Published in final edited form as:
Pain Med. 2014 June ; 15(6): 938–946.

Illness Representations of Restricting Back Pain: The Older Person's Perspective

UE Makris[1,2,3], **TV Melhado**[2], **SC Lee**[2], **HA Hamann**[2], **LM Walke**[4], **TM Gill**[4], and **L Fraenkel**[4,5]

[1]Dept. of Internal Medicine, UT Southwestern Medical Center, Dallas, TX.

[2]Dept of Clinical Sciences, UT Southwestern Medical Center, Dallas, TX.

[3]Dept. of Veterans Affairs, Dallas, TX.

[4]Dept. of Medicine, Yale School of Medicine, New Haven, CT.

[5]Dept. of Veterans Affairs, West Haven, CT.

Abstract

Objective—Back pain is the most common type of pain reported by older adults, leading to considerable morbidity and cost. Yet little is known about the segment of the population ≥80 years old that can be used to guide care in this age group. Illness representations provide a useful framework to understand older adults' beliefs and perceptions of their back pain. The objective of this study was to understand illness representations of back pain, severe enough to restrict activity (restricting back pain).

Design—Qualitative research using semi-structured interviews.

Subjects—Twenty-three community-living older adults ≥80 years old with restricting back pain.

Methods—We used an interview guide to stimulate discussion about how older adults understand and perceive living with restricting back pain. Thematic codes were created to categorize the nuances of participants' restricting back pain experiences.

Results—Participants reported five important components of illness representation: 1) *identity*, the label and symptoms individuals assign to the illness, 2) *timeline*, the individual's perceived clinical course of the illness, 3) *cause*, the individual's perceived etiology of the illness, 4) *consequences*, the perceived impact of the illness, and 5) *cure-control*, the perceived degree to which cure or management is possible/ likely.

Conclusions—Thematic analysis revealed that restricting back pain in older adults has variable and noteworthy physical, psychological and social consequences. There are several components of the illness representation of restricting back pain, specifically, the perceptions of consequences and control that may offer potential targets for clinical intervention.

Address correspondence to Dr. Una Makris, UT Southwestern Medical Center, 5323 Harry Hines Blvd Dallas, TX 75390-9169. Telephone: 214-648-3133, Fax: 214-648-3232. una.makris@utsouthwestern.edu.

Presentations: American Geriatrics Society Presidential poster session, May 3, 2013 Grapevine, TX; accepted at American College of Rheumatology Scientific Meeting, October 29, 2013 and at Gerontological Society of America, November 22, 2013, New Orleans, LA.

Conflict of Interest: The authors of this manuscript have no conflicts of interest.

Keywords

Aging; Back Pain; Qualitative Research; Musculoskeletal Conditions

BACKGROUND

Back pain is the most common type of pain reported by older adults[1]; it is the leading complaint for which patients visit a primary care doctor's office[2,3]. Each year, more than $100 billion is spent in the US on back pain[4], and we can expect to see increasing costs to the individual and society as our population ages[5].

Cross-sectional studies show that back pain is associated with functional limitation, disability, and poor health-related quality of life in older adults[6,7]. Back pain, even when labeled "chronic," lasting three or more months, is dynamic and often characterized by a waxing and waning course punctuated by exacerbations and flares[8,9]. Longitudinal studies have documented an association between back pain severe enough to restrict activity, hereafter referred to as restricting back pain[8], and depressive symptoms[10] as well as mobility disability in older persons[11,12]. Previous work has emphasized that pain intensity may be comparable in older versus younger adults, however, qualitative characteristics of the pain experience may differ in these populations[13]. The literature is rich with qualitative studies describing the chronic pain experience[14–16]. The majority of these studies, however, describe experiences related to generalized chronic pain in younger populations[17] or chronic low back pain in working older adults[18], yet little is known about the experience of living with restricting back pain from the older person's perspective. The subjective nature of pain for each individual, along with multimorbidity, polypharmacy, potential frailty, as well as changing family and social circumstances common in later life, emphasizes the need to understand the experience of living with back pain from the perspective of the older person[13,19]. Further, there is a paucity of literature available on the segment of the population ≥80 years old, that can be used to guide care (that is relevant and appropriate) in this age group[20,21].

Qualitative research methods are ideal for eliciting the older person's experience with back pain because interviews provide an in-depth, richer account of the experience as compared to a quantitative representation of the human experience. In the current study, we used qualitative methods to identify patient-reported dimensions of the restricting back pain experience. Through an enhanced understanding of the older person's experience with restricting back pain we can begin to more effectively tailor assessment and management options for this population.

METHODS

Semi-structured interviews were conducted with persons aged ≥ 80 years who reported restricting back pain, defined as staying in bed or cutting down on usual activities due to back pain[8]. Semi-structured interviews consist of open-ended inquiries and are ideally suited to elicit detailed accounts of an individual's experience[22]. The interview guide intended to explore the character and clinical course of restricting back pain in the context of other

illnesses or conditions, as well as its impact on activities of daily life, including symptom management and quality of life, social relationships, coping strategies and other adaptive behaviors (see Appendix). This paper focuses on the illness representations of restricting back pain. In depth individual interviews were conducted by a single investigator (UEM) in participants' homes and ranged from 25–60 minutes in length.

Potential participants were drawn from the Precipitating Events Project (PEP), an on-going longitudinal study of non-disabled community-living persons who were aged 70 and older at the time of enrollment in 1998[23]. PEP participants who completed the 144-month comprehensive home-based assessment as part of the parent study and who had reported restricting back pain during any of the previous three months were considered for inclusion in this study. Exclusion criteria included residence in a nursing home, severe hearing impairment, or moderate/severe cognitive impairment, as defined by mini-mental state exam <20 and item recall <3. We purposely sampled for a balance of male and female participants. Of the 79 participants approached, 60 reported having back pain in the last 3 months; 27 of these participants confirmed having *restricting* back pain, and 23 completed an interview. Recruitment ended once no new information related to our study purpose was collected. This study was approved by the Yale University and UT Southwestern IRB (STU042012–052).

All interviews were transcribed verbatim by a transcriptionist and analyzed as each participant was enrolled. Analysis consisted of iterative thematic analysis where codes were created to categorize the nuances of participants' restricting back pain experiences. After six interviews were completed, members of team (UEM, LMW, LF) refined the guide to capture more fully the primary concepts emerging from the data. Data were stored and managed in NVivo 9.0 (QSR International, AUS). Investigators collectively identified preliminary themes and then engaged in iterative discussions to interpret the themes[24,25]. To promote inter-coder reliability, coding discrepancies were resolved through group discussion until consensus was reached[24,26].

RESULTS

The sociodemographic and medical characteristics of the 23 participants are summarized in the Table 1. The participants were 57% female, and the age of participants ranged from 82–99, with a median age of 86. On average, participants each had three chronic conditions. Of the 23 participants, 18 (78.3%) reported other types of pain (in addition to back), including knee (n=15), shoulder (n=10), hip (n=8), hand (n=3), trochanteric bursitis (n=2), neuropathic pain (n=1).

In this paper, we refer to back pain as an *illness*, the subjective experience of a disease, rather than a *disease*, an objective biological event due to disruption of specific structures or organ systems. Illness refers to how individuals live with and respond to symptoms of disability[27]. Theories of illness representation, most notably Leventhal's Common Sense model[28–30], provide useful frameworks to understand, and in our research, to present, older adults' beliefs and perceptions of their back pain. After preliminary analysis and coding, members of the team believed that the data were reflective of Leventhal's illness

representation, and thus, we have used this part of the model to organize the data. This is an appropriate function of theory in qualitative research, according to Sandelowski[31].

Leventhal's model focuses on five important components of illness representation: 1) *identity*, the label and symptoms individuals assign to the illness, 2) *timeline*, the individual's perceived clinical course of the illness, 3) *cause*, the individual's perceived etiology of the illness, 4) *consequences*, the perceived impact of the illness, and 5) *cure-control*, the perceived degree to which cure or management is possible/ likely[28,30,32]. Illness representations have been shown to correlate with disease-specific outcomes, quality of life, care seeking behavior, and adherence, often above and beyond other patient-reported measures and clinician evaluations of disease impact[28,29,32,33]. The substantial impact of illness representations have been previously demonstrated for rheumatic diseases, such as osteoarthritis[29,34] and chronic musculoskeletal pain, albeit, in younger populations[35].

We used Leventhal's Common Sense model to organize illustrative quotes describing participants' illness representations of restricting back pain.

Identity

The participants were asked to describe restricting back pain in terms of the symptoms they experience, including severity and character of pain. All participants confirmed their back pain was severe enough to restrict activity in the last three months. The character of restricting back pain varied between sharp or stabbing (61% of participants), and dull or aching (65% of participants).

> I have back pain almost all the time. It's the lower back but at times it goes up to the neck area… It's very, very sore and achy. The one across my lower back spreads from one hip to the other and I can't walk by myself without holding onto something. (84 year old woman)

> If it's a good spasm when I get caught, it takes a good while for it to straighten up and go away. It's just like a [vice] grabbing you…like an electric shock…It takes your breath away. (82 year old man)

30% of participants endorsed fluctuating symptoms that included both sharp and dull back pain.

> It'll be sharp, like I say, if I'm lifting something up, which I don't do anymore. But most of the time, it's a dull…like when I go bed and bend down to do my shoes. (85 year old man)

Timeline

Participants reported a varying clinical course of restricting back pain over time. Most of the back pain was described as episodic or periodic, with intermittent flares. For some participants, restricting back pain episodes were unpredictable, while others could anticipate when the back pain would be aggravated or precipitated by specific activities.

> When it does come on, it comes on periodically…I may go for 10–11 months and not have back pain and then all of a sudden it will come on for no apparent reason. (86 year old man)

Eleven of the 23 (48%) participants reported back pain that was constant and unremitting. However, these participants also reported fluctuations in the severity of symptoms:

> Well I have chronic back pain. I mean, when I'm sitting here, I'm fine. But when I move around, it does hurt. And particularly when I bend over…It really gets very intense…it's not a stabbing pain. It's steady…sometimes it's dull and sometimes it's intense. (87 year old woman)

> I have back pain every day. Day and night plus the other pain that I encounter…It's never over…It's a constant pain and sometimes it worse than at other times. Sometimes I feel like I'm disconnected. I try not to feel sorry for myself about it but it something you wish you didn't have and it's something that you know is not going to get better. (86 year old woman)

Many participants reflected on the chronicity of their restricting back pain and how they perceived the symptoms will persist.

> But I never thought it would last this long. I keep thinking it's going to stop. (87 year old woman)

Perceived Cause and Precipitants

Participants described two main perceived causes of restricting back pain: related to prior occupational/ physical exertion and age-related degeneration/arthritis. Several participants believed that prior work or activity "brought on" the initial back pain that had, over time, led to their current symptoms.

> Most of my ailments come from…when I was on the fire department. I had 2 knees operated on, 2 shoulders, then a neck fusion. I hurt it in a fire and between all these injuries, sliding the pole, my back went out on me and it kept going out on me. (85 year old man)

The second perceived cause of restricting back pain, reported by half the participants, was age-related and "likely from arthritis".

> Well I just got older and the bones, probably it's brittle, same way as my fingers. The bone, now they ache like a toothache. See they're crooked…See and the same thing's happening to my back…[arthritis] is affecting my back. (99 year old woman)

> "Absolutely [it comes with aging]…Because I didn't have it when I was young, you know…I don't even think it's a medical problem, I don't even think that it's anything that the doctors will be able to do anything about." (92 year old woman)

Participants identified particular aggravating factors or precipitating events that they associated with developing restricting back pain. Nearly all of the participants recognized specific stimuli, especially certain common body movements that prompted or exacerbated their back pain.

> If I'm shaving and I want to wash my face and I bend over the sink for any length of time, then all of a sudden it just grabs and I have to straighten up…that's what bothers it. (82 year old man)

> During the night, I'm fine but during the daytime when I stand too long or I walk too far, I get terrific pains down in the back …the lower back… Only if I'm walking or standing too long. (99 year old woman)

Only a few participants were unable to identify a position, movement, or event that prompted their back pain.

> Most times for no reason that I can really determine. But it just comes on suddenly, and that's it…it's unpredictable. (86 year old man)

Consequences

The discussion guide focused on the impact of restricting back pain; prompted by our interview questions, all participants described the perceived consequences of restricting back pain on their daily activities and quality of life. Many participants offered general statements about their quality of life as well as specific examples of how restricting back pain impacted specific physical, psychological and social dimensions of life.

> You have no quality of life! …It *limits* anything. It doesn't limit, it *eliminates* anything I could do. (86 year old man)

Commonly, participants reported how restricting back pain affected their independence and directly resulted in the need for more support to carry out particular functions. This lack of independence and inability to carry on with usual activities was described as emotionally frustrating.

> It frustrates me that I can't just get up and go. (88 year old woman)

> The fact that I can't get out on my own, that I have to depend on everybody for my life's problems to help… [back pain] makes me stop and ask somebody else to do something for me. And that's very, very aggravating. (84 year old woman)

> It's very debilitating both mentally and physically because I'm not able to do what I want to do. My head says yes and my body says no. (84 year old woman)

The majority of participants (74%) commented on how restricting back pain resulted in consequences that affected them socially, most often by limiting their physical capabilities to participate in activities that they enjoy.

> I can say that the back pain probably keeps me from even wanting to go down the stairs, play Bingo with the rest of the people. I don't do the things that I used to love doing. (84 year old woman)

Participants also focused on the specific physical and emotional consequences of restricting back pain. The perceived impacts on social functioning were also closely related to perceived psychological impacts of restricting back pain.

> "I'm miserable. Because I'm invited someplace…I don't know if I can go all the time…Just walking or climbing stairs…if I have to go to my sister's 90th birthday

> party, I didn't know where I was going or how many stairs I had to climb and so I didn't go!" (87 year old woman)

In contrast to participants who reported daily consequences from restricting back pain, others expressed how they have accepted or adapted to having this chronic condition. For example,

> Well, I just accept it, I think. But that's my mentality. I mean, I'm not going to let it get me down. (98 year old woman)

> Well, I've had it for so long that I just accept it when it comes. (86 year old man)

Some participants described how coping mechanisms such as rationalization and minimizing help reduced the emotional burden of restricting back pain.

> I feel, I don't feel angry about it. I don't resent it. I feel that…I have such good health that this is just something you live with, put up with. No I don't look for a doctor to give me an instant cure or anything like that. I just try to be careful, not uh lift up, pick anything heavy and so on. Even trying to walk limited, bending to pick things off the floor and so on… But I don't consider it a great cost to bear. (86 year old man)

> To me, I don't think it's important because I'm not a person that said, oh, I've got to stay in bed because I can't move…Yeah but I don't let it bother me. I just keep going. (90 year old woman)

Participants also commented on the relative importance/severity of their comorbid conditions as one reason they may not have perceived restricting back pain as resulting in severe consequences.

> My concentration at this point is my diabetes…I've had that for almost 30 years. Then they know more about that than what I'm going through with my back. (87 year old woman)

> Well back pain doesn't require any treatment…As far as my experience has been. Whereas the other things I do have to really pay attention to. I mean, I have to watch my diet. And I do have to see the doctor regularly for my kidney condition. So I don't worry about the back pains. I just worry about having a fall or something. (87 year old woman)

Cure vs. Control

Nearly all of the participants understood that there is no cure for back pain, and that back pain management consisted mostly of "controlling" the symptoms. Some participants perceived an ability to control their restricting back pain.

> It's –hey you have your teeth all your life, and once in a while you're gonna get a tooth ache. It's like, when I get a tooth ache, I go and see the doctor, you know and I treat my back. (84 year old man)

> It's an effort to walk to the mailbox. It's an effort to walk down to the end of the hall. The pain is constant, but doctors, they're aware of the situation. But when it

> gets bad that I can't move, then I got to go to the hospital, get the injections, and that's it. (86 year old man)

Another participant described how wearing a supportive belt consistently worked to both prevent and treat his back pain episodes. He was one of the few participants who offered an intervention or alleviating factor that he perceived as consistently effective and, therefore, expressed control over his restricting back pain.

> I have a belt that I'll put on, and when I use that belt, when I leave it on for 3 or 4 hours in the morning, the pain goes away. Because what I'm doing works. And if I can wear a belt for 3 or 4 or 5 days and the pains gone for a period of months again, I can live with that. (86 year old man)

More often, however, participants expressed a lack of control over their pain resulting in frustration and struggling with an inability to manage their back symptoms effectively or consistently.

> Just that it annoys me when I get it and when you go sit down and rest and it goes away, I'm fine until the next time. But there's nothing that they can do. I take my pills, it numbs the pain and that's it. (99 year old woman)

> Nah.. I honestly think that at this point, my body is broken, it's worn out…that's why I say, someone in their 70s you could help a lot more, but I honestly don't know what could be done now outside of keeping comfortable. (98 year old woman)

> Physically and emotionally. I find it annoying…In other words, why can't they do something? Why do I have to live like this day in and day out? (86 year old man)

DISCUSSION

Our findings demonstrated that restricting back pain in older adults has variable and noteworthy physical, psychological and social consequences. This study contributes valuable perspectives from older adults (≥80) living with restricting back pain. Our results demonstrate how older participants' illness representations may influence health-related decisions, including health behaviors and coping responses. For example, from the standpoint of self-regulation theory[28], an older adult who perceives restricting back pain as an illness threat (with consequence) will select a coping mechanism and subsequently appraise its efficacy, resulting in modification or change in the coping strategy, if necessary.

Our analysis suggests that there are several components of the illness representation of restricting back pain, specifically, the perceptions of consequences and control that may offer potential targets for clinical intervention[36,37]. For example, older adults may be more willing to accept management options if they perceive restricting back pain as having a significant impact or resulting in downstream consequences[35]; this has not yet been tested in older adults, specifically. Educational tools, for example, focused on illness representations regarding controllability of symptoms may also prove effective in management of restricting back pain in older adults [37]. Such interventions must either align or change older adults' beliefs or illness representations regarding restricting back pain to be effective.

In our study, restricting back pain was described as episodic which is consistent with existing literature describing the frequency and recurrence of restricting back pain over 10 years[8]. Suri and colleagues, via a telephone survey, reported that flare-ups of chronic nonspecific back pain are common and independently associated with higher levels of pain intensity and disability than among those without flare-ups[9]. The older participants in our study emphasized how unpredictability of back pain resulted in physical, psychological, and social consequences; this mirrors much of the back pain literature in younger adults[38–40]. The perceived causes of restricting back pain in our study were described, broadly, as either occupational or age-related. This is important since older adults who believe their back symptoms arise from previous occupational injury may be more amenable to seeking care than older adults who attribute their symptoms to aging.

Our findings regarding illness precipitants are consistent with prior work published on triggers of back pain flare-ups in younger adults[9]. The authors surveyed 317 individuals, mean age 46.7, who reported flare-ups of chronic nonspecific back pain and reported the following most frequent triggers: lifting (27.4%), bending (23%), over-activity (20.5%), and moving wrong (13.9%). These precipitants, once identified by the individual, may be amenable to self-management; increased vigilance, mindfulness, and caution with regard to body movements may help avoid future back pain episodes[38].

At the core of each interview, the participants recounted a detailed description of the various important consequences of restricting back pain and its impact on their daily life. As expected, older adults described the physical ways in which back pain restricted them, but they also presented a consistent pattern of how the physical restriction leads to social limitations (i.e., interacting with friends) and subsequent emotional or other psychological impacts (i.e., frustration). They described back pain at the heart of a cycle of worsening physical limitation, psychological distress and social isolation. These self-identified consequences of restricting back pain, especially social impacts, are not all routinely evaluated by physicians in the context of back pain. This is an important area for future research.

For a number of our participants, other medical conditions seemed to take precedence over their restricting back pain. The explanations for giving other conditions (such as diabetes) priority included: 1) checking blood glucose was something that they had to do multiple times a day and, therefore, a constant reminder, and 2) greater ability to control diabetes with medications prescribed as opposed to perceived lack of effective medications and management modalities (lack of control) for back pain. However, nearly all participants understood that the mainstay for back pain treatment is control of symptoms and reducing frequency of episodes, rather than completely eliminating (or “curing”) back pain symptoms. Individuals who felt “in control” of their back pain were more likely to report satisfaction with treatment or, alternatively, they had developed effective coping or adaptive behaviors.

Several limitations of our study design are worth mentioning. Given the long follow-up of the PEP cohort, survival bias is present, however, this is inevitable in studies seeking to evaluate the population ≥80 years old. As with all research involving small sample sizes, we

are unable to generalize our findings to other populations. Moreover, since our sample consisted primarily of non-Hispanic White participants who are all English speakers we are unable to determine whether a more diverse population of older adults with back pain might yield variations in their perceptions and experiences. Similarly, it should be noted that illness representations can be dynamic, as symptoms and other life circumstances change. This research provides a snapshot of the older adult's illness representations; future research is needed to evaluate patterns of back pain-related illness representations over time.

Our qualitative research provides a greater depth of understanding of restricting back pain in older adults; it also points towards a need for further research in several areas. First, we have much to learn about the various alleviating factors and coping mechanisms used by older adults to manage restricting back pain. In the absence of existing guidelines for managing back pain in older adults, perhaps we could learn more on this topic from older adults who are successfully self-managing their illness. Second, additional research should focus on how illness representation predisposes individuals to specific coping strategies. Third, we heard from older adults that particular domains, such as social functioning, are an important consequence of restricting back pain. Future research efforts should focus on dimensions of the back pain experience that older adults identify as important, as these patient-identified targets for intervention may be more likely to result in meaningful change to older adults[41,42].

In conclusion, this qualitative study is the first to report on illness representations of restricting back pain as described by older community-living adults, ≥80 years old. This is a traditionally under-represented population in the back pain literature. The use of qualitative methods facilitated a more nuanced assessment of the experiences of restricting back pain among older adults and suggests that there is a need to develop and refine existing measures to more accurately reflect older adults' needs and priorities[43], and that take into account illness representations.

Acknowledgments

Contributors: We thank Emily Marks, M.S., Maria Funes M.P.H., and Robin Higashi Ph.D for assistance with coding and interpretation of the qualitative data; Margaret Drickamer M.D. for assistance with early discussions about coding; Linda Leo-Summers M.P.H. and Evelyne Gahbauer M.D., M.P.H. for assistance with obtaining the descriptive data on the PEP participants; lastly, Andrea Benjamin, B.S.N., for assistance with recruitment.

Funding: The work for this report was funded by grants from the National Institute on Aging (R37AG17560). The study was conducted at the Yale Claude D. Pepper Older Americans Independence Center (P30AG21342).

Dr. Makris was supported by the Yale Training Program in Geriatric Clinical Epidemiology and Aging Related Research (T32AG19134), and she is currently supported by the American College of Rheumatology Research and Education Foundation/ASP Junior Career Development Award in Geriatric Medicine, an NIA GEMSSTAR (R03AG040653) and the UT-STAR (UL1TR000451). The content is solely the responsibility of the authors and does not necessarily represent the official views of UT-STAR, UTSW at Dallas and its affiliated academic and health care centers, the National Center for Advancing Translational Sciences, or the National Institutes of Health. Dr. Fraenkel is supported by K24AR060231–02, and Dr. Gill is supported by K07AG043587. Dr. Lee and Dr. Hamann are supported by UT-STAR (UL1TR000451).

References

1. Lawrence RC, Helmick CG, Arnett FC, et al. Estimates of the prevalence of arthritis and selected musculoskeletal disorders in the United States. Arthritis Rheum. 1998; 41:778–799. [PubMed: 9588729]
2. Ryan CG, Ryan HE. Persistent Pain in Older Adults: A Brief Overview. Pain and Rehabilitation - Journal of the Physiotherapy Pain Association. 2011:10–15.
3. Deyo RA, Mirza SK, Martin BI. Back pain prevalence and visit rates: estimates from U.S national surveys, 2002. Spine. 2006; 31:2724–2727. [PubMed: 17077742]
4. Katz JN. Lumbar disc disorders and low-back pain: socioeconomic factors and consequences. J Bone Joint Surg Am. 2006; 88:21–24. [PubMed: 16595438]
5. Freburger JK, Holmes GM, Agans RP, et al. The rising prevalence of chronic low back pain. Arch Intern Med. 2009; 169:251–258. [PubMed: 19204216]
6. Hicks GE, Gaines JM, Shardell M, Simonsick EM. Associations of back and leg pain with health status and functional capacity of older adults: findings from the retirement community back pain study. Arthritis Rheum. 2008; 59:1306–1313. [PubMed: 18759261]
7. Muraki S, Akune T, Oka H, et al. Health-related quality of life in subjects with low back pain and knee pain in a population-based cohort study of Japanese men: the Research on Osteoarthritis Against Disability study. Spine. 2011; 36:1312–1319. [PubMed: 21730819]
8. Makris UE, Fraenkel L, Han L, Leo-Summers L, Gill TM. Epidemiology of restricting back pain in community-living older persons. J Am Geriatr Soc. 2011; 59:610–614. [PubMed: 21410444]
9. Suri P, Saunders KW, Von Korff M. Prevalence and characteristics of flare-ups of chronic nonspecific back pain in primary care: a telephone survey. Clin J Pain. 2012; 28:573–580. [PubMed: 22699128]
10. Reid MC, Williams CS, Concato J, Tinetti ME, Gill TM. Depressive symptoms as a risk factor for disabling back pain in community-dwelling older persons. J Am Geriatr Soc. 2003; 51:1710–1717. [PubMed: 14687348]
11. Leveille SG, Bean J, Ngo L, McMullen W, Guralnik JM. The pathway from musculoskeletal pain to mobility difficulty in older disabled women. Pain. 2007; 128:69–77. [PubMed: 17055167]
12. Shah RC, Buchman AS, Boyle PA, et al. Musculoskeletal pain is associated with incident mobility disability in community-dwelling elders. J Gerontol A Biol Sci Med Sci. 2011; 66:82–88. [PubMed: 20966101]
13. Gagliese L, Melzack R. Age-related differences in the qualities but riot the intensity of chronic pain. Pain. 2003; 104:597–608. [PubMed: 12927632]
14. Willman A, Petzall K, Ostberg A-L, Hall-Lord ML. The psycho-social dimension of pain and health-related quality of life in the oldest old. Scandinavian J Caring Sciences. 2013; 27:534–540.
15. Sofaer B, Moore AP, Holloway I, Lamberty JM, Thorp TAS, O'Dwyer J. Chronic pain as perceived by older people: a qualitative study. Age Ageing. 2005; 34:462–466. [PubMed: 16043446]
16. Borkan J, Reis S, Hermoni D, Biderman A. Talking about the pain: A patient-centered study of low back pain in primary care. Social Science Med. 1995; 40:977–988.
17. Teh CF, Karp JF, Kleinman A, Reynolds CF III, Weiner DK, Cleary PD. Older People's Experiences of Patient-Centered Treatment for Chronic Pain: A Qualitative Study Pain Medicine. Pain Med. 2009; 10:521–530. [PubMed: 19207235]
18. Bunzli S, Watkins R, Smith A, Schutze R, O'Sullivan P. Lives on Hold: A Qualitative Synthesis Exploring the Experience of Chronic Low-back Pain. Clin J Pain. 2013 (Epub ahead of print).
19. Dobriansky PJ, Suzman RM, Hodes RJ. Why population aging matters: A global perspective. National Institute on Aging NIoH, ed. 2007
20. Zulman DM, Sussman JB, Chen X, Cigolle CT, Blaum CS, Hayward RA. Examining the evidence: a systematic review of the inclusion and analysis of older adults in randomized controlled trials. J Gen Intern Med. 2011; 26:783–790. [PubMed: 21286840]

21. Reid MC, Bennett DA, Chen WG, et al. Improving the pharmacologic management of pain in older adults: identifying the research gaps and methods to address them. Pain Med. 2011; 12:1336–1357. [PubMed: 21834914]
22. Kvale, S. Interviews: An Introduction to Qualitative Research Interviewing. Thousand Oaks: Sage; 1996.
23. Gill TM, Desai MM, Gahbauer EA, Holford TR, Williams CS. Restricted activity among community-living older persons: incidence, precipitants, and health care utilization. Ann Intern Med. 2001; 135:313–321. [PubMed: 11529694]
24. Cohen DJ, Crabtree BF. Evaluative criteria for qualitative research in health care: controversies and recommendations. Ann Family Med. 2008; 6:331–339.
25. Mays N, Pope C. Rigour and qualitative research. BMJ. 1995; 311:109–112. [PubMed: 7613363]
26. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. Health Serv Res. 2007; 42:1758–1772. [PubMed: 17286625]
27. Turk, D.; Monarch, E. Biopsychosocial perspective on chronic pain. In: Turk, D.; Gatchel, R., editors. Psychological Approaches to Pain Management: A Practitioner's Handbook. 2nd ed. ed. New York: Guilford; 2002.
28. Hale ED, Treharne GJ, Kitas GD. The common-sense model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? Rheumatology. 2007; 46:904–906. [PubMed: 17449488]
29. Petrie, KJ.; Weinman, JA., editors. Amsterdam: Harwood Academic Publishers. 1997. Perceptions of Health and Illness: Current Research and Applications.
30. Leventhal, H.; Brisette, I.; Leventhal, E. The common-sense model of self-regulation of health and ilnness. In: Cameron, L.; Leventhal, H., editors. The self-regulation of health and illness behavior. London: Routledge; 2003. p. 42-65.
31. Sandelowski M. Theory unmasked: the uses and guises of theory in qualitative research. Res Nurs Health. 1993; 16:213–218. [PubMed: 8497673]
32. Diefenbach MA, Leventhal H. The Common-Sense Model of Illness Representation: Theoretical and Practical Considerations. J Social Distress Homeless. 1996; 5:11–38.
33. Hagger MS, Orbell S. A Meta-Analytic Review of the Common-Sense Model of Illness Representations. Psychol Health. 2003; 18:141–184.
34. Hampson SE, Glasgow RE, Zeiss AM. Personal models of osteoarthritis and their relation to self-management activities and quality of life. J Behavior Med. 1994; 17:143–158.
35. Fraenkel L, Falzer P, Fried T, et al. Measuring pain impact versus pain severity using a numeric rating scale. J Gen Intern Med. 2012; 27:555–560. [PubMed: 22081365]
36. Foster NE, Bishop A, Thomas E, et al. Illness perceptions of low back pain patients in primary care: What are they, do they change and are they associated with outcome? Pain. 2008:2136.
37. Glattacker M, Heyduck K, Meffert C. Illness beliefs, treatment beliefs and information needs as starting points for patient information - Evaluation of an intervention for patients with chronic back pain. Patient education and counseling. 2012; 86:378–389. [PubMed: 21719235]
38. Crowe M, Whitehead L, Gagan MJ, Baxter GD, Pankhurst A, Valledor V. Listening to the body and talking to myself - the impact of chronic lower back pain: A qualitative study. Internt J Nursing Studies. 2010; 47:586–592.
39. Snelgrove S, Liossi C. An interpretative phenomenological analysis of living with chronic low back pain. British J Health Psych. 2009; 14:735–749.
40. Schmidt AJ, Arntz A. Psychological research and chronic low back pain: a stand-still or breakthrough? Soc Sci Med. 1987; 25:1095–1104. [PubMed: 2961066]
41. Reuben DB, Tinetti ME. Goal-oriented patient care--an alternative health outcomes paradigm. N Engl J Med. 2012; 366:777–779. [PubMed: 22375966]
42. Fried TR, McGraw S, Agostini JV, Tinetti ME. Views of older persons with multiple morbidities on competing outcomes and clinical decision-making. J Am Geriatr Soc. 2008; 56:1839–1844. [PubMed: 18771453]

43. Rothrock NE, Kaiser KA, Cella D. Developing a valid patient-reported outcome measure. Clin Pharm Therap. 2011; 90:737–742.

44. Kohout FJ, Berkman LF, Evans DA, Cornoni-Huntley J. Two shorter forms of the CES-D (Center for Epidemiological Studies Depression) depression symptoms index. J Aging Health. 1993; 5:179–193. [PubMed: 10125443]

APPENDIX: Back Pain Discussion Guide

To begin our discussion I would like you to:

1. Think back to the last time you had back pain. Can you tell me what happens when you get back pain? OR Can you tell me what the back pain feels like?
    a. Probes:
        i. When was the last time you had it?
        ii. How long does it last? Hours? Days? Months?
        iii. Does it come and go?
        iv. Is it constant? Do you always have some back pain?
        v. Does it come suddenly or gradually?
        vi. Where is it located?
        vii. Is it sharp or dull?
        viii. Confirmatory question from screening criteria: Did it cause you to stay in bed for half a day or cut down on usual activities? Why, or why not?
2. Have you had more than one episode of back pain? If yes,
    a. When did you first develop back pain?
    b. Are you pain free in between back pain episodes?
    c. How often do you get back pain?
    d. Are the episodes of back pain the same or different each time?
3. Does back pain impact your quality of life? If yes, how?
4. How did the back pain affect you? (understand how it impacts independence/ functionality)
    a. Probes:
        i. Did it stop you from doing anything?
        ii. What is your day like if you don’t have back pain?
        iii. What is your day like if you do have back pain?
        iv. Does your back pain affect your sleep? Do you take any medication for sleep?

5. What is most concerning (bothers you most) about your back pain?
6. What, if anything, about your back pain worries you?
7. How do you think your back pain will affect you in the future?
8. What are your goals for managing your back pain? How important is it to you to have your back pain treated?
9. What do you think makes the back pain worse?
10. What do you think makes the pain better? Is there anything you do to lessen your back pain?
    a. Probes:
        i. What has been most helpful to you?
11. What do you think causes your back pain? (etiology or precipitating events)
    a. Probes:
        i. Trauma (exs: fall, MVA)
        ii. Cancer?
        iii. Infection?
        iv. Certain movements or activities
        v. Arthritis of the back?
        vi. Vertebral fracture?
        vii. Muscle strain?
        viii. Old age (does patient perceive back pain as normal aging)?
12. Tell me about what you do to care for your back pain?
    a. What treatment modalities (including coping mechanisms) are you using or have you used for your back pain?
    b. Have you had any experiences taking medication for back pain?
    c. Probes:
        i. Medications (including over the counter, herbal, natural substances)
        ii. Exercise, Water aerobics
        iii. Physical Therapy
        iv. Yoga, Tai Chi, Meditation
        v. Acupuncture
        vi. Hot/cold (heat pads), massage therapy
        vii. Reading books/ educating yourself

13. Have you had surgery on your back? If yes, when and was it helpful?
14. Do you have any other medical conditions? If yes,
    a. How do your other medical/health conditions affect the way you experience back pain?
    b. How does your back pain affect the way you experience your other health conditions?
15. Does your back pain affect you physically? If yes, how?
    a. Do you use a cane or walker? For back pain?
16. Does your back pain affect you emotionally? If yes, how?
17. How does your back pain affect your relationships (friends, spouse, family, care-providers)?
18. Do you talk with your friends or family about your back pain?
19. Do you think that back pain is a normal part of aging? Can you tell me more?
20. In addition to back pain, do you have other sources of pain?
    a. If yes, where?
    b. How does your back pain affect these other pains?
    c. How does the other pain affect your back pain?
21. Is there a role for your doctor in managing your back pain? If yes, what is it?
22. Do you tell your doctor about your back pain?
    a. What type of doctor do you tell about your back pain?
    b. What has your doctor told you about your back pain?
        i. Do you wish you knew more about back pain?
    c. What can your doctor do better to help you with your back pain?

Table 1

Participant Characteristics

Characteristics	**n=23**
	n (%)
Age	
80–84 years	7 (30)
≥85 years	16 (70)
Gender	
Female	13 (57)
Race/Ethnicity	
African American/Black	2 (9)
Non-Hispanic White	21 (91)
Education level	
Less than 12 years*	5 (22)
Living alone‡	12 (52)
High depressive symptoms ‡¥	9 (39)

*Did not complete high school

‡Living situation and depressive symptoms were updated at the PEP 144 month interview.

¥Depressive symptoms were defined based on the Center for Epidemiologic Studies Depression (CES-D) scale score ≥ 16. [44]