

PRIMARY CARE & HEALTH SERVICES SECTION

Original Research Article

“They Don’t Want Anything to Do with You”: Patient Views of Primary Care Management of Chronic Pain

Carole C. Upshur, EdD,* Gonzalo Bacigalupe, EdD,† and Roger Luckmann, MD, MPH*

*Department of Family Medicine and Community Health, University of Massachusetts Medical School, Worcester;

†Department of Counseling, University of Massachusetts, Boston, Massachusetts, USA

Reprint requests to: Carole C. Upshur, EdD, Department of Counseling, Graduate School of Education, University of Massachusetts, 100 Morrissey Blvd., Boston, MA 02125, USA; Tel: 774-443-7267; Fax: 774-441-6212; E-mail: carole.upshur@umassmed.edu.

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Abstract

Objective. Chronic pain is one of the most frequent complaints of patients in primary care, yet both patients and providers report low satisfaction with chronic pain care. This study was designed to explore the views held by a diverse sample of patients with chronic pain complaints about their care experiences to identify ways to improve care.

Design. Qualitative analysis of 17 patient focus groups (size 3–7 participants). Groups used structured questions and were tape recorded, transcribed, and coded using qualitative software.

Eleven groups were conducted in English, six groups in Spanish.

Patients. Convenience sample of 72 adult patients (68% female, 44% Latino, mean age = 48.1 years) recruited from four diverse primary care practices in Central Massachusetts.

Results. Across all 17 groups, and all gender, ethnicity, and age groups, most patients reported suboptimal interactions with their providers when seeking care for chronic pain. Subjects acknowledged feeling disrespected and distrusted, suspected of drug-seeking, and having their symptoms dismissed as trivial and/or not warranting medical care. Patients reported more satisfaction when they felt a provider listened to them, trusted them, was accessible to address pain concerns between visits, and used patient-centered approaches to establish goals and treatment plans. Patients also recommended some management techniques related to the chronic disease management model to improve pain care.

Conclusions. Implementing patient-centered approaches in caring for individuals with chronic pain and using principles drawn from the chronic disease management model to improve care systems may improve both patient and provider satisfaction with chronic pain care.

Key Words. Chronic Pain; Patient Views; Primary Care; Pain Management; Qualitative Methods; Focus Groups

Introduction

Population estimates suggest that 13–46% of the adult population has experienced chronic pain [1–7], one of the most common patient complaints occurring in primary care practices [8,9]. Studies have shown that physicians report insufficient training in pain management, and rate their satisfaction with treating chronic pain lower than treating acute, cancer, or terminal illness pain [8–10].

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Patients are also dissatisfied with care for acute and chronic musculoskeletal pain. In one study, only 9% of low back pain patients reported that treatment helped, and only 29% were satisfied with their last treatment [11]. In another study, only 18% rated care "excellent," and only 59% would recommend the physician to friends [12]. The current study was conducted as part of a multi-faceted investigation of provider and patient views concerning treatment of chronic pain in primary care. Results from providers have been previously reported [9,13]. The focus here is to explore patient views of their care experience, and to use such perspectives to inform possible practice improvement strategies.

The research team included sociologists and psychologists with experience in focus group and qualitative methods, but no prior experience working with chronic pain patients, and a primary care physician with an active panel of chronic pain patients. The theoretical orientation was that patient-centered care [14,15], for example, patient-provider shared decision-making and open communication, would be viewed as positive by patients. The investigators anticipated that Spanish-speaking Latino patients might have different perspectives than patients fluent in English, and therefore we oversampled for this group. The study was approved by the University of Massachusetts Medical School Institutional Review Board and all focus group participants provided informed consent.

Methods

We recruited a convenience sample from four large primary care practice populations in Central Massachusetts. Three sites were Federally Qualified Health Centers; one was a hospital-based family medicine clinic. Letters and flyers in both English and Spanish invited patients to call a bilingual telephone line to express interest or to return a pre-addressed envelope with contact information. Flyers were posted in waiting rooms and given to appropriate patients by providers or nursing staff. Providers and nurses were encouraged to identify patients who met the inclusion criterion of having any type of nonmalignant pain complaints (inclusive of musculoskeletal pain, arthritis, headache, abdominal pain, neuropathic pain, general pain, fibromyalgia, or other chronic pain) for at least 3 months in the last year, or who were receiving prescription medications for chronic pain for more than 3 months. Patients with acute pain complaints, or cancer-related pain were excluded. At two sites, a bilingual nursing assistant called patients recommended for the study by providers. Respondents received a telephone screening in their preferred language to verify they met the inclusion criteria, collect basic demographics, and schedule groups held at the clinic sites. Reimbursements for transportation, and for childcare were provided, as well as a gift card.

Groups were run by one of the first two co-authors, or one of two other PhD collaborators, and lasted 90 minutes. Originally, 12 groups were planned with anticipated attendance of 6–8 in each group. Because attendance was often less than expected, additional groups were sched-

uled to assure the study included a wide diversity of patient backgrounds, and to reach theoretical saturation. Each group had a research assistant to help with administration and to take process notes. The two bilingual team members and a bilingual research assistant conducted the Spanish language groups. Facilitators used five scripted questions and additional probes: 1) Tell us how your pain started and what medical help you have asked for to treat it (probe for cause of initial pain, type of pain, examples of treatment sought); 2) How have things gone since your pain started? (probe for what seems to work well in relieving pain, what has not worked so well; life style and other impacts); 3) Are there things doctors/nurses ask you to do about your pain that you find hard to do? (probe for difficulties following through with physical therapy or exercise; work and home activity restrictions; getting to appointments or picking up prescriptions; views about being referred for mental health counseling); 4) What things do you do for yourself that seem to help your pain? (probe for exercise, biofeedback, complementary and alternative medicine, relaxation techniques, social support); and 5) What recommendations would you make to your doctors and nurses about the best way to help you deal with your pain problem? At the end of each group, the facilitator and research assistant wrote a field note describing the main themes. These were used to monitor for theoretical saturation.

Groups were tape recorded, and transcribed. Transcripts were entered and coded in NVIVO-8 qualitative software [16]. The four group leaders and one research assistant each developed initial open coding themes based on two randomly selected transcripts using the framework of grounded theory [17]. Themes were discussed, discrepancies resolved, axial coding (higher order categories such as "barriers to care") was created, and then each transcript recoded. Initial open and axial themes were used to code 6 additional transcripts. New codes and axial categories were generated on an iterative basis. Inter-coder reliability for multiple pairs of coders was assessed for eight transcripts. Discrepancies were resolved to 85% agreement, transcripts were recoded, and then team members who participated in inter-coder reliability coded the remaining transcripts. Subsequently, texts were organized by codes in order to synthesize and produce narrative description. The physician author participated in reviewing coded text and synthesizing and developing the final narrative.

Results

Participants

Seventy-two individuals, out of 117 who expressed interest, participated in 17 groups of 3–7 participants. No differences in gender, ethnicity, or health insurance status were found between participants and nonparticipants, however participants reported more co-morbid medical conditions ($P < 0.05$). Eleven groups were conducted in English and six in Spanish. The majority of participants were female, and middle-aged, with about equal numbers

Table 1 Characteristics of study participants (n = 72)

Variable	N (%)
Gender: Female	49 (68.0)
Age (Mean) (SD)	48.1 (9.5)
	Range 21–68
Ethnicity	
White	36 (50.0)
Hispanic	32 (44.4)
African American or Other	4 (5.5)
Years education (Mean) (SD)	11.9 (3.4)
U.S. born	43 (59.7)
Years in U.S. non-U.S. born (Mean) (SD)	20.7 (12.3)
Employed	17 (23.6)
Type of reported pain	
Low back pain	49 (68.0)
Arthritis	37 (51.4)
Neck pain	26 (36.1)
Headache/migraines	25 (34.7)
Hand pain	21 (29.2)
Pelvic pain	13 (18.1)
Fibromyalgia	9 (12.5)
Abdominal	7 (9.7)
Neuropathic	5 (6.9)
General	5 (6.9)
Other	43 (59.7)
Medical co-morbidity	
Overweight	29 (40.3)
Hypertension	28 (38.9)
Asthma	23 (31.9)
Diabetes	17 (23.6)
Heart condition	8 (11.1)
Any health insurance	68 (94.4)
Medicaid insurance	47 (65.3)
Self reported health status	
Poor	21 (29.2)
Fair	31 (43.1)
Good	17 (23.6)
Excellent	3 (4.2)
Pain rating at time of group participation	
None	1 (1.4)
A small amount	4 (5.6)
A moderate amount	47 (65.3)
A large amount	20 (27.8)

of White and Latino ethnicity (see Table 1). Almost all had public health insurance. Only 23.6% were currently employed. Participants reported multiple types of chronic pain, the most common being low back pain.

Themes

Eight major themes were identified, each with a number of subthemes: description of pain, consequences of pain, care outcomes, barriers to care, coping strategies, good provider–patient relationships, general life philosophy, and comments about the focus group. Here we focus on provider-related barriers to care and the provider–patient relationship.

Barriers to Care

Provider-related barriers were central themes in all groups and most subthemes appeared in multiple groups (see Table 2). Embedded in the stories of many participants were perceived failures of providers to fully respect, trust, and accept the patient, to offer positive feedback and support, and to believe the participants’ reports of the severity and adverse effects of their pain. Participants reported being “labeled” as hypochondriacs, and accused of drug seeking and of lying about their experience of pain, regardless of presenting with chronic musculoskeletal pain (e.g., nonspecific lower back); congenital conditions, or what ended up to be definitive acute health problem. A respondent with a congenital condition said: “I was born with a club foot and I was having trouble with my foot at that time and the minute I walked into his office . . . he did nothing but put me down” (Group 12, paragraph 139). Another participant with severe migraines was told to go home and take ibuprofen because:

You know they seem to have a mentality and if they do give you pain medication, it’s like, hum, it’s like you are a drug user . . . they don’t take you serious . . . finally they got so tired of my whining that they did an MRI and low and behold they found a brain tumor. (Group 16, paragraph 30)

Some participants reported feeling that providers viewed them as undeserving of treatment, and it was implied that they kept providers from seeing a sick child as quickly, or other patients with more important needs. They experienced providers avoiding them, hurrying them, or minimizing their pain:

And so sometimes you kinda feel like they give you the cold shoulder or they want to get rid of you, usher you out real quick. You know and that’s not a good feeling. (Group 4, paragraph 250)

Participants also stated they felt they received lower quality of care than other patients, as well as inadequate time with the provider:

I show up before time then I have to sit in a room another half an hour while he is attending 10 other patients at one time . . . then he comes in and asked me “how are you feeling, how is your pain? . . . Okay, I’ll fill the prescription” and in 5 minutes I am at the door . . . I’m in there for 2 hours, he comes and gives me a prescription and kicks me out the door and says I’ll see you in 3 months. That’s a lot of care, right? (Group 10, paragraph 383)

Participants of all ages indicated that providers sometimes stopped or limited opioid prescriptions because of concerns about abuse or diversion. A few participants openly admitted an addiction history and conveyed they understood provider concerns, while others who had no such history felt they were automatically treated suspiciously. In three different groups, participants also suggested providers were concerned about legal or insurance oversight.

Well I think the pain medications that I used worked, but she didn’t want to keep giving it to me and she didn’t want to raise the number of pills . . . I

Table 2 Frequencies of major themes and subthemes coded in English speaking groups (n = 11) and Spanish speaking groups (n = 6)

Theme or Subtheme	English Speaking Groups n (%)	Spanish Speaking Groups n (%)
Theme: Barriers to care-provider domain	11 (100)	6 (100)
Subthemes:		
Provider does not provide positive communication to patient	11 (100)	5 (83)
Provider does not believe pain is real	11 (100)	4 (67)
Provider rejects or pushes away patient	10 (91)	3 (50)
Provider shows mistrust of patient	9 (82)	2 (33)
Provide limits opioid prescriptions	9 (82)	1 (17)
Provider does not show respect for patient	8 (73)	1 (17)
Provider does not spend enough time with patient	5 (45)	3 (50)
Provider does not refer to specialists	2 (18)	4 (67)
Provider stops treatment (especially opioids)	2 (18)	2 (33)
Patient has difficulty communicating with provider due to language barriers	0	2 (33)
Theme: Good patient-provider relationship	11 (100)	6 (100)
Subtheme: Provider cares about patient	11 (100)	6 (100)
Provider listens	11 (100)	3 (50)
Shared decision making	11 (100)	3 (50)
Provider is empathic	10 (91)	4 (67)
Provider trusts patient	10 (91)	3 (50)
Provider understands patient's pain level	10 (19)	0
Flexible prescribing practices	9 (82)	3 (50)
Provider understands affects of different medications on patient	8 (73)	4 (67)
Provider gives clear information	7 (64)	1 (17)
Subtheme: Ways providers or practices could improve pain management	11 (100)	4 (67)
Improve access to care (appointments, prescription pick up, referrals)	7 (64)	3 (50)
Use technology (electronic medical records, electronic "chips")	4 (36)	0
Work with office staff (teams, coverage for absent providers)	4 (35)	1 (17)
Allow direct phone contact with provider	3 (27)	1 (17)
Provide e-mail or voice mail access to provider	2 (18)	0

think she was afraid . . . she told me. I'm not losing my license because of you. Start writing pain prescriptions, they start looking at your license and I can't do that. (Group 5, paragraphs 801 and 805)

Positive Provider–Patient Relationships

Participants also described good relationships and caring providers. The elements of a positive provider–patient relationship were grouped under two overarching themes: one involving the ways providers express genuine concern for the patient, and one about how providers do or should facilitate access to care (see Table 2). Themes of caring and empathizing were common, and these were strongly linked to themes of listening to the patient, understanding the patient, and shared decision making, especially about medications. Patients who felt affirmed described, “you can tell he’s actually listening to you . . . he knows I am in pain.” In addition to just being empathic, however, patients indicated that the most positive experience was when the provider “. . . acknowledged people’s intelligence on what’s working and not working,” instead of using criteria that might not be related to the particular patient’s circumstances.

Patients also recognized that providers were wary about opioid medications because of the potential for misuse. At the same time, they wanted a genuine engagement in finding a workable treatment, such as developing a plan with “options” and reviewing the options and recommendations with the patient.

If they don't want to give you narcotics that's fine, give me [something else]. Don't tell me to go home and take Motrin. (Group 16, paragraph 312 & 314)

For those patients where opioid medications provided relief, patients were very positive about providers who let them have some control over dosing, such that they could have extra doses during times when they had to be especially active.

. . . during [harvest season], I've got five acres to pick out there with the guys and I need a little something extra this week. (Group 4 paragraphs 28, 78, 340–342)

Another important dimension of positive provider interaction was acknowledgement of patients as individuals with goals and responsibilities beyond their pain

treatment. This included making sure that the patient did not misuse medication:

... find out about the person. What did you do, where do you see life going? ... You got kids? ... The only way you're really gonna understand me and keep your eye on me is I want you to know me a bit. To make sure I'm not fooling you. (Group 4, paragraph 332 & 671)

System Barriers and Recommendations

Participants expressed concern about barriers to talking to or seeing their providers promptly, particularly around prescription renewals and breakthrough pain episodes. To address these barriers, participants recommended improved access through use of direct phone lines to leave providers voice mail messages, and the use of email.

Another barrier to care was limited provider access to comprehensive documentation of their pain condition and treatment. Participants noted that when they had to see a provider other than their usual primary care physician (PCP), the alternative provider often could not access treatment history information needed to assist them adequately. Improvements recommended included the use of electronic records, or an electronic "chip" carried by patients, encoded with information about a patient's pain diagnoses and treatments that any provider could "read."

Many participants felt that providers and office staff perceived them as a "burden." To address this issue, several participants also suggested that pain care "teams," including nurses or a "professional liaison" for them to the medical provider could be helpful. These teams would be aware of, and responsive to, the special needs of pain patients including need for frequent contact with providers, prescription refills, and referrals.

... people who come in with chronic pain ... if there could be one or two persons that could be ID'd as people who are the pain persons, like Doctor X is out, which is my primary provider, but the person I'm going to be calling is Ms. Y, that knows all the pains [sic]. (Group 6, paragraph 651)

Discussion

The purpose of this study was to identify both positive and negative aspects of the pain treatment experience from the patient point of view in order to inform chronic pain care improvement. Prior studies have shown that both patients and providers are dissatisfied with process and outcomes of treatment for chronic pain complaints [8–13]. Despite calls for research on patient perspectives [18], few studies have been completed that describe patient views beyond satisfaction ratings.

Participants in all groups described feeling as if primary care providers did not either believe or understand the terrible burden of persistent pain. They described some providers as disrespectful, and reported experiencing hurried encounters, in which they felt that providers implied that the patient was keeping them from other

patients with "real" illnesses. Despite their stated openness to exploring nonpharmacologic therapies, some patients said they were labeled as potential "drug seekers." These themes were found across gender, ethnicity, age, language, and socioeconomic background, and among participants with and without an addiction history. Participants perceived these attitudes as one possible reason they did not receive thorough, empathic medical care.

Nevertheless, participants frequently recognized the dilemmas providers face in diagnosing and managing chronic pain. Some acknowledged that while opioid medications may provide some relief, they appreciated providers' efforts to limit adverse effects of these drugs and limit the risk of addiction. Patients were attuned to the media and law enforcement concerns about opioid misuse and why providers would want to be cautious in prescribing opioid medication [19,20]. Instead of providers clearly explaining their concerns, however, many participants felt that fears about misuse of opioids limited providers from a thorough assessment of their pain, and developing systematic approaches to help manage their chronic pain, including consideration of prescribed opioids.

These negative views of primary care provider management of chronic pain are very similar to those reported in a smaller focus group study conducted to obtain patient views of a depression and musculoskeletal pain intervention (SCAMP) [21,22]. While the 18 SCAMP focus group patients were older, more often female and White than the present study, they similarly described not being understood or listened to, having difficulties obtaining enough pain medication, and having few treatment options other than medication.

We fully expected to identify different themes and perhaps less satisfaction with care in our Latino groups. Instead, we found remarkably similar themes across patients from all ages, genders, and ethnicities. In addition to the qualitative data collected, at the beginning of the each focus group patients filled out a brief questionnaire on their background that included several standardized ambulatory provider satisfaction questions (in Spanish and English) drawn from the Consumer Assessment of Health Plans Survey (CAHPS) validated surveys [23]. Analyzing for ethnic differences we found that there were no differences between Latinos and other focus group participants for any of the provider quality questions, including shared decision making, perceived helpfulness, listening, explaining, showing respect, and spending enough time. Similar to the qualitative analysis, only a provider–patient communication item focused on the patient's understanding of the provider showed statistically significant differences, with Latino participants reporting more difficulty understanding their provider because of language issues.

In contrast to common agreement about other themes, Spanish-speaking patients, however, did offer fewer recommendations to improve care. The reasons for this may

be complex and related to empowerment, coping strategies, or acculturation. Because our Latino sample was predominately Puerto Rican with an average length of stay in the United States of 20.7 years, acculturation per se may not have played a major role, and simple approaches to measuring acculturation have been called into question [24]. However, research has shown that cultural patterns in coping strategies such as “the acceptance of insurmountable circumstances” [25] and “stoicism” as a pain coping strategy [26] may be more prevalent among Latinos. This may explain reluctance to suggest changes in their own medical care.

Participants across backgrounds did, however, report several barriers to effective pain management and related ideas to improve care through the use of physician-extenders (nurses, care managers), facilitation of communication with providers, and better organization of the prescription refill process. The ideas patients offered to improve care are very similar to ideas voiced by providers concerned about the need to improve chronic pain management systems [13].

Several recent studies have explored how to address patient and provider concerns about the quality of chronic pain care by using elements of the chronic disease management model previously developed for diabetes, asthma, and other chronic illnesses. The chronic disease management model was derived from analysis of effective interventions to improve patient outcomes among patients with a need for ongoing treatment management instead of episodic acute care. The model advocates that productive interactions between patients and providers require an “informed and activated patient” and a “prepared and proactive practice team” that result from specific changes in the way health care is organized [27,28]. There are six basic elements to the model, that start with a health care organization motivated to improve quality, and community resources that complement health care systems by providing needed supports for patients outside of the health care setting (such as places to exercise, educational resources). Within health care there are four additional requirements: self-management and patient education support so that patients participate in their care and follow through with the treatment plan; delivery system redesign that allows for easier access to and communication with care providers, often using nurses or care managers to provide more frequent contact and support; clinical protocols and evidence-based guidelines for providers to follow; and finally a clinical information system with key measureable patient outcome data that providers can routinely access and use to adjust the treatment plan.

The most common elements of the chronic care model that have been studied for chronic pain care are implementing improved patient self-management programs, and delivery system designs that involve a care manager to proactively outreach and support patients [21,22,29–32]. One intervention that provided patient self-management education in the form of a booklet was less successful in improving patient pain and functioning com-

pared with patient education materials plus telephone calls from a nurse educator [29]. Dobscha et al. implemented a clinician education program, one visit with a care manager, individualized treatment planning, telephone follow-up, and workshops on patient activation over a 12-month period for VA clinic patients with chronic pain. This study found modest improvements in the intervention group in pain-related disability, pain intensity, and reductions in depression symptoms compared with the usual care group, but no differences in health-related quality of life or patient satisfaction with care [30]. Similar outcomes in pain and depressive symptoms were found in the SCAMP intervention [31], which combined 3 months of intensive depression medication treatment for pain patients with depression, followed by 3 months of self-management education and support from a nurse care manager. However, the SCAMP study did find more widespread patient-reported improvements in both pain and quality of life indicators. Finally, a nurse manager-led methadone intervention for chronic pain patients resulted in only 57% of patients being satisfied or very satisfied with their care [32]. Adapting the chronic care model to treat chronic pain patients has thus been associated with some improvement in patient-reported pain and functional status, but has led to mixed effects on patient health-related quality of life, treatment satisfaction, or ratings of treatment effectiveness [29–32].

Patients in the SCAMP study focus groups [21,22] were particularly favorable about the role of the specially trained nurse care managers in terms of “listening, understanding, and providing support” (p. 31), which they did not find available from the primary care providers. The lack of consistent positive reports about these interventions from the patient point of view suggests that while using a chronic disease management approach may improve some aspects of care, equally as important may be efforts to address the participants’ concerns about the personal dimensions of the provider–patient relationship.

Participants in the current study appreciated provider–patient interactions in which they perceived genuine concern about their pain and absence of unfounded suspicion about drug abuse, and were invited to share decision making about care. Participants desired care that closely parallels the dimensions of patient-centered care [14,15], which has been associated with improved patient satisfaction, adherence, and outcomes [33–35]. Patient-centered care constructs have evolved over the last decade, but include dimensions of providers incorporating the bio-psychosocial perspective in understanding health and illness; addressing the “patient as a person”; understanding the individual experience of illness; sharing power, responsibility and decision making about treatment; and being attuned to the patient’s assets and limitations to cope with the medical condition [36]. Recently, these dimensions have been reshaped as part of health care reform to improve patient outcomes in the form of the “patient-centered medical home” concept [37]. The patient-centered medical home model advocates continuity of care treating the “whole person” across life stages

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and diseases, with a “compassionate partnership” involving shared decision making, use of evidence-based guidelines, and continuous quality improvement.

Addressing provider–patient relationship issues in the context of also implementing systems designed using the elements of the chronic care model and the patient-centered medical home may improve both the patient and provider experience in treating chronic pain [15,18]. Such an approach may also help providers more effectively implement guidelines for chronic pain diagnosis and management [30] and shift the care paradigm from “fixing” the problem, to treating the patient, with associated improvements in patient satisfaction, outcomes, and medical care costs [38,39].

Limitations of the study include the convenience sample from one geographic area of Massachusetts. Chronic pain patients with other characteristics in different locations may have different views. In addition, while we included a large sample of Latino patients to solicit potential differences from other participants in terms of qualitative themes, we did not include specific measures to explore potential cultural differences in approaches to pain coping or perceptions of medical mistrust. The study however fills a gap in understanding patient perspectives on chronic pain care. The diversity and size of the sample, and the commonality of experiences across age, gender, and ethnic groups also suggest that the findings may generalize to chronic pain patients in other clinical settings. Further exploration of whether patients with other types of chronic conditions (such as diabetes, chronic obstructive pulmonary disease) also experience similarly frustrating interactions with their medical providers would add to the understanding of whether patients with chronic pain have unique difficulties in seeking medical care.

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