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Older People's Experiences of Patient-Centered Treatment for Chronic Pain: A Qualitative Study

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Abstract

Introduction—Older adults with chronic pain who seek treatment often are in a health care environment that emphasizes patient-directed care, a change from the patriarchal model of care to which many older adults are accustomed.

Objective—To explore the experiences of older adults seeking treatment for chronic pain, with respect to patient-directed care and the patient-provider relationship.

Design—In-depth interviews with 15 Caucasian older adults with chronic pain who had been evaluated at a university-based pain clinic. All interviews were audiotaped and the transcripts were analyzed using a grounded theory based approach.

Results—Older adults with chronic pain vary in their willingness to be involved in their treatment decisions. Many frequently participate in decisions about their pain treatment by asking for or refusing specific treatments, demanding quality care, or operating outside of the patient—provider relationship to manage pain on their own. However, others prefer to let their provider make the decisions. In either case, having a mutually respectful patient—provider relationship is important to this population. Specifically, participants described the importance of "being heard" and "being understood" by providers.

Conclusions—As some providers switch from a patriarchal model of care toward a model of care that emphasizes patient activation and patient-centeredness, the development and cultivation of valued patient—provider relationships may change. While it is important to encourage patient involvement in treatment decisions, high-quality, patient-centered care for older adults with chronic pain should include efforts to strengthen the patient—provider relationship by attending to differences in patients' willingness to engage in patient-directed care and emphasizing shared decision-making.

Keywords

C	hronic I	Pain;	Older .	People;	Patient-	Provider I	Relations	hıp; Qı	ualitative;	Patient-l	Directed	Care
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Introduction

Older adults with chronic pain who seek treatment are in a rapidly changing health care environment. Over the past decade, the concept of patient-centered care has been growing in importance in the U.S. health care system [1–5]. Patient-centered care models acknowledge the patient as the "source of control" in the health care setting and recommend that "patients ... be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them" [5].

The notion of the patient as the "source of control" is a dramatic shift from the paternalistic model of health care and has changed the very concept of what it means to be a patient. The "good patient" of the 1950s was expected to respect the authority of the physician above all else [6], in stark contrast with the "good patient" of today who often is expected to be an active consumer of care, involved in making treatment decisions and working in partnership with the physician.

Although much has been written about the development of empowered patients [7–9] and what it means for physicians and other providers [10–12], there is little understanding of the extent to which older adults accept the mantle of being the "source of control" over their care. For a variety of reasons, older adults may be uncomfortable speaking up for themselves, questioning their health care providers, and assuming control over the management of their care [13,14]. This article examines this issue in the context of chronic pain, which is common among older adults [15]. Chronic pain is often tenacious and difficult to treat and providers are often poorly educated about pain evaluation and treatment [16–19]. Without patient involvement in care, the risk of undertreatment of pain, and thus increased suffering, rises significantly [20–22].

Through in-depth interviews with a group of older adults with chronic pain, we explore how this group of patients makes treatment decisions and to what extent they accept the mantle of being the "source of control." Second, we explore what it is that matters to patients in their relationships with their providers.

Methods

Sample

Letters describing the study were mailed to 65 patients who had been referred to a university-based pain clinic by their primary care providers and had previously participated in a study of older adults with chronic pain [23].

Potential participants were asked to return by mail an enclosed postcard if they were interested in participating. Twenty people (31%) responded; one woman no longer had pain and was not interviewed, two people had changed their phone numbers and could not be contacted, and two people did not return phone calls. The final sample consisted of 15 older adults (10 women and five men) with chronic pain severe enough to warrant referral and treatment at a pain clinic.

All participants had low back pain, although most had additional sources of pain from osteoarthritis, fibromyalgia, peripheral neuropathy, vulvodynia, and other conditions. All participants experienced pain "every day or almost every day" and had lived with this pain for at least 3 months at the time of their initial evaluation at the pain clinic.

Participants were 63–86 years old and had completed 9–20 years of schooling. Eight were currently married, four were widowed, and three had never been married. All of the respondents were Caucasian and lived in the Pittsburgh metropolitan area.

Data Collection

The interviews were conducted over 4 months. They were conducted by the first author either in the respondent's home (N=10) or at an office in a medical clinic (N=5); location of the interviews depended on the respondent's preference. Each respondent was interviewed once, and the interview lasted 45–90 minutes. Interviews solicited respondents' pain history and experiences getting treatment for the pain. For example, the interview often began with the question, "First, I'd like to know about your pain story. When did you first start feeling pain?" and were followed by the question, "What has your experience been like getting medical treatment for your pain?" Although the interviewer had constructed an interview guide, this was used more as a point of reference if a respondent required additional prompting or clarification about the types of experiences that were being sought rather than as a strict guide. To obtain more in-depth responses, probes such as "Could you tell me more about that?" and "What do you mean by that?" were used. The goal of these interviews was to allow the respondents to speak freely about their experiences with minimal guidance from the interviewer.

All interviews were recorded and transcribed verbatim. The first author conducted spot-checks on a subset of interviews to ensure the accuracy of the transcriptions by listening to an interview recording while reading the associated transcript. The written transcripts became the primary data source for analysis.

This study was subject to ethical review and approval from the Institutional Review Board at the University of Pittsburgh. Participation was voluntary and based on written informed consent, with confidentiality and anonymity assured. In the text, all participants' names have been changed to ensure anonymity.

Data Analysis

We used a qualitative approach based on the principles of grounded theory [24]. Data collection and analysis occurred simultaneously. As each interview and transcript was completed, data were analyzed and coded before conducting the next interview. This enabled us to identify thematic areas of interest and incorporate these into the next scheduled interview. For example, as it became clear that methods of assuming (or not assuming) control over health care decisions was an important issue, subsequent interviewees were probed about their experiences with medical decision-making.

To analyze each transcript, we used a multistage approach based on the grounded theory methodology described by Strauss and Corbin (1998). First, we conducted a microanalysis of the data by examining and open coding each line of data in each transcript. Second, we grouped the codes into categories by collapsing related codes. Finally, we used "axial coding" to relate the categories to subcategories, to discover the relationships among the categories, and to come up with the major themes and concepts.

Although respondents' stories incorporated many themes, we chose to concentrate on the concepts of 1) participation in pain treatment and 2) relationships with providers, because these themes were pervasive and seemed to reflect what respondents chose to emphasize in the interviews.

The first author conducted all interviews and coded all transcripts, though the evolving codes and categories were discussed with experts in the field (J.K., C.R.), who supported the developing categories and themes. Atlas.ti (Version 5.0), a software program for qualitative data analysis, was used to organize transcripts, codes, categories, and themes.

Results

Two themes emerged from our analysis: 1) participation in pain treatment and 2) importance of strong relationships with health care providers (HCPs). We found that many older adults with chronic pain take an active role in treatment decisions and that having trusting and mutually respectful relationships with HCPs plays a critical role in respondents' satisfaction with their care.

When participants spoke about HCPs, they referred to a variety of providers: primary care physicians, surgeons, chiropractors, physiatrists, and physical therapists. In this analysis, all provider types have been grouped together, as the interpersonal qualities of HCPs that are important to respondents are relevant across provider type.

The theme of participation in pain treatment had several subthemes: 1) involvement with treatment decisions, 2) involvement with the quality of care, 3) working outside the patient–provider relationship, and 4) not wanting to be harmed.

Patient Involvement with Treatment Decision-making

Participants described a variety of ways that they were involved in their pain treatment decisions: asking for or refusing certain treatments, speaking up for themselves when they were receiving substandard care, and working outside the HCP-patient relationship to manage their symptoms by changing their medication dosages or taking nutritional supplements. A critical aspect of these patients' involvement with their treatment was their relationships (or lack of a relationship) with their HCPs. People who had good relationships with their HCPs often experienced more satisfaction with their care and were able to successfully advocate for themselves.

Participants reported asking their physicians for specific kinds of pain treatments, even though not all requests were honored.

For example, Irene, age 75, had educated herself about various pain treatments through involvement with an Internet support group for people with chronic pain. She was currently taking an opiod, but wished to switch to a stronger opiod. She said, "I've been asking for that OxyContin, [but] nobody will [prescribe it]. They're afraid I'll become addicted. I'm almost 76. What kind of addict am I gonna be? ... It's not fair." In this case, Irene took medications that left her experiencing troubling side effects and therefore took less medication than was recommended; she lived in pain as a result. She said, "[The medication] makes me kind of numb... lot of times, I just put up with the pain. I can go ten or twelve hours, sometimes." Irene tried to be an active participant in her pain treatment, but did not have a provider who was willing to work with her to achieve an optimal outcome—a necessity for the provision of patient-centered care.

Other studies have similarly found that patients with chronic pain and their providers may be misaligned in treatment decisions; patients often prefer treatments that maximize daily functioning regardless of health benefits, while providers may prefer treatments that maximize health benefits without considering effects on daily functioning [25]. This misalignment can lead to patient dissatisfaction with and withdrawal from treatment [26,27]. Attesting to this, participants reported that they had refused specific pain treatments, such as surgery, medication, injections, and physical therapy.

Laura, age 78, was adamant that she would not take any pain medication. "Dr. X gave me a prescription for pain, but I won't—I'm not even going to get it filled." She was already taking several other medications for other conditions and did not want to add

another medication. Laura also suffered from arthritis pain in her leg. Another doctor had suggested surgery to help, but she was insistent that she didn't want surgery: "They wanted to work on the foot, and I said, 'No' ".

Our finding that older adults with chronic pain refuse treatments is consistent with other studies [28,29]. Without an environment of shared decision-making and open communication, patients may take control over their care by withdrawing from treatment and thereby suffer needlessly.

Patient Involvement with Quality of Care

Participants also described instances where they demanded better treatment, thus taking an active role in the type and quality of care they were receiving.

Ned, age 76, was undergoing physical therapy for his pain and felt that there was no continuity to his treatments. He decided to speak up for himself and demand better care: "I demanded to see someone higher up. And I told them that I didn't think there was any continuity to the treatment. And then I was assigned to someone who was the same, and there seemed to be reference to what was done previously ... It affirmed in my mind from now on, that it pays to demand what you have to."

However, other respondents were reluctant to speak up about the quality of their care.

Laura was injured during a session of physical therapy and when asked whether she told anyone about what happened, she said "No. I didn't ... I don't say negative things. I don't do that. I won't do that to anybody. And, I just didn't go back." She also had a negative reaction to a cortisone shot and similarly decided not to say anything about it. "I won't do that ... I don't want to hurt anybody, I don't want anybody to get into trouble, any kind of trouble."

Working Outside the Patient-Provider Relationship

Some participants decided to work outside of the HCP-patient relationship to control their pain treatments. For example, several people reported changing their pain medications on their own, without consulting with their HCPs. None of the participants reported that they had increased their dose of pain medications; rather, people reported that they did not like taking pain medication or being reliant on them, and instead "experimented" with taking less pain medication.

Mary, age 85, was cutting back on her medications, "trying to see if [she could] get along without as much" and hoped that her HCP would "let [her] mind [her] own business" in this regard.

Leo, age 69, felt that it was his right to have control over the medications: "I think it's all right to give [people] a little medicine chest and say guide your-self, like if you're going to take a little trip on the road, don't go too fast, but you have to give the instruction and let the person drive, and do the trip, like you have to do in life." To help people who would like to "drive," or manage their pain medications on their own, this patient suggested that the "medical community" should "[make] charts that were available to patients" with information about all medications used to treat pain, their dosages, and their side effects so that patients could make informed decisions about their own pain control. In describing his desire to have "charts" like this, he revealed his desire to be able to have more control over his pain treatment, and ultimately over his pain. He lacked the medical knowledge to successfully manage his pain and pain treatment on his own and felt strongly that the "medical community" had an obligation to provide him with the information necessary to enable him to be completely in control.

Other older adults worked outside the patient– provider relationship by taking nutritional supplements, vitamins or homeopathic remedies that they had discovered on their own. Many said that it was necessary to do this, as there were limitations of the effectiveness of traditional medicine.

Leo explained, "Since there's no medicine, I'm jumping to the homeopathic with all the C's and the this and the that and the vitamins. I don't know any other course to take."

Linda, age 70, agreed: "You just keep experimenting. That's all you do. You know, you hear of this, you try that, this works, that doesn't work. This person suggests this, someone else suggests something else." When asked whether she told her physicians about the supplements she was experimenting with, Linda said, "Not always. The [supplement] I didn't, I told him after the fact."

Lansbury (2000) similarly found older adults to be resourceful in finding pain relief from self-administered strategies such as nutritional supplements, rather than medications [30]. In part this may be due to older adults' fear of becoming addicted to pain medications, but also may be due to a sense that "there's no medicine" for their pain and a resultant trial-and-error effort to find relief. It may be the case that as patients have been encouraged to take a larger role in their health care decisions that they have interpreted this to mean searching for, and experimenting with, treatments on their own rather than working collabo-ratively with their HCP.

Not Wanting to Be Harmed

Not all participants were as eager to be involved in treatment decision-making, however. While in the minority, several respondents expressed preference for a more traditional role in treatment decision-making. Several people reported that they would never disagree with their HCPs, "because after all, they're the doctors, they have the degrees. And I let them decide." When people did disagree with their HCP, some were reluctant to voice this disagreement because they were concerned about jeopardizing their relationship with their HCP.

Linda had to wait for three hours past her appointment time to see her HCP. When asked whether she had said anything to her doctor about the wait, she said, "no… this is one doctor that unfortunately I have to have, I need."

Other people were concerned with being "nice" to their HCPs, perhaps again worrying that they would lose or damage their relationship with them if they were to disagree with treatment recommendations or express displeasure with their care.

Laura, age 78, said that she wouldn't tell her HCP that she was not planning on taking the pain medication she had been prescribed because "I don't want to hurt her because she's a great lady, and she's helped me tremendously."

Some study participants were especially concerned with "being a good patient" by "being nice" to their HCPs.

Linda, age 70, routinely wrote down her questions for her HCP because "you don't want to take up too much of their time."

Edith, age 81, was concerned that if she was not compliant with treatment that she would be harmed: "I do exactly what my doctors tell me to do. Because I feel that it could be dangerous if I strayed from what they tell me to do."

Role of the Provider: Understanding, Remembering, Hearing, and Consistency

Regardless of the extent to which participants were involved with treatment decision-making, they placed a high priority on having a meaningful relationship with their providers; they wanted their providers to sympathize with their pain and disability, to understand the psychosocial context in which they lived and experienced pain, and to know them as a whole person.

An important component of the patient– provider relationship was the concept of *being understood*. In this sense, "being understood" meant that a provider understood pain and the effect it had on these participants' lives. For many people, having an HCP who was experienced in treating pain was very important, as it increased the chance that they would be understood.

Ned, age 76, worried that he would be seen as a "drug-seeker" and as a result he delayed seeking treatment for his pain "because I just had a feeling that people wouldn't understand me." However, when he finally went to a pain clinic, he found that "they were ... very realistic and very sympathetic and understanding of my pain ... The people [there] were probably the first people that really understood pain. I really found that to be... very interesting. Because finally I had somebody I could talk to, and they knew what I was talking about."

Not finding an HCP who "understood" could lead to a sense of vulnerability, isolation, and feeling "alone with the pain."

As Rachel, age 86, put it, "I've given up on all of them, to be honest with you. I don't think they know what it's all about, and they don't understand me. They don't feel my pain, and I hope they don't, but sometimes I wish they would."

"Being understood" resonates with the construct of legitimacy. If respondents' pain was "understood" by their HCPs, it would signal to them that the pain was legitimate. Johansson et al. (1999) similarly found that it was important for women with chronic pain to be taken seriously by their providers and suggested that doctors are often seen by those with chronic pain as "legitimizing agents" [31].

Another important aspect of the patient– provider relationship was the sense of being heard.

As Linda said of a well-liked HCP, "She listens to me. She's the only one that does... I trust her with everything... She... doesn't cut me of... she'll... listen to anything I have to tell her, and then that's it... she does not cut me off."

Not being heard made people feel like their HCPs were not interested or did not care about them.

As George, age 63, expressed it, "I just felt... that he was not interested in listening to [my pain]... I felt that they're really not interested in me."

Frank, age 85, reported that he had not been able to find any HCP who would listen to him, despite his attempt to make himself heard: "I tell my doctors [about the pain] and they continue writing out their Medicare forms. I think 90% of doctors have their hearing aids off when you're talking to them anyways... you talk and I don't think anybody listens. Nobody gives you any answers."

These findings are consistent with the literature; for example, Walker et al. (1999) describe chronic pain patients' feelings of being misunderstood, insignificant, and dissatisfied with the medical process [32]. Older adults with chronic pain value having a provider who listens to them and understands how they feel [25,33,34]. Other studies have highlighted the importance of empathy and mutual respect in the patient–provider relationship. For example, Dobkin et al. (2006) found that patient– physician concordance on well-being predicted medication

adherence; the more empathetic physicians were about the patient's condition, the more adherent patients were [35].

When people went for an HCP visit, they wanted to feel as though their HCP remembered who they were and remembered the treatment plan they had agreed upon. *Being remembered* was a signal to the patient that they were "known" to the provider—that their provider recognized them as a person with a context and history, rather than as a number. *Being remembered* also made people feel comfortable and safe within the medical interaction and the treatment decisions that were being made. For some, their HCP remembering them was a signal that they were a "caring" or empa-thetic provider.

As Bob, age 66, expressed: "Dr. X is a caring, superb human being. You see him two years later and he remembers you. If a doctor comes in and they look at you and read your chart to know who you are I'm not too impressed, but if they remember you..."

Finally, *continuity of care* was also important to the integrity of the patient–provider relationship. Several people reported that they had been with a particular provider for many years and that this allowed them to be known and understood by their HCP.

Ned, age 76, explained: "I have a lot of confidence in my... doctor. And we can sit down and talk... I've been going to him for about 17 years... And he's willing to talk about anything that I might have, and we've built up that rapport, and he knows that I respect him..."

However, not all participants had this kind of relationship with their HCPs. People who did not have a long term or continuous relationship with their HCP often felt lost in the health care system, contributing to an overall sense of *being unknown*. Not having a regular source of care also caused problems for people filling prescriptions for pain medications.

George changed prescription plans and as a result was not able to go to his usual pharmacy to pick up his prescription of a narcotic. When he went to his new pharmacy, he said that the pharmacist "basically accused me of being—you know, am I selling the drugs, am I a druggie... she just went on and on about it, and... it really embarrassed me." Although he was eventually able to get his prescription filled, the experience haunted him. For him, the experience of *being unknown* threatened his ability to manage his pain and caused him considerable psychic stress.

Our finding of the importance of the patient– provider relationship is consistent with the literature. Haugli et al. (2004) found that chronic pain patients believe their relationships with providers are instrumental in their treatment [36]. Similarly, Campbell and Guy (2007) describe a dependence on medical professionals among those with chronic low back pain [37]. Ensuring that chronic pain patients feel "cared for" (i.e., understood, heard, and remembered) by HCPs seems to be essential to the provision of adequate pain treatment.

Discussion

These results suggest that older adults with chronic pain vary in their willingness to be the "source of control" over their pain treatment. Older adults, who for years were socialized to never question their physician, are now sometimes expected to take a role in directing their medical treatment. As one study participant said, "When I was young you didn't ever contradict a doctor. You didn't even ask a question. But now you do." The movement toward patient-directed care, then, may have complex repercussions for older adults with persistent pain, who are caught in the middle of this transformation at a stage in life where they are likely to interact frequently with the medical system.

Patient-directed Care

Encouraging patient-directed care in older adults with chronic pain requires an understanding of the extent to which each patient is interested in being involved in treatment decisions. This study illustrated a variety of ways in which older adults take control over their pain care—asking for or refusing specific treatments, demanding better quality of care, and acting on their own to manage their pain.

However, although many older adults are likely to want a role in decision-making, others prefer to have their HCP make the decisions. Those with the latter preference are likely to have an "external locus of control" [38]. External locus of control has been associated with greater health services use and higher health care costs among patients with chronic pain [39], as they seek frequent treatment from a variety of health care providers in search of a cure. Patients with an external locus of control are not likely to want the responsibility of making treatment decisions for themselves or assuming control over the management of their chronic pain. Since treating chronic pain requires patients and providers to work together, older adults with chronic pain who are reluctant to have a participatory role in their care are at increased risk for undertreatment.

Patient involvement in pain treatment is critical to ensuring optimal outcomes. HCPs should encourage all patients to engage in shared decision-making and should establish an environment of open communication in their practices. Shared decision-making [40,41] is a collaborative approach that includes: 1) exchange of information, where HCPs inform patients about various treatment options and the risks and benefits associated with each, and patients inform HCPs about their preferences, values, and lifestyle concerns, 2) deliberation, where patients and HCPs engage in a discussion about treatment options and HCPs help patients weigh the risk/benefit ratio and come to a decision, and 3) implementation of the treatment decision. Shared decision-making is critical in the treatment of chronic pain; in fact, a recent study found that shared decision-making can improve HCP satisfaction with treating patients with chronic pain [42]. In addition, shared decision-making can enhance patient satisfaction and treatment adherence [33,43], and may reduce pain [44], thereby improving the quality of care delivered to this vulnerable population.

Without an environment of shared decision-making, this article suggests that older adults with chronic pain may act on their own to manage their pain. As reported, some respondents reduced the amount of medication they were taking or took nutritional supplements without discussing it with their HCPs. Since the consequences of these actions could at best leave the patient to suffer from more pain than is necessary and at worst have dangerous results (i.e., adverse interactions between supplements and medications), the importance of trust and communication between patient and provider cannot be overstated.

The Patient-Provider Relationship

As we report, older adults with chronic pain value a provider who is respectful in terms of understanding, listening to, and remembering them. Inadequate communication with their provider can lead patients to feel not cared about, vulnerable, and alone with their pain. Even in cases where providers are not able to relieve pain— where medicine fails—they may be able to alleviate suffering by opening communication with their patients, listening earnestly to their concerns, and being empathetic. As Cassell has described, the bond formed between a health care provider and patient itself has therapeutic power [45] and the caring and support a provider provides is often just as important as the medicine she dispenses.

On the flip side, as older adults with chronic pain begin to assume more control over their health care, they may be more likely to question treatment decisions and even worry that their

HCP is not acting in their best interests [46]. As patients are asked to be more involved with their treatment, some may even begin to question the ability of their HCP to relieve their symptoms and cure their disease. However, questioning HCPs' ability to provide relief may actually be appropriate, as many HCPs are poorly educated about pain management [16,18, 19,47]. Although strengthening the education and training of HCPs in this area is imperative, patients need to be encouraged to be actively involved in their treatment. By opening a dialog about treatment options, patients may help to ensure that they are receiving the most appropriate care. The more informed patients can be about their conditions and the variety of treatment options that exist, the more control they may feel over their pain and the better they can collaborate with their HCPs to create a treatment plan.

Limitations and Future Research

Our sample was composed of older adults with chronic pain of both genders and various ages, perceived income levels and living situations. There are, however, limitations to the sample. First, all study participants had been evaluated at a university-based specialty pain clinic. Although these respondents report on their experiences with HCPs outside of the pain clinic setting, their overall experience getting treatment may or may not reflect that of the majority of older adults with chronic pain who are not evaluated at a specialty clinic. Second, we had a low response rate (31%) to our initial request for participation in this study. Although we did not find that those who did participate differed significantly from those who did not participate, there may be characteristics of people who volunteer to participate in qualitative research studies that set them apart from those who choose not to participate in these types of studies. As such, these results are not generaliz-able, though that is not the goal of qualitative research. Themes and concepts elucidated through qualitative research methods can be transferred to other settings. Third, only one person conducted the interviews and coded the data. Although the codes and categories were discussed with other authors, having a single coder may have introduced bias in the analysis. Finally, these findings are limited to the extent that participants may have withheld important information when being interviewed. Although all participants were informed that their responses were confidential, some may have worried nonetheless that their remarks would be relayed to their HCPs. If multiple interviews had been conducted with each person, the level of trust may have been greater and perhaps different themes related to the experience of getting treatment for chronic pain would have been revealed.

This report serves as a description of the experiences of Caucasian older adults living in Pittsburgh; people in other parts of the country or with different racial, cultural, and social backgrounds may have different experiences [48,49].

In future studies, it will be important to try to understand the reasons why older adults with chronic pain are or are not involved with treatment decision-making. Studies focusing on the experience of physicians in treating older adults with chronic pain would enable us to understand how providers view the patient–provider relationship and what matters to them in treating people with chronic pain. Finally, although this study focused on the experience of older adults with chronic pain, these findings may be applicable to other age groups and chronic conditions, as the elements critical to ensuring quality chronic disease treatment and the challenges of delivering patient-centered care are likely to be similar for other populations. Future research should explore these issues in a variety of populations and settings to better understand how best to improve care for those suffering from chronic conditions.

Conclusions

This study illustrates the challenges of providing patient-directed care to older adults with chronic pain. Even though many older adults with chronic pain would like to have some control over their treatment, they still need to be guided through their treatment options and engaged

in shared decision-making. Providers of pain care must take time to know their patients beyond their medical history and to learn what outcomes are important to them in treatment, so that pain treatment options are in alignment with patients' priorities [33]. For this to succeed, health system changes such as adequate provider compensation and restructuring care to allow time for these critical conversations are necessary [12].

References

- Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. J Gen Intern Med 2005;20(10):953–957. [PubMed: 16191145]
- Fremont AM, Cleary PD, Hargraves JL, Rowe RM, Jacobson NB, Ayanian JZ. Patient-centered processes of care and long-term outcomes of myocardial infarction. J Gen Intern Med 2001;16(12): 800–808. [PubMed: 11903758]
- 3. Hibbard JH. Moving toward a more patient-centered health care delivery system. Health Aff (Millwood) 2004:VAR133–VAR135. (Suppl Web Exclusive). [PubMed: 15471780]
- 4. Sullivan M. The new subjective medicine: Taking the patient's point of view on health care and health. Soc Sci Med 2003;56(7):1595–1604. [PubMed: 12614708]
- Committee on Quality of Healthcare in America, Institute of Medicine. Washington, DC: National Academy Press; 2001. Crossing the Quality Chasm: A New Health System for the 21st Century.
- Parsons T. Illness and the role of the physician: A sociological perspective. Am J Orthopsychiatry 1951;21(3):452–460. [PubMed: 14857123]
- 7. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: Polysemy or cacophony? Patient Educ Couns 2007;66(1):13–20. [PubMed: 17084059]
- 8. Salmon P, Hall GM. Patient empowerment and control: A psychological discourse in the service of medicine. Soc Sci Med 2003;57(10):1969–80. [PubMed: 14499519]
- 9. Werner A, Malterud K. "The pain isn't as disabling as it used to be": How can the patient experience empowerment instead of vulnerability in the consultation. Scand J Public Health Suppl 2005;66:41–46. [PubMed: 16214722]
- 10. Audet AM, Davis K, Schoenbaum SC. Adoption of patient-centered care practices by physicians: Results from a national survey. Arch Intern Med 2006;166(7):754–9. [PubMed: 16606812]
- 11. Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in patient-physician consultations: Theoretical and practical issues. Soc Sci Med 2005;61(7):1516–28. [PubMed: 16005784]
- 12. Fiscella K, Meldrum S, Franks P, et al. Patient trust: Is it related to patient-centered behavior of primary care physicians. Med Care 2004;42(11):1049–1055. [PubMed: 15586831]
- 13. Ellins, J.; Coulter, A. How Enagaged are People in Their Health Care? Findings from a National Telephone Survey. Oxford: Picker Institute Europe and The Health Foundation; 2005.
- Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. A national study of public preferences. J Gen Intern Med 2005;20(6):531–535. [PubMed: 15987329]
- 15. Jacobs JM, Hammerman-Rozenberg R, Cohen A, Stessman J. Chronic back pain among the elderly: Prevalence, associations, and predictors. Spine 2006;31(7):E203–E207. [PubMed: 16582841]
- 16. Billings JA, Block S. Palliative care in undergraduate medical education. Status report and future directions. JAMA 1997;278(9):733–738. [PubMed: 9286833]
- 17. Green CR, Wheeler JR, Marchant B, LaPorte F, Guerrero E. Analysis of the physician variable in pain management. Pain Med 2001;2(4):317–327. [PubMed: 15102236]
- 18. Von Roenn JH, Cleeland CS, Gonin R, Hatfield AK, Pandya KJ. Physician attitudes and practice in cancer pain management. A survey from the Eastern Cooperative Oncology Group. Ann Intern Med 1993;119(2):121–126. [PubMed: 8099769]
- 19. Weiner DK, Turner GH, Hennon JG, Perera S, Hartmann S. The state of chronic pain education in geriatric medicine fellowship training programs: Results of a national survey. J Am Geriatr Soc 2005;53(10):1798–805. [PubMed: 16181182]
- 20. Gagliese L, Melzack R. Chronic pain in elderly people. Pain 1997;70(1):3-14. [PubMed: 9106804]

21. Resnik DB, Rehm M, Minard RB. The undertreat-ment of pain: Scientific, clinical, cultural, and philosophical factors. Med Health Care Philos 2001;4(3):277–288. [PubMed: 11760227]

- 22. Pasero C, McCaffery M. The undertreatment of pain. Am J Nurs 2001;101(11):62–5. [PubMed: 11718118]
- 23. Karp JF, Reynolds CF 3rd, Butters MA, et al. The relationship between pain and mental flexibility in older adult pain clinic patients. Pain Med 2006;7(5):444–452. [PubMed: 17014605]
- 24. Strauss, A.; Corbin, J. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Thousand Oaks, CA: Sage Publications; 1998.
- Frantsve LM, Kerns RD. Patient-provider interactions in the management of chronic pain: Current findings within the context of shared medical decision making. Pain Med 2007;8(1):25–35. [PubMed: 17244101]
- 26. Hirsh AT, Atchison JW, Berger JJ, et al. Patient satisfaction with treatment for chronic pain: Predictors and relationship to compliance. Clin J Pain 2005;21(4):302–310. [PubMed: 15951647]
- 27. McCracken LM, Klock PA, Mingay DJ, Asbury JK, Sinclair DM. Assessment of satisfaction with treatment for chronic pain. J Pain Symptom Manage 1997;14(5):292–299. [PubMed: 9392923]
- 28. Hudak PL, Clark JP, Hawker GA, et al. "You're perfect for the procedure! Why don't you want it?" Elderly arthritis patients' unwillingness to consider total joint arthroplasty surgery: A qualitative study. Med Decis Making 2002;22(3):272–278. [PubMed: 12058784]
- 29. Sale JE, Gignac M, Hawker G. How "bad" does the pain have to be? A qualitative study examining adherence to pain medication in older adults with osteoarthritis. Arthritis Rheum 2006;55(2):272–278. [PubMed: 16583418]
- 30. Lansbury G. Chronic pain management: A qualitative study of elderly people's preferred coping strategies and barriers to management. Disabil Rehabil 2000;22(1–2):2–14. [PubMed: 10661753]
- 31. Johansson EE, Hamberg K, Westman G, Lindgren G. The meanings of pain: An exploration of women's descriptions of symptoms. Soc Sci Med 1999;48(12):1791–1802. [PubMed: 10405017]
- 32. Walker J, Holloway I, Sofaer B. In the system: The lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. Pain 1999;80(3):621–628. [PubMed: 10342423]
- 33. Barry CA, Stevenson FA, Britten N, Barber N, Bradley CP. Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. Soc Sci Med 2001;53(4):487–505. [PubMed: 11459399]
- 34. Jackson, JE. "After a while no one believes you": real and unreal pain. In: Good, MD.; Brodwin, PE.; Good, BJ.; Kleinman, A., editors. Pain as Human Experience: An Anthropological Perspective. Berkeley, CA: University of California Press; 1992.
- 35. Dobkin PL, Sita A, Sewitch MJ. Predictors of adherence to treatment in women with fibromyalgia. Clin J Pain 2006;22(3):286–294. [PubMed: 16514330]
- 36. Haugli L, Strand E, Finset A. How do patients with rheumatic disease experience their relationship with their doctors? A qualitative study of experiences of stress and support in the doctor-patient relationship. Patient Educ Couns 2004;52(2):169–174. [PubMed: 15132522]
- 37. Campbell C, Guy A. Why can't they do anything for a simple back problem? A qualitative examination of expectations for low back pain treatment and outcome. J Health Psychol 2007;12(4):641–652. [PubMed: 17584815]
- 38. Gibson SJ, Helme RD. Cognitive factors and the experience of pain and suffering in older persons. Pain 2000;85(3):375–383. [PubMed: 10781910]
- 39. Cross MJ, March LM, Lapsley HM, Byrne E, Brooks PM. Patient self-efficacy and health locus of control: Relationships with health status and arthritis-related expenditure. Rheumatology (Oxford) 2006;45(1):92–96. [PubMed: 16287930]
- 40. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. Soc Sci Med 1999;49(5):651–661. [PubMed: 10452420]
- 41. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). Soc Sci Med 1997;44(5):681–692. [PubMed: 9032835]
- 42. Sullivan MD, Leigh J, Gaster B. Brief report: Training internists in shared decision making about chronic opioid treatment for noncancer pain. J Gen Intern Med 2006;21(4):360–362. [PubMed: 16686813]

43. Kerse N, Buetow S, Mainous AG 3rd, Young G, Coster G, Arroll B. Physician-patient relationship and medication compliance: A primary care investigation. Ann Fam Med 2004;2(5):455–461. [PubMed: 15506581]

- 44. Borders TF, Xu KT, Heavner J, Kruse G. Patient involvement in medical decision-making and pain among elders: Physician or patient-driven. BMC Health Serv Res 2005;5(1):4. [PubMed: 15651985]
- 45. Cassell, EJ. The Nature of Suffering and the Goals of Medicine. New York: Oxford University Press; 1991.
- Kao AC, Green DC, Davis NA, Koplan JP, Cleary PD. Patients' trust in their physicians: Effects of choice, continuity, and payment method. J Gen Intern Med 1998;13(10):681–686. [PubMed: 9798815]
- 47. Green CR, Wheeler JR, LaPorte F, Marchant B, Guerrero E. How well is chronic pain managed? Who does it well? Pain Med 2002;3(1):56–65. [PubMed: 15102219]
- 48. Green CR, Anderson KO, Baker TA, et al. The unequal burden of pain: Confronting racial and ethnic disparities in pain. Pain Med 2003;4(3):277–294. [PubMed: 12974827]
- 49. Green CR, Ndao-Brumblay SK, Nagrant AM, Baker TA, Rothman E. Race, age, and gender influences among clusters of African American and white patients with chronic pain. J Pain 2004;5(3):171–182. [PubMed: 15106130]