

Eliciting the Patient Experience: Qualitative Interviews with Latina Patients with Chronic Pain to Improve Care

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Abstract

Chronic pain is an increasingly common diagnosis in primary care and social determinants seen in community health center patients, as well as Latina women, strongly influence outcomes. As part of an internal quality improvement project, we interviewed patients with chronic pain (N=17) at an urban community health center. Interview themes point to the prevalence of psychosocial comorbidities and the all-consuming physical and emotional nature of chronic pain. Patients expressed interest in non-pharmacologic, mind-body approaches to pain treatment as well as support groups and health coaching. Based on patients' experiences and feedback, we are designing a pilot group visit intervention.

Keywords: Chronic pain, Latina women, Quality improvement, Community health, Patient interviews

Introduction

Chronic pain is an increasingly common diagnosis in primary care. Social determinants-including income, education, primary language, gender and sex-strongly influence outcomes [1]. Community health center (CHC) patients experience co-morbid illnesses and social disadvantage based on low-income, immigrant, and non-English-speaking status and high rates of unemployment [2]. Women with pain are particularly vulnerable to social isolation, lifetime exposure to trauma, and mental health effects [3, 4]. Amidst the crisis in opiate use, it is critical to design programs that reduce pain, promote well-being and incorporate a wide range of treatment modalities. However, residents of low-income communities have less access to approaches available to more affluent patients including physical therapy, massage, acupuncture and mind-body techniques [5, 6]. The multidisciplinary model of CHCs supports clinical innovations including cross-disciplinary collaboration, medical and mental health co-location, and use of nurses and support staff in extended roles. Eliciting patients' perspectives is critical in designing new approaches to care.

Brookside Community Health Center is a multidisciplinary community health clinic in Jamaica Plain, Massachusetts, affiliated with Brigham and Women's Hospital and Harvard Medical School. Brookside's patient population is predominantly Latino and low-income and over half of patients are insured through state Medicaid programs. In 2014, clinicians and administrators at Brookside identified chronic pain as a prevalent chief complaint within the CHC that called for collaborative efforts to improve care. Furthermore, opiate prescribing and misuse

have received increased focus from local, state, and national policy efforts [7, 8]. In addition to the risks of misuse and overdose, evidence to support the use of narcotics to manage chronic pain is slim [9]. This focus calls for medical providers and the health system to look beyond opiates in chronic pain management. Brookside's peer CHCs in greater Boston has implemented clinical innovations to improve care for this patient population.

Description

We developed a semi-structured thematic interview to elicit detailed descriptions from patients about their experience of chronic pain. We situated patient interviews within a literature review, site visits, focus groups, and key-informant interviews to develop a sustainable model of care for patients with chronic pain that utilizes the full spectrum of health center resources and offers a wider range of modalities than prescription pain medications.

The interview included questions in the following categories: general background; health history; pain history; impact of pain on daily living and function; meaning of pain; coping mechanisms; social support and familial views on pain; experience of pain treatment in the medical system; views on medication; use of or interest in non-medical approaches and modalities for pain; and treatment goals.

We initially recruited women aged 18-65 with chronic pain and medical co-morbidities who had used narcotic medication for more than six months and had three or more emergency room visits for any reason in the past year. Eligible patients were referred to the interview by their primary care provider or by facilitators of a bi-weekly women's mindfulness group at the CHC. A research assistant conducted the interviews in Spanish or in English. After reaching

thematic saturation, we opened recruitment to male patients, non-Latino women, and to patients who control their pain (of at least three months) with non-narcotic medications and/or other modalities in order to broaden our understanding of the pain experience of our target group. Of the 17 interview subjects, 12 (71%) were female and 13 (76%) were Latino/a.

Patients provided verbal consent for the research assistant to take notes and/or record the interview. Interview notes were reviewed independently by a primary care physician and a research assistant for themes.

In addition to in-depth interviews, we conducted focus groups in which patients reviewed clinical tools to measure pain and other patient-centered outcomes. We conducted site visits at local CHCs and academic medical centers to observe clinical innovations designed to improve models of care for vulnerable patients with chronic pain or for Latina women.

This project was undertaken as a Quality Improvement initiative at Brookside, and as such was not formally supervised by the Brigham and Women's Hospital Institutional Review Board per their policies.

Results

Patients valued the opportunity to express themselves and feel listened to and heard. The interview was received positively by patients as an effort of the CHC to understand and validate their experiences of chronic pain. Primary themes from interviews include chronic pain as an agent of transformation in patients' lives; prevalence of psychosocial co-morbidities; and the all-consuming physical and emotional nature of chronic pain. As one patient described pain's overwhelming influence on her daily life: "I can't wake up in the morning and be in peace."

Another salient theme in our patient population is the familial expectations of care giving placed upon women, even when pain inhibits their daily living and function. The responsibilities of this caregiver role can isolate patients from their family members: as one patient described, "My children only understand [my pain] if they're sick. It gets frustrating because you're there for everybody but nobody can be there for you. So I stick to myself."

Patients value faith or religious practice, such as prayer, in coping with their pain; this theme suggests an area of potential development for CHCs which are well positioned to partner with community-based organizations, as well as the potential endorsement by CHCs of mind-body techniques that parallel activities patients initiate on their own. Of the seven subjects who endorsed prayer as a method of pain management, two connected their practices of prayer and meditation.

Patients hold divergent opinions on the role of narcotic medication in their pain management. Overall, patients expressed reliance on narcotics' pain relief and frustration at their short-term effects. Alongside this general ambivalence, five patients spontaneously expressed wanting to limit or decrease the dose of their prescription medication.

Some patients have tried non-pharmacologic approaches and modalities-including mental health care, yoga, physical therapy, and meditation-to manage their pain. Among those patients, experiences with non-medical approaches to chronic pain vary. Of the five

patients who have received mental health care, three have found it helpful to discuss their pain with a counselor while two have found it unproductive to talk about their pain. This divergence reflects a larger theme from the interviews: patients express varying degrees of comfort with any sort of self-disclosure of their pain. Some patients find empowerment in sharing experiences with pain with family and friends; others describe discussing pain as alienating. Further, within this predominantly female and Latina population, some women wish to not burden their family or friends by discussing their pain.

Among patients both with and without prior exposure to non-pharmacologic modalities, most interest is expressed for massage, exercise support/physical therapy, and acupuncture. Patients expressed lesser but marked interest in yoga, meditation, sleep therapy, and creative outlets. Perceptions of these mind-body approaches vary alongside the extent to which patients understand their pain as a strictly medical condition. Patients for whom chronic pain represents a strictly medical illness find mind-body techniques less appealing or worthwhile.

Patients value their relationship with their primary care provider, but they recognize constraints on providers' time and accept the potential role of other team members, especially as a means of increased access to CHC resources. Patients expressed high interest in a support group and interacting with a health coach to help navigate their pain management.

In patient focus groups, measurement tools were perceived positively as means of validating experiences and marking clinical progress.

Lessons learned

Based on these interviews, we have designed a pilot intervention that incorporates our patients' experiences and values, as well as best practices at peer institutions in the management of pain in primary care settings [10]. Instead of a monthly PCP visit, patients will attend a group session for pain. While patients will see their PCP for a brief visit immediately before or after the group, the group will allow them interaction with a wider range of CHC providers and staff. An RN and a mental health provider will together facilitate each session; medical assistants and LPNs will provide support; and, each session will incorporate patient education led by experts in specific components of pain management. This rotating curriculum will include sleep hygiene, nutrition and physical therapy, as well as creative and reflective activities. Each session will conclude with mind-body techniques, including yoga, meditation and massage. To maximize impact, the group sessions will emphasize home practice and medical assistants will contact patients in between monthly sessions for coaching conversations about skills and strategies in pain management.

This structure will provide patients increased time and support at the CHC as well as a wider range of tools for pain management.

Conclusions

In a community health setting, engaging patients in the improvement of their care allows their experiences to be heard and understood. Chronic pain is often all-consuming and merits an in-depth exploration of its impact on patients' lives. Brief, provider-driven medical visits do not enable in-depth exploration of patients' experiences, values and preferences regarding chronic pain and treatment options. Providers may underestimate patients' interest in treatment modalities that might complement or ultimately substitute

for chronic use of narcotics. An in-depth quality improvement interview allows for increased understanding between patient and CHC and directly incorporates patients' feedback into innovative models of care.

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Declaration of conflicting interests

The Authors declare that there is no conflict of interest.

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