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Intro practice

Incorporating patient input into the design of a disease management program for COPD

Ranjani K. Paradise^{a,*}, Eileen Dryden^b, David Elvin^c, Carolyn Fisher^a, Sharon Touw^a,
Lisa Trumble^c, Maren Batalden^c

^a Institute for Community Health, USA

^b Center for Healthcare Organization and Implementation Research, Department of Veterans Affairs, USA

^c Cambridge Health Alliance, USA

ABSTRACT

In the era of value-based payment contracts, there is increasing emphasis on disease management as a strategy for improving care quality and reducing costs. To design effective disease management programs, healthcare systems should understand the day-to-day experience of living with particular health conditions, and ensure that evidence-based services and interventions are adapted to align with the realities of patients' lives and their priorities. For healthcare systems operating with limited resources, there is a need for practical and small-scale approaches for collecting and using patient input as part of program design and operations. This case study describes a targeted interview process that Cambridge Health Alliance (CHA) used to gather patient input during the design of a disease management program for chronic obstructive pulmonary disease. The patient perspectives gathered through the interviews influenced several aspects of the program design. The key lessons from CHA's experience are: 1) A small-scale approach with cycles of 5–10 interviews can produce valuable insights for program design; 2) Short patient vignettes can be used to summarize patient data in a simple and compelling format; and 3) Clinicians' perspectives are critical for interpreting patient input and extracting information that is most likely to be useful for program design. CHA's approach provides an example of a systematic and practical process for gathering patient input that other healthcare systems can adapt to their local contexts.

1. Background

As value-based payment systems become increasingly common, healthcare delivery systems need to identify effective strategies for reducing costs and improving quality of care. Disease management programs can help accomplish these goals for patients with specific health conditions. "Disease management" generally refers to a systematic population-based approach to meeting health-related needs that emphasizes coordinated and comprehensive care along the continuum of disease and across the healthcare delivery system.¹ Most disease management programs are complex and have many components including registries for patient identification, evidence-based guidelines, patient education and self-management support, care management, and monitoring with process and outcome metrics.^{1–3}

To design effective programs, it is important for healthcare systems to understand patients' lived experience, and how that experience impacts care-seeking and disease self-management.^{4–8} Though the value of patient perspectives in this work seems self-evident, programs are often built by clinicians and administrators without active patient partnership. When patient input is not incorporated during the program design phase, significant resources can be invested in services that do not align with patients' priorities and do not achieve desired outcomes.⁹

Understanding patient perspectives is especially important in safety-net settings where many patients have unique challenges and complexities related to social determinants of health that require a 'whole-person' approach to care going beyond standard evidence-based guidelines.

Questions about lived experience with illness are often addressed in qualitative research studies, but these studies typically are not designed with operational goals in mind and do not focus on practical application of patient input into programmatic decision-making. While there are some published frameworks and approaches for incorporating patient perspectives into program design, these tend to be time-consuming and expensive and may require technical expertise not readily available in many healthcare delivery systems.^{6,7,10,11}

There is a need to identify smaller-scale pragmatic approaches for collecting patient input that can yield useful information for program design and improvement. Here, we describe how the patient voice was integrated into the design of a disease management program for chronic obstructive pulmonary disease (COPD) at Cambridge Health Alliance (CHA). This case study shares CHA's process for collecting patient input through brief, targeted interviews, and examples of some key insights that influenced program design and delivery.

* Corresponding author.

E-mail address: rparadise@icommunityhealth.org (R.K. Paradise).

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2. Organizational context

Cambridge Health Alliance is an integrated healthcare delivery system in Massachusetts that provides ambulatory care to a panel of 117,000 patients across twelve primary care clinics. CHA also maintains three emergency departments that manage approximately 100,000 visits annually, two community hospitals with a total of 200 inpatient beds, and a comprehensive continuum of behavioral health services.

As a safety-net system, CHA serves a diverse patient population and is committed to the care of vulnerable communities, including immigrant, refugee, and low-income populations. CHA's payer mix is about 22% commercial insurance, 26% Medicare, 44% Medicaid, and 8% uninsured or covered by the Health Safety Net (a state-run program for residents who are not eligible for or cannot afford to pay for health insurance).

CHA is actively building its capacity to function as an Accountable Care Organization (ACO) in several contracts with Medicare, Medicaid, and commercial insurance. Approximately half of the system's patients receive care through an alternative payment contract rather than traditional fee-for-service financing, and the proportion of patients managed within the ACO is growing annually.

3. Personal context

CHA's disease management effort is led by the Medical Director of Medical Management for the ACO (hereafter referred to as the "program director"), a practicing general internist who also serves as the institution's Associate Chief Quality Officer. The program director is committed to the concept that healthcare service outcomes are necessarily "coproduced" by patients and families working with healthcare professionals¹²; therefore, recognizing and supporting the critical role that patients play in creating their own health outcomes is fundamental to successful ACO performance. CHA's ACO leadership provided financial resources and executive sponsorship for the work described here, reflecting their dedication to developing programs in an intellectually rigorous and patient-centered manner.

4. Problem

A key element of CHA's population health management strategy is to develop disease management programs that improve outcomes and reduce costs for patients with particular chronic conditions. CHA focused initial disease management efforts on COPD, a relatively common chronic condition with fairly high rates of emergency department and hospital use. CHA commissioned a multidisciplinary task force to steer the COPD disease management effort. The task force began by building a quantitative description of the COPD patient population using data from the electronic health record (EHR) and available claims databases, reviewing the literature to identify evidence-based care guidelines, and identifying validated clinical quality metrics.

In reviewing the literature, the task force found that the breadth and heterogeneity of described COPD management programs^{13–15} made it difficult to determine the key ingredients for success and identify how best to invest resources, especially when considering vulnerable and complex patients. The evidence of effectiveness for reported programs was mixed, with one program even showing increased mortality for the intervention group.¹⁶ Furthermore, as with every chronic disease, COPD health outcomes and care costs are determined not only by the healthcare system and its available offerings, but also by the behaviors of patients.¹⁷ In the context of this complexity, the task force felt that it was critical to ground CHA's program design in an understanding of patient capabilities, resources, priorities, and limitations. Therefore, the task force prioritized gathering patient input as an important complement to the quantitative EHR data and the review of evidence-based guidelines and metrics.

CHA's goal was to gather practical information that could be readily applied to programmatic decision-making, rather than to conduct a qualitative research study using methodologies designed to produce generalizable knowledge. To accomplish this goal within existing resources constraints, CHA needed a systematic and low-cost process for gathering patient input that would yield useful information for program design and operations.

5. Solution

CHA considered several options for how to incorporate patient perspectives into the COPD disease management program design. First, the program director reviewed qualitative research on the lived experience of having COPD and gathered information from the online patient community PatientsLikeMe.¹⁸ These sources highlighted interesting themes, such as the prevalence of pain as a symptom associated with COPD,¹⁸ a sense of confinement and social isolation,^{19–21} significant emotional distress and fear,^{20,22–24} difficulty conducting activities of daily living,^{21,22,25} and the presence of other co-occurring conditions that take priority over COPD.²⁶ However, the published studies were conducted in varied settings, and it was not clear which themes were most relevant to CHA's patients. Program leaders felt that it was critical to understand the specific contextual experience of CHA's patient population, including how patients interact with the CHA system.

Program leaders considered engaging the existing Patient and Family Advisory Council, but this group was focused on providing general feedback about CHA's services rather than disease-specific input. Program leaders also considered including patients on the disease management task force; however, individuals with COPD declined the invitation, citing illness-related disability and difficulty leaving the house. Furthermore, the task force was of necessity often focused on internal operational workflows that would be of relatively low interest to most patient volunteers.

Informed in part by the United Kingdom National Health Service's Experience-Based Design framework,²⁷ the task force identified targeted patient interviews as a strategy that would allow collection of useful input from patients at key points in time, with the opportunity to probe about specific topics relevant to the program design. The task force also wanted to demonstrate to clinical stakeholders that the program aimed to create meaningful improvement in patients' lives, not just reduce costs. Interviews can produce compelling narratives, and the task force felt that sharing patient stories along with the ways in which patient perspectives influenced programmatic decisions would help build clinician support for the program.

In determining the interview approach, feasibility was a key consideration. The task force aimed to gather the minimal amount of information that would be useful for decision-making, and decided to conduct short, targeted interviews with cycles of 5–10 patients. Within this range, the actual number of completed interviews was based on practical considerations – success in connecting with patients within a reasonable timeframe – and judgments from clinical members of the task force about the representative quality of the solicited perspectives. As the goal was to inform local program design and improvement, CHA's Institutional Review Board (IRB) determined that these interviews were a quality improvement activity, not research, and the project did not require IRB review.

For the interviews, CHA partnered with the Institute for Community Health (ICH), a local organization with a long history of collaboration with CHA and extensive experience with patient and community interviews. For the first interview cycle, ICH developed an interview guide that focused on the experience of living with COPD, strategies for managing exacerbations, interactions with the healthcare system, and feedback on services and supports that the program might include (Appendix A). The target population was patients with recent COPD-related hospitalizations. Initially, ICH attempted to interview patients

on the inpatient units at CHA's hospitals. However, these patients were often busy with care teams or resting, resulting in ICH staff spending unproductive time at the hospital waiting for patients to become available. Even when available, some patients were too ill or tired to participate meaningfully in interviews. ICH completed two interviews this way, but pivoted to a telephone interview approach for the rest of the cycle. For the telephone interviews, the program director provided a list of recent COPD-related hospital discharges, and ICH called those patients during business hours. ICH made approximately three phone calls for each completed interview, and most unsuccessful attempts were due to patients not picking up the phone, rather than declining to participate. The telephone method was more efficient than in-person interviews, resulting in only a few minutes of unproductive time for unsuccessful calls, compared to 1–2 hours of unproductive time for some in-person interview attempts. ICH completed three telephone interviews, and interviews were typically about 15–20 minutes long.

Rather than completing a thematic analysis as is typically done in qualitative research studies with sample sizes that achieve data saturation, ICH prepared a profile of each patient - a one-page vignette that illustrated the patient's story (Appendix B). These were reviewed by approximately 10 clinical members of the disease management task force, including physicians, nurses, and pharmacists, who used their clinical experience to identify aspects of the interviewees' stories that would likely resonate with the broader patient population. Incorporating clinicians' perspectives was critical for interpreting the patient input and identifying which pieces of information should inform decision-making. From the initial set of interviews, the disease management task force gleaned several insights that informed programmatic design. For example, the task force learned that some patients were interested in having a "rescue pack" of medications²⁸ that would help them more effectively manage COPD exacerbations at home, and that the rescue pack protocol needed to be tailored to patients' comfort level and ability to safely administer medications. Interviews also highlighted the prominence of depression and anxiety among patients with COPD and led the team to build screening and referral for mental health services into the COPD care bundle. See Table 1 for a more comprehensive summary of information from interviews.

A second interview cycle was conducted in the following year. For this cycle, ICH used the same basic telephone recruitment approach, but also offered a \$20 gift card to participants. Because ICH did not experience difficulty recruiting patients for telephone interviews in the first cycle, the purpose of the gift card was to thank patients for their input, not to increase the participation rate. The primary aim for the second interview cycle was to inform the design of a new pulmonary rehabilitation program, and a secondary aim was to build on the initial set of interviews and deepen understanding of patients' experiences living with COPD. For these interviews, CHA clinicians recommended patients who would benefit from pulmonary rehabilitation as potential interview participants. ICH completed eight interviews in this cycle. As with the first cycle, ICH prepared a profile for each participant, and the profiles were reviewed by clinicians. These interviews reinforced some of the findings from the first cycle and also highlighted insights specific to the pulmonary rehabilitation program (Table 1). For example, the task force learned that the program should be targeted at patients with less severe disease who would be more able to engage, and that transportation would be a significant barrier for many patients.

Overall, the two cycles of patient interviews provided perspectives and input that were critical in helping CHA define a COPD disease management care bundle that incorporated patient priorities as well as the available evidence base and externally developed guidelines. The interviews also helped program designers anticipate challenges patients might encounter in engaging with the program. Informed in part by the interviews, CHA ultimately arrived at a service bundle that includes five key elements: 1) tobacco cessation, 2) pharmacist referral for inhaler teaching and rescue pack prescription, 3) pulmonologist referral for medication optimization and pulmonary rehabilitation, 4) mental

health screening and treatment if necessary; and 5) attention to advanced care planning and palliative care services if appropriate. Though many of the elements of this bundle are supported in the published literature on COPD – the importance of tobacco cessation²⁹ and inhaler teaching,³⁰ the impact of pulmonary rehabilitation and the challenges of engaging patients,³¹ and the importance of attention to mental health^{32,33} – the interviews provided a critical lens for interpreting and prioritizing the available evidence.

Through this work, CHA developed a systematic and streamlined process for gathering patient input that involved the following key steps: 1) developing interview questions that can elicit operationally useful information and also enable open-ended exploration of the patient illness experience; 2) using clinician input to identify representative patients to interview; 3) conducting a small set of interviews; 4) preparing brief patient profiles to function as "personas" that can ground program design discussions; and 5) partnering with clinicians to review profiles and identify the information that is most relevant to program design. Since the time of this work, CHA has used variations of this small-scale interview process in the early stages of program design for other disease areas, and has found the resulting patient input to be extremely helpful.

6. Unresolved questions and lessons for the field

With a small-scale interview approach, the aim is not to reach the standard of data saturation typically used for qualitative research, but rather to gather a set of patient perspectives that can inform program design. With the limitations that are inherent to small convenience samples, it is important to utilize other information sources to corroborate the information gleaned from interviews. For CHA, involving multidisciplinary clinicians in interpreting this information was an essential step, as clinicians were able to use their subject matter expertise and patient care experience to identify what was likely to be reflective of many patients rather than idiosyncratic to an individual interviewee. The second cycle of interviews also provided an opportunity for CHA to gather additional patient perspectives on some of the topics that were raised during the first cycle. Finally, when making programmatic decisions, the disease management task force considered the patient interviews together with several other sources of information, including the academic literature on the lived experience of having COPD, evidence-based guidelines for COPD management, internal EHR data, and claims reports.

A key lesson learned through this work is that simple patient summaries are sufficient and high-value for program design purposes. The brief and targeted nature of CHA' interviews facilitated the creation of short profiles that painted a picture of how each patient experiences COPD. Although some of the information gleaned through the interviews had been previously described in the literature, the profiles added value by highlighting the relevance of the issues for CHA's own patients and bringing the concepts to life, especially for administrators. The profiles were also used to introduce clinical teams to specific elements of the COPD service bundle. By keeping the patient voice at the forefront during the program design and development, the profiles connected the disease management agenda with patient care values and helped assure clinicians that patient needs remained a top priority.

Two unique factors helped make this work possible at CHA. First, CHA's ACO leadership saw value in gathering patient input, and dedicated financial resources to the interview process. Even a small set of interviews requires staff time, and this must be included in the program budget for the work to remain a priority. For other institutions interested in doing something similar, the authors recommend budgeting approximately 7 h per interview as a starting point – this includes the staff time required from start to finish, including developing interview questions and writing summary profiles. In CHA's experience, telephone recruitment for COPD interviews was efficient and low-cost, because the nature of the illness and the older patient demographic meant that

Table 1
Key findings from qualitative interviews of patients with COPD.

Key finding	Descriptive details	Implications for program design
Urgency associated with a COPD exacerbation and the reliance on 911	Patients shared feelings of anxiety and fear associated with a COPD exacerbation. Several patients described reaching out to family, friends, and neighbors during the onset of a disease exacerbation. None described reaching out to primary care. Interviewees generally felt that 911 was the only option and some had mixed feelings about this.	The emotional and physical intensity of disease exacerbation or “flare” is incompatible with the tempo of a primary care clinic response. In order to avoid potentially avoidable ED visits, CHA introduced the COPD rescue pack. Though most patients were supportive of the idea of initiating treatment on their own, at least one expressed concern about that level of independence, saying “I am not a doctor, how would I know when I really should take it?” Due to the heterogeneity of patient confidence and capability, CHA recognized that the COPD rescue pack protocol must be tailored and monitored for safety.
Challenges with medications	Several patients noted that they were not entirely sure what medications had been prescribed and which of their medications were for COPD. Some expressed concern about side effects and difficulty with navigating insurance coverage for inhalers. As one patient said, he needed to be sure that he had all his medicines lined up in the morning because he had “a bad case of Alzheimer’s.”	Recognizing the challenges associated with polypharmacy and difficult device delivery systems for inhaled medications, CHA incorporated into the care bundle a consultative referral with a clinic-based pharmacist for dedicated sessions of medication management and inhaler teaching.
Resignation and shame about the illness	Knowing that there is no “cure” for COPD, several express a fatalistic attitude toward disease management. As one patient stated, “Sometimes it hurts, but what can you do?” Recognizing the role of tobacco use in COPD, some expressed regret. One patient noted that she had “done it to herself” and another said in reference to his COPD diagnosis, “What did I expect? This is not a surprise”.	The emotional experience of the illness contributes significantly to patient overall well-being. Though not prominently noted in most evidence-based guidelines, CHA elected to incorporate into the care bundle screening for depression and anxiety and referral to mental health services.
COPD as one of several medical problems	Several patients expressed the opinion that their COPD was less problematic in their daily lives than other medical conditions such as chronic diarrhea, obesity, or back and leg pain. In the face of other co-occurring conditions, some did not feel that improving COPD management was a priority.	Given the prevalence of comorbid conditions for patients with COPD, CHA elected not to hire dedicated disease-specific coaches or care managers for COPD. Rather, CHA opted to work with existing clinical staff and care managers to incorporate COPD-specific scripts and tools into whole-person care plans. Recognizing that many patients with advanced COPD and other co-occurring conditions are nearing the end of life, CHA also incorporated attention to end of life preferences and referral to palliative care.
Daily limitations imposed by COPD and resulting value of home-based services	For many, shortness of breath limits walking, climbing stairs, engaging in activities of daily living, or getting together with friends and family. Many patients reported being largely housebound. One patient made reference to a home care provider but noted that this person did not provide COPD education or self-management support.	The dyspnea associated with the illness complicates patients’ active participation in programs. Recognizing the difficulty of leaving the home for patients with COPD, CHA chose to expand partnerships with Visiting Nurse Association (VNA) services and engage VNA staff in delivering elements of the self-management program. With the significant burden that this disease imposes as it progresses, CHA learned that pulmonary rehabilitation should be targeted to patients with less severe disease.
Transportation barriers limiting engagement in hospital-based programs	Most of the interviewed patients did not drive and relied on cabs, public transit, or family members to get to CHA. Transportation barriers were significant and limited patients’ ability to participate in hospital-based programs such as pulmonary rehabilitation or access services outside of the home.	Recognizing that transportation would be a significant barrier, the pulmonary rehabilitation coordinator enrolls patients in a public transportation service that provides door-to-door transportation for patients meeting eligibility criteria. CHA also makes use of a partnership with a local ambulance company and is exploring the possibility of a dedicated account with a commercial ride share service.

patients were likely to be home when the interviewers called. Adaptation of this approach to other disease areas or patient populations may require different recruitment approaches, and this could change the time investment required.

The partnership with ICH also facilitated this process by giving CHA access to staff with relevant professional experience, thus minimizing the time required from CHA’s clinicians and leadership. Though ICH may be a unique resource, clinical leaders in other institutions may be able to identify opportunities for collaboration with students, community-based social service or advocacy organizations, or staff within their healthcare system’s quality improvement and/or patient experience departments.

Healthcare organizations in the United States are rapidly transforming their operations and care delivery models to align with value-based payment systems. Many institutions are actively engaged in the design of population health services such as disease management programs and other initiatives to improve quality and reduce costs. Incorporating information about the patient experience into program design can facilitate successful achievement of these goals, especially for systems caring for vulnerable and complex patients. CHA’s small-

scale interview process could be a useful example for other institutions seeking a practical approach for collecting patient input to inform program design.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.hjdsi.2019.05.003>.

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