but most physicians and nurses approved of the support group as long as there were medical providers present.

> Nurse: "...coming from my long years of working with support groups for a variety of things – the ones that helped me the best, there was a piece of education."

> Physician: "If there were to be focused visits with patients that have asthma, it would be valued to do it in a group setting with other patients that have asthma."

PN Characteristics

Patients wanted the PN to both facilitate communication with their providers and be their advocate. They suggested a PN with characteristics of research coordinators from the earlier study. These were recent college graduates interested in health careers; some, but not all, were of the same race/ethnicity as the patients; all had training in asthma education; and their work was overseen by medical professionals. Nurses and physicians believed these qualifications should be the minimum and thought additional social work or medical qualifications would be ideal.

> Physician: "Obviously the PN should understand asthma and the disease process, the meds and how they work, including how to use meds, even just physically how to use an inhaler."

DISCUSSION

We explored the feasibility of a PN providing support for patients with moderate or severe asthma, most living in an inner city environment, and many of whom had had an ED visit or hospitalization during the year before entering the randomized controlled trial. Both patients and providers agreed that a PN could facilitate patient self-management of asthma and wanted to be sure the patient's point of view was understood. Patients valued instrumental support most; physicians emphasized informational support related to medical concepts; and nurses thought a combination of both instrumental and informational support important. These preferences explain why patients preferred the term "advocate" while providers liked "navigator." Patients valued medical information but also wanted an "advocate," someone respected by medical personnel who would help them prepare for emergencies, address concerns about medicine side effects, and assist with overwhelming administrative burdens. Providers wanted a "navigator," someone aware of a patient's environmental context and social situation to guide them in achieving control and avoiding exacerbations through promoting understanding of medical information. The physicians hoped that the PN could make up for the lack of time to communicate with patients during the visit.

The focus groups suggested that a PN for asthma would provide two unique services compared with PNs in existing programs for other conditions: 1) helping with exacerbations, and 2) providing ongoing intermittent assistance. While many of the asthma participants had had at least one ED visit or hospitalization in the last 5 years, none discussed action plans for providing support during asthma emergencies.[29] It is possible written action plans were not mentioned by patients because they had not received self-management education using written action plans[30] or because these plans are difficult to understand.[31, 32] PNs could assist providers with customizing patient plans to incorporate the patient's existing social support structure, identify additional instrumental support components, ensure that the plan is simple enough for the patient to execute, and assist with "teach-back." The plan would require careful communication, be approved by providers and patients, and become part of the medical record.

To manage a chronic illness like asthma, many patients need ongoing, but intermittent assistance, however to make it cost-effective, a PN's availability could not be 24/7. The PN's time spent with individual patients would vary based on their health and circumstances. Ideally the PN will help the patient identify family members or friends who could be trained as a PN. If this is not possible the PN could perform the tasks, or inform the practice so these activities could be distributed among the providers at the practice's discretion. For a long-term PN program, health benefits and cost savings must be shown. Thus far, the efficacy of PN programs has primarily been demonstrated through increases in the percentage of populations receiving diagnostic tests and in reductions in days to treatment. Other considerations for PN programs are ownership and oversight, specifically whether a PN would be tied to a practice or to one

disease. Regardless of structure, this study showed a desire from patients, nurses, and physicians to develop PN programs specifically to help manage barriers related to the care and maintenance of asthma.

An underlying theme for the asthma patients in this study was the idea of vigilance and self-reliance – that they have taken responsibility for managing asthma. This idea of self-reliance may be one reason patients stressed the need for receiving help during asthma attacks and emergency visits – as those are situations that make them feel out of control. Although management of exacerbations was not discussed by clinicians, perhaps because they did not see a PN as able to play a role in emergency care, preventing these events is clearly important to providers too. This suggests that the PN will need to be positioned not as "help because patients need it," but instead as "supporting what patients already do so they can do it better," perhaps in individualizing and ensuring comprehension of action plans.

Our study has limitations. Like all qualitative projects, the sample size is small and selected. Nevertheless, our patients are at high risk for asthma morbidity. The PN solution is generalizable in that it is an individualized intervention tailored to each patient and the resources of the patient, the practice, and its providers. While our discussion about PN activities focused on one condition, our patients like many patients often had several medical problems. Focus group patients and providers suggested activities that would be applicable to appointments for a wide variety of conditions and for patients with several co-morbidities. Some examples include: enhancing communication by prompting patient preparation for a medical visit, accompanying a patient during a medical visit to take notes and help review recommendations, and afterward providing assistance with administrative tasks. These activities do not require highly trained health professionals.

While focus groups have been criticized for encouraging participants' to give responses that they believe the moderator wants to hear, our moderator received formal training in techniques to gather unbiased responses by eliciting the full spectrum of opinions. Indeed responses within and across groups were diverse regarding some of the activities of the navigator, the type of assistance that patients would need and the characteristics best suited for navigators. Two patient groups had experienced a "problem-solving" intervention and two had not. While we believe participation in the intervention facilitated patients' ease of response in the focus groups, all four patient groups were able to propose useful services a PN could provide.

A PN is a promising intervention for facilitating patient self-management of asthma by enhancing motivation and skills. Here we determined such an individualized intervention is acceptable and potentially feasible, the first step in determining its true cost-effectiveness. It is possible the PN activities may be accomplished by one person or distributed across a family, the community, or the practice. Linking such multiple support units has been successful in other settings.[33] In summary, a PN has the potential to increase the understanding of patients' individual contexts while strengthening social support networks for the management of a chronic disease.

Acknowledgments

ABBREVIATIONS

PN   Patient Navigator

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Table I

Demographics of Patient Subjects (n= 27)

Age[a]	54 ± 13
Female	22 (82%)
Race	
Black	19 (71%)
White	6 (22%)
Other	2 (7%)
Ethnicity: Hispanic/Latino	0 (0%)
High school graduate	24 (89%)
Household income <$30,000/year	16 (59%)
Disease Severity	
Average Age of asthma onset	26 ± 21
FEV1 percent predicted[a]	73 ± 18
#[*] with at least one ED visit for asthma in past year	14 (52%)
#[*] hospitalized in past year for asthma	9 (33%)

[a]Mean ± Standard Deviation

[*]At enrollment in the randomized trial