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An analysis of contextual information relevant to medical care unexpectedly volunteered to researchers by asthma patients

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Abstract

Objective—To describe and categorize contextual information relevant to patients' medical care unexpectedly volunteered to research personnel as part of a patient advocate intervention to facilitate access health care, communication with medical personnel, and self-management of a chronic disease like asthma.

Methods—We adapted a patient navigator intervention, to overcome barriers to access and communication for adults with moderate or severe asthma. Informed by focus groups of patients and providers, our Patient Advocates facilitated preparation for a visit with an asthma provider, attended the visit, confirmed understanding, and assisted with post-visit activities. During meetings with researchers, either for PA activities or data collection, participants frequently volunteered personal and medical information relevant for achieving successful self-management that was not routinely shared with medical personnel. For this project, researchers journaled information not captured by the structured questionnaires and protocol. Using a qualitative analysis, we describe 1) researchers' journals of these unique communications, 2) their relevance for accomplishing self-management, 3) Patient Advocates' formal activities including teach-back, advocacy, and facilitating appointment-making, and 4) observations of patients' interactions with the clinical practices.

Results—In 83 journals, patients' social support (83%), health (68%), and deportment (69%) were described. Patient Advocate assistance with navigating the medical system (59%), teach-back (46%), and observed interactions with patient and medical staff (76%) were also journaled. Implicit were ways patients and practices could overcome barriers to access and communication.

Conclusions—These journals describe the importance of seeking contextual and medically relevant information from all patients and especially those with significant morbidities, prompting patients for barriers to accessing care, and confirming understanding of medical information.

Keywords

patient advocate; patient navigator; asthma; health communication; health literacy; health access

INTRODUCTION

Interventions that address barriers to access to health care, communication with health care providers, and patient-management for chronic diseases are needed to improve health outcomes particularly of poor and under-served patient groups.(1) We designed and are

testing such an intervention, called a Patient Advocate (PA) Intervention, in adults with moderate or severe asthma. During testing, we were surprised to find that patient participants volunteered contextual and medically relevant information to researchers, whether the researcher was acting as the PA of the intervention or simply asking scripted questions as a data collector (DC). We describe researchers' recounts. While many patient navigator studies in the past have reported the researchers' tasks or responsibilities, there has been a lack of reporting of the types of communication exchanges that occur between the navigators and patients, which we found relevant to medical care.

The PA intervention was adapted from the Patient Navigator which was first proposed by Harold Freeman, MD to promote early diagnosis and treatment of cancer of patients living in poverty in Harlem.(2–4) Informed by focus groups of patients and providers,(5) we adapted navigator activities to promote patient-provider communication and access to care for adults with moderate or severe asthma, living in low-income urban neighborhoods. The Patient Advocate (PA), a name preferred by patients in the focus groups, facilitated preparation for a visit with an asthma provider, attended the visit, confirmed understanding, and assisted with post-visit tasks.

Using a qualitative analysis, we describe 1) researchers' journals of these unique communications, 2) their relevance for asthma management, 3) PAs' formal activities including teach-back, advocacy, and facilitating appointment-making, and 4) observations of patients' interactions with the clinical practices. Our findings are applicable to patient care in other medical settings and can be applied to future research studies.

METHODS

Study design and protocol summary

The parent study was a randomized controlled trial that compared electronically monitored adherence to inhaled corticosteroid regimens in adults with moderate or severe asthma who were randomly assigned to a PA or to standard asthma education. It was a pilot study assessing the feasibility and acceptability of this intervention to be tested later in a study of longer duration with a larger sample size. The qualitative study reported here analyzes journal entries made by members of the research team, either PAs or Data Collectors (DC), upon visits with participants. PAs only met with participants assigned to this intervention. DCs, who met with all participants on 6 occasions, downloaded monitoring data and administered questionnaires to all participants, but did not perform PA activities.

PAs met briefly with participants randomized to the PA intervention after the first and second data collection visits to introduce themselves. The PAs then met with the participants for up to three occasions surrounding medical visits as they occurred over the 14-week study period. PAs coached and modeled effective communication; assisted with preparations for a medical visit; attended the visit, with the permission of participant and provider; and confirmed patient understanding after the visit. PAs also facilitated: scheduling, obtaining insurance coverage, overcoming patients' unique social barriers to carrying out medical advice, and transferring information between providers and patients. PA activities were individualized, multimodal, and took comorbidities into account. Their activities were informed by earlier focus groups of patients and providers.(5)

We found that patients volunteered contextual information that was of medical relevance to both PAs and DCs, even though DCs adhered to a strict script of questions. Thus, both PAs and DCs, were asked to journal their thoughts about participants and their own activities whenever they observed additional information beyond what was captured in case report

forms. Journals were shared on a protected website accessible only to team members. The University of Pennsylvania Institutional Review Board approved the protocol.

Study Subjects: Patient participants

Patient participants were at least 18 years old with moderate or severe asthma according to National Heart Lung and Blood Institute Expert Panel Report 3 guidelines.(6) 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 forced vital capacity (FVC) with bronchodilator (increase in the percent predicted FEV1 or FVC of at least 12%, with 200 ml in absolute FEV1 after two to three puffs of inhaled albuterol or increase of 15%, and 200 ml in absolute FEV1 with asthma treatment). Participants were identified by reviewing the medical records of all patients with upcoming appointments in participating primary care and asthma specialty practices. These clinics serve low-income urban neighborhoods where the prevalence of asthma morbidity is high.

Researchers: Patient Advocates (PA) and Data Collectors (DC)

There were two PAs and two DCs who were recent college graduates with the same race/ethnicity distribution as participants, interested in health-related schooling, research experience, and working with patients. Researchers trained for three weeks, using training manuals of recruitment, protocol, and data collection procedures. Training topics included asthma pathophysiology and education; spirometry; human subjects research; cultural competence; interpersonal skills; cultivating relationships with practice personnel; administrative tasks required of patients; procedures for reviewing medical records, screening, enrolling, obtaining consent, recognition of adverse and serious adverse events, and data collection.(7)

DCs met participants in a quiet area of the clinic. PAs met participants in the waiting room and almost always accompanied the participant to one or more medical visits. Through conversations while waiting, PAs became acquainted with patients and information about them, thereby developing a rapport that was used to model and facilitate steps patients could take to prepare for and enhance communication with medical personnel and access health care.

Descriptive data—Sociodemographics, information on asthma severity and comorbidities, and health literacy assessments were collected. Literacy was measured by a test of reading comprehension, the Short Test of Functional Health Literacy in Adults (S-TOFHLA),(8) and our test of asthma-related numerical ability, the Asthma Numeracy Questionnaire (ANQ).(9) The ANQ is a validated brief verbally-administered 4-item questionnaire of numerical concepts (arithmetic and percentage) adapted from standard asthma education.(9) The score is the number correct. The S-TOFHLA consists of 36 modified Cloze procedure items.(8) The score is the number of items correct. A score less than 23 corresponds to difficulty reading and interpreting health texts.(10)

Analysis

The content of the journals was similar to field notes containing observations of the researchers and their accounts of the interactions that took place. Journals did not contain full transcripts of interviews or conversations, which would have allowed for deeper analysis of patient speech patterns, word choice and multi-layered phenomenological content theming. Instead, they were analyzed using a technique designed for ethnographic field notes (11) to describe and categorize what was observed. A two-step qualitative technique of open and then focused coding based on a Grounded Theory(12) approach was used to

generate a codebook (Table 1). Two investigators then independently coded the journal entries (HB, AA). Code definitions were revised until the investigators reached 80% agreement across randomly selected journals representing at least 25% of the total. The frequency of the codes was then analyzed to create categories describing the interactions that PAs and DCs documented.

RESULTS

Eighty-three journals were collected from January 2010 to January 2011, documenting interactions with 46 patients; 46 journals were written by PAs and 37 by DCs. Each PA journaled on approximately 17 subjects; each DC journaled on 6–7 subjects. Some patients were the subject of more than one journal as they had as many as three PA visits and all subjects had six DC visits. Those randomized to the control arm had interactions only with DCs. The journals documented researchers' observations of: 1) patients' social and medical condition; 2) descriptions of patients and their perspectives, 3) PA activities: navigating; insuring communication including confirming understanding of medical information, and 4) patients' interactions with the clinical practices.

The 46 patient participants, who were the subjects of the journals, were mostly female, African American, from households earning less than \$30,000/y (Table 1). More than half had an asthma-related ED visit and more than a quarter were hospitalized for asthma in the year before enrollment. More than half had hypertension; more than one-quarter had diabetes. Two-thirds had BMIs of at least 30.

Patients' social and medical condition

In the normal course of conversation during appointments with PAs and DCs, with no formal scripting of the interactions, patients spontaneously shared information. The most frequent (83% of journals) patient comments were about social support usually directly about medical issues. Researchers learned about: the patients' living situations (20% of journals), current transportation / difficulty of commute to appointments (20%), caregiver status (19%), any social support available from family or friends (7%), and whether there was someone who could act as the patient's PA at the conclusion of the study (6%).

"The patient grew up primarily in Florida with a foster family, with whom she was very close. Now as an adult,... she had to return to Philadelphia, her birth city, because the subsidized health care in Florida was not sufficient for someone with her issues." – DC

"The patient is a senior citizen living independently and drives to his doctor's appointments. He sees all other specialists closer to his home but drives about 45 minutes to the pulmonary doctor every six months." – PA

"The patient had full custody of her two grandchildren... She kept all her appointments, although it was clear that she would meet me according to her schedule and therefore allowed little flexibility with regard to making appointments." – DC

PAs and DCs learned about patients' socio-economic status, personality and preferences, including: work situation (12%), age (12%), education level (10%), financial challenges (6%), important hobbies (6%), communications style (6%), and support preferences (3%).

"The patient works as a security guard for a boxer. He travels quite frequently for boxing matches around the country." – PA

“The patient wanted to ask the doctor why all of a sudden she felt out of breath so often. The patient is a runner and is concerned that she will not be able to properly train for her upcoming half marathon in September.” – PA

“The patient is very quiet and speaks very softly. She usually doesn’t talk unless otherwise prompted.” – PA

Patients discussed their current (45%) and past (23%) health conditions and the impact of their health on their lives (7%), including hospitalizations (16%). Patient participants also revealed their struggles to: manage their health (7%) and insurance (7%), overcome drug abuse (6%), cope with exposure to violence (4%), and recent family deaths (3%).

“The patient told me she has been having health problems like high cholesterol, high blood pressure and worries that she may get diabetes since it runs in her family. Her previous visit with the doctor included a talk about weight loss programs, but she said she could not afford Weight Watchers or expensive gyms.” – PA

“The patient was a recovering crack addict, and had been clean for quite some time. During the course of the study, she moved from a group home to her own apartment.” – DC

The majority of health issues raised were asthma-related (62%). Participants revealed: feelings about taking asthma medications (23%), strategies used to control asthma (9%), views on adherence (9%), level of knowledge about asthma (7%), knowledge about their triggers (9%), communication style in appointments (2%), and the impact of insurance on their lives and care (5%).

“The patient adjusts her own dosage of Advair, taking it daily instead of twice daily because she feels that [the dose] is too much.” – DC

“The patient was able to answer all of the questions regarding her asthma symptoms. However, she did not know which medication was a controller or a reliever.... She could not list all of the asthma medications. She did not have a comprehensive action plan. She would only take her albuterol inhaler... She did not know how to take ICS as prescribed. However, she did mention that she does not feel the effect of [her ICS] as well as she does with albuterol and nebulizer machine.” – DC

Descriptions of patients and their perspectives

The journals included researchers’ assessments of patients’ behavior (69%), personality (44%), interactions with providers (21%), and likelihood to benefit from the PA program (40%).

“The patient was in need of help in nearly every area of his life; it was sometimes emotionally difficult to meet with him because his struggles were so palpable. I am not certain as to whether he would have benefited from a PA, simply because he was beset by so many problems – poor health, poverty, addiction, obesity, lack of education etc. – although in combination with a social worker, I do think a PA could have at least helped him navigate his doctor’s visits more effectively.” – DC

Patients shared their feelings about the visit, the provider, and the study itself in 34% of the journals.

“The patient found the study to be helpful in the treatment of his asthma because he now knows how to take his inhaler. He says that physicians generally just give you a medication and do not tell you how to use it properly. He also noticed that he

scored higher on the knowledge questionnaire. He is interested in participating in another asthma study in the future.” – DC

PA activities: navigating, confirming understanding, facilitating communication

In the 46 PA journals, interactions were coded into five categories of protocol-defined PA activities: assisting the patient with navigating the medical system (59%), teach-back (46%-- asking patients to recount medical recommendations in their own words), encouraging patient action (30%), facilitating communication with providers (11%), and advocacy (7%).

Navigating—Assisting patients with navigating the medical system, the most frequently coded activity, consisted of: making calls, helping with referrals, and providing patients with phone numbers.

“The patient expressed to me how hard it was to make appointments at these places and I got the sense she was very frustrated and had given up. I offered to help make the appointments for her... It took me about 15 minutes for the woman at the front desk to give me the numbers. I was given the wrong number for Neurology. It took me another 15 minutes to get the correct phone number to make appointments.” - PA

“The day of the appointment, the patient was scheduled to see the doctor at 10:30 am, but when she had not shown 30 minutes later, I called her.... She said that she really would have liked to see the doctor but a meeting at her son’s school had made her late and she did not know if the doctor would still see her. I told her that I would find out if the doctor would still see her later in the day. The doctor agreed to see her and the patient arrived at noon.” - PA

Confirming understanding: teach-back—The second most frequently documented PA protocol-defined activity was teach-back after the visit.

“During the teach-back, I commended the patient for naming her top three concerns and having them addressed. She was able to recite all the instructions back to me and I reminded her that I would meet with her next week as well.” – PA

“During the teach-back session, I reminded the patient that she really had to pay attention to her symptoms for the next week so she would be able to alert the doctor.” – PA

Encouraging the patient to take specific action was the third most frequently mentioned protocol-defined activity.

“While waiting for the provider, the patient mentioned that she uses her sister’s nebulizer at night. I suggested that she mention this to the doctor and maybe she could get her own.” - PA

“The patient sought my opinion on whether she should get the [lab tests] done that night (it was 6:15 pm) or wait. I suggested she get them now since the lab was open until 6:30 pm and she would have to take a vacation day from work since the lab did not have weekend hours.” – PA

Facilitating communication—PAs facilitated communication with providers by encouraging patients to speak up or directly transmitted information to providers (with the patients’ permission). Although PAs did not give medical information, they listened to patients’ concerns, reviewed information and answered questions.

“I [the PA] made sure that the provider knew that the patient was not able to afford the [medicine]. In response, the provider gave the patient samples and recommended that she call her insurance company to make sure it would be covered.” - PA

“The patient was concerned about having the pulmonary function tests done because the doctor had mentioned that she would have the tests done inside of a glass box... I explained to her that the box was not closed and that it was clear glass and that not all of the tests were performed while inside the box. She felt a bit more comfortable.” - PA

Advocacy—Though PAs most often encouraged patients to act, they occasionally were advocates for patients they accompanied.

“The patient arrived at the emergency department a few minutes before I did, but I was able to give her information for her to the nurses because she could not speak. I explained how she had gotten to the state she was in and let them know that she had had two nebulizer treatments already... The nurses were very attentive and the patient expressed to me that she was very grateful that I had gone to the ED with her because she was being taken care of quicker than in the past.” - PA

“In the office the patient was taken back for vitals and spirometry. The woman conducting the test was filling in for someone. The nurse handed me the spirometry and I noticed that it was not under the patient’s name. I handed it back and she printed the patient’s correct spirometry. Apparently the nurse had grabbed the wrong sheet from the printer and had not noticed.” - PA

The PA role was similar to that of visit companions. In 17% of the journals, patients told researchers that providers acted differently because a companion was present. Examples included a physician apologizing for long wait times, and following up after the visit before the patients and PAs left the practice.

Observations of patients’ interactions with practices

Seventy-six percent of the PA journals (35) recorded observations of patients’ interactions with medical staff, typically describing: patients’ reactions to information offered; questions patients asked; and providers’ recommendations, instructions for tests and medications.

“The patient expressed his shortness of breath problem, which he was having despite taking his asthma meds like the doctor had prescribed.” – PA

“The patient did not have many questions for the doctor. The patient brought a letter from her insurance company that they were no longer covering her medication. The physician called the number listed on the letter to file a medical exception.” – PA

In 7%, PAs recorded observations of patients’ interactions with practices: primarily wait times, how patients handled issues with insurance, and making appointments.

“After waiting almost two hours the patient was taken for vitals at noon. We then proceeded to wait in the waiting room until almost 2 pm when we were called back. ...At 2:45 pm the doctor arrived. The patient had lost considerable interest in following through on his appointment.” – PA

“At the time of enrollment the patient was insured, but became uninsured shortly thereafter and at the study’s conclusion, she was waiting for May, at which point she would be insured again.” – DC

DISCUSSION

The Patient Advocates' and Data Collectors' journals provided a surprisingly rich source of information that did not emerge in our observed conversations between patients and providers captured in research report forms. The journals described relevant aspects of patients' social background. Such information about the patient's environment can affect health (e.g. exposure to pollution) and also health behavior. For example, patients living in a neighborhood perceived to be unsafe may delay filling a prescription.(13) Journals' description of patients' perspectives, and PA activities centering on facilitating navigation of the health system, accessing care, insuring communication, and confirming understanding of medical information; all are useful in making recommendations. The information gained, particularly about navigating and interacting with the health system and practices, may be useful for improving practice operations and also for medical decision-making, but frequently is unavailable to practitioners. The use of teach-back by providers, or messaging and cues incorporated through an electronic health record to the patient or to other health care personnel are examples of potential interventions suggested by these journals.

As judged by frequency of description, the most pressing patient need was assistance with navigating the healthcare system. Assistance with navigation helped patients master the steps needed to access care such as: making appointments, obtaining referrals or test results, and phoning physician offices or insurance carriers. Teach-back was the second most frequently described activity. Teach-back ensured patients understood what was discussed during the visit, helping them internalize information about their medicines (type and how to take them) and their prescribed self-care activities. The need for teach-back is supported by a recent study of patients with diabetes. In that study physicians assessed recall and comprehension of new concepts in only 20% of visits for 12% of new concepts.(14)

Providers recognized the positive impact of the PA on their relationships with patients. PAs in this study played a similar role to other persons in patients' lives who might accompany patients to their visits. PA activities were designed to model appropriate behaviors for patients and then support patients as they began to take action. PAs frequently found themselves encouraging patient action and occasionally acting as advocates for patients. In their 2011 meta-analysis of studies of "visit companions", Wolff and Roter reported that 37% of adults have companions attending routine medical visits.(15, 16) Patients with visit companions were more likely to be older, sicker, and female. Visit companions were most often a spouse or adult child. Communication between physicians and patients was found to be partially based on the role of the companion in the visit. When the companion was more engaged, communication was enhanced as: 1) the patient was prompted to ask more questions, and 2) the companion gave the physician additional information about the patients' situations. (15, 16)

As in all studies, ours has limitations. Qualitative research deeply investigates a subject and focuses on relatively small samples of specific populations. Small samples can limit the generalizability of conclusions to larger populations; however, the information gained is often more comprehensive than through larger samples of quantitative research.(17) The majority of information obtained was not specific to asthma or, in a sense, to these patients, which increases its generalizability to patients in other settings and those with comorbidities.

CONCLUSIONS/KEY FINDINGS

Analyzing the journaled interactions between researchers and patients identified three categories of information important for clinicians and researchers to obtain about their patients. This information includes an understanding of: 1) patients' social environment that patients often do not realize is medically relevant to volunteer to physicians, 2) navigation

barriers and clinical practice patterns that might be addressed to improve patient access to care, and 3) the importance of confirming understanding of medical advice.

PA activities require time and therefore add to costs; however, our experiences suggest that not all patients need PAs. We found highly educated and employed patients did not enroll. Future studies and cost-effectiveness analyses can further clarify the costs and benefits from various perspectives including those of individual patients, practices, and society. Among those patients who need a PA, PAs are not likely to be needed indefinitely. A strength of this study demonstrates that PA activities need not be performed by medically trained professionals, thus, these activities could be performed by a variety of healthcare workers with a variety of training, or by individuals who serve more than one clinic. One important requirement is that these individuals are accepted and trusted by patients and healthcare workers alike. Also important is the ability to assist with navigation, improve access to care, conduct teach-back, facilitate information transfer between patient and provider, and to empower patients. It is possible that information transfer through the electronic health record could, in a cost-effective manner, facilitate navigation of the health system or communication between patient and providers or groups of providers.

In conclusion, providers should be alert to the need to prompt patients for information on patients' social context, their understanding of medical information, and navigation barriers.

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Table 1

Codes, definitions, sub-codes with their sources used in the codebook.

Code	Definition	Sub-Codes	Source
Patient situation	Information about the patient's environment or situation that is not overtly medical. Some aspects of a patients' situation includes medical issues that have happened in the past or do not have immediate bearing on the current appointment. They may be part of the patient's history if the asthma clinician knows about them. The sub category for these is "medical." Often the medical situation is interwoven with the rest of the patient's non-medical situation.	Patient situation - nonmedical Patient situation - medical	PA & DC
Patient reaction to study	Patients tell the PAs or DCs about their reactions to the study un-prompted. A sub-category of "patient results" was used when PAs or DCs observed or were told by patients about positive results or progress that a patient is experiencing. Some results may be new and therefore not captured in the current quantitative measures of the study.	Positive results or progress Other reactions	PA & DC
Patient Concerns/ Feelings about provider	Specific complaints or concerns that the patient tells the PAs or DCs about providers or the health system.		PA & DC
Observations	Personal observations about the patients and their situation made by PAs and DCs. Observations that describe the PA's or DC's thoughts about the patient's personality, improvement, and the amount that a patient may benefit from the PA program are "opinion". Another sub-category of observation is used when a PA observes something taking place that is before or after the patient is in the medical visit with the physician: "outside the medical visit." The final sub-category is used when the PA observes the interaction between the physician and patient in the visit "during medical visit."	Opinion Outside medical visit During medical visit	PA & DC
Health Issues	Specific complaints or health issues that the patient is bringing into the appointment and any information about their current treatment, or beliefs about the current treatment, that would be important for the doctor to know.		PA Only
Patient reaction to visit	Patients' reactions to the interaction with the physician that day or their reactions to the visit, un-prompted.		PA Only
Provider reaction to the study / changing behavior	The physician/provider changes his or her behavior, or engages in unusual behavior, as a direct result of the PA being in the visit.		PA Only
PA Duties	Documentation of the PA activities/duties in terms of: conducting the teach-back; giving the provider information about the patient's situation either directly or by encouraging the patient to tell the provider (disclosing situation); helping the patient navigate the healthcare system by assisting with making calls, helping with referrals, providing the patients with numbers to call etc. (assisting with process); discussing specific concerns that the patient had or reviewing specific information or answering questions (getting the facts); encouraging the patient to take specific action (encouraging patient action); and looking out for the patient during the appointment to make sure all goes well (advocacy).	Teach-back Facilitating communication Promoting navigation of the practice or health system Getting the facts Encouraging patient action Advocacy	PA Only

Table 2

Characteristics of Patient Subjects (n=46)

Age *	46 ± 15
Female	34 (74%)
Race	
Black	36 (78%)
White	4 (9%)
Other	6 (13%)
Ethnicity: Hispanic/Latino	1 (2%)
Reading comprehension **	31 ± 6.4
Numeracy ***	1.6 ± 1.3
High school graduate	34 (74%)
Household income <\$30,000/year	35 (76%)
Disease Severity	
Average Age of asthma onset *	19 ± 18
FEV1 percent predicted *	67 ± 17
# with at least one ED visit for asthma in past year	25 (54%)
# hospitalized in past year for asthma	13 (28%)
Comorbidities	
Hypertension	26 (57%)
Diabetes	13 (28%)
BMI *	33.8 ± 8.7

* Mean ± Standard Deviation**

** Short Test of Functional Health Literacy in Adults,(8)range 0–36, with score ≥ 23 adequate

*** Asthma Numeracy Questionnaire, (9) range 0–4.