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Measuring pain in the context of homelessness

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Abstract

Purpose—The primary objective of this study was to inform the development of measures of pain impact appropriate for all respondents, including homeless individuals, so that they can be used in clinical research and practice. The secondary objective was to increase understanding about the unique experience of homeless people with pain.

Methods—Seventeen homeless individuals with chronic health conditions (often associated with pain) participated in cognitive interviews to test the functioning of 56 pain measurement items and provided information about their experience living with and accessing treatment for pain.

Results—The most common problems identified with items were that they lacked clarity or were irrelevant in the context of homelessness. Items that were unclear, irrelevant and/or had other identified problems made it difficult for participants to respond. Participants also described multiple ways in which their pain was exacerbated by conditions of homelessness and identified barriers to accessing appropriate treatment.

Conclusions—Results suggested that the majority of items were problematic for the homeless and require substantial modifications to make the pain impact bank relevant to this population. Additional recommendations include involving homeless in future item bank development, conducting research on the topic of pain and homelessness, and using cognitive interviewing in other types of health disparities research.

Keywords

Homeless; Pain; Pain measurement; Psychometrics; Patient-reported outcomes; Cognitive interviewing

Introduction

Homeless people disproportionately suffer from health problems, many of which are associated with acute or chronic pain (e.g., tooth decay, arthritis), and frequently these health problems go untreated due to substantial barriers to receiving appropriate care [1-3]. Common health problems identified among the homeless include diabetes, cancer, anemia, hypertension, asthma, heart disease, peripheral vascular disease, dental problems, neurological disorders, musculoskeletal problems (i.e., arthritis), ulcer, depression, amputation, or other disabilities [4-6]. In addition, untreated injuries and infections can become chronic conditions [3]. Health problems are exacerbated by the conditions of homelessness such as lack of a comfortable sleeping place, exposure to weather, prevalence of violence, inadequate health and hygiene practices, overcrowding at shelters, unreliable food sources, and extensive walking [4].

One of the barriers homeless individuals encounter when seeking appropriate health care is lack of health insurance or inadequate coverage [7]. According to the 2005 census, 14.3% of the U.S. population lacked health insurance. Greater than 50% of homeless persons are without health insurance; most who have insurance are covered by Medicaid, Medicare, or Veterans Affairs insurance [8]. Other barriers to receiving appropriate health care include inability to pay, lack of transportation, fragmented and discontinuous care options, discriminatory treatment of homeless people by health care professionals, and mistrust and fear of health care professionals [9,10]. High rates of mental health and substance abuse problems [11,12], and low literacy levels [13,14] create additional health care barriers [15].

It is estimated that 2.3-3.5 million people experience homelessness each year in the United States, and this is expected to increase by another 1.5 million over the next 2 years due to the recession [16]. Data from 2007 report that at a point in time 22/10,000 individuals in the United States, 36/10,000 in Washington State, and 42/10,000 in King County (the study location) are homeless[17].

Pain and homelessness

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage [18]. While it is known that homeless individuals experience more chronic health problems (many of which are associated with pain) than domiciled individuals, pain prevalence among homeless persons is not known. In fact, there is very little research on homelessness and pain. A literature review conducted via PubMed, CINAHL, and PsychInfo using keywords 'homeless,' 'homelessness,' and 'pain' (limited to abstracts/titles) in the past 10 years identified no articles that addressed pain as the primary topic. The 24 articles in which pain was a secondary topic addressed issues such as homelessness and health service utilization, end-of-life care, oral health, substance abuse, and diseases and conditions such as HIV/AIDS and hepatitis C [19-23].

Data collected in 2006 by the Seattle Health Care for the Homeless Network estimated the local prevalence of acute or chronic pain at 24% for patients seeking health care at shelters, transitional housing programs, or homeless-specific clinics [24]. Pain complaints were associated with oral health status, musculoskeletal conditions, and specific symptoms such as headache, abdominal discomfort, chest pain, dysuria, dysmenorrhea, and pain in general.

Pain measurement

It is generally accepted in the research community that the experience of pain is subjective, and therefore the most meaningful approach to measuring pain is self-report. As noted by "The Initiative on Methods, Measurement and Pain Assessment in Clinical Trials," patient-reported outcomes are "particularly important for conditions that involve symptoms such as pain and

fatigue” [25]. Numerous pain instruments are currently used by researchers and clinicians to assess pain, but we found no study that included the homeless in the validation samples. The same was true for other underserved populations. Two studies were found that evaluated the validity of health surveys (Short-Form 36, Short-Form 12) in a sample of homeless persons, but both surveys assess overall health status and do not focus on pain [26,27].

Purpose

This study was conducted under the umbrella of the patient-reported outcomes measurement information system (PROMIS) initiative that is developing dynamic and validated measures for the measurement of self-reported outcomes. PROMIS is one of the National Institute of Health (NIH) Roadmap initiatives. The NIH is committed to addressing health disparities across all NIH institutes and centers and has identified increased representation of underserved populations in clinical research as a goal of this comprehensive effort [28,29]. This study, that involves an underrepresented population, is part of a larger PROMIS research project aimed at validating pain measurement items. The purpose of this study was to (1) ensure that item banks for measuring interference of pain, that were generated by the larger PROMIS research project, are suitable for homeless individuals and can be used in clinical research and practice and (2) increase understanding among health care providers, researchers, and policy makers about the unique experience of homeless people with pain, specifically their experience seeking treatment for pain. Scale developers, typically work at academic institution, have advanced educational levels and come from upper middle class background and therefore may have difficulties reflecting the experiences of the underprivileged in their work. This often results in scales that are appropriate for middle class respondents with experiences similar to those of scale developers. To lessen this bias, PROMIS investigators conducted extensive interviews with individuals experiencing pain from a broad range of socioeconomic and ethnic backgrounds. However, due to the difficulties involving homeless people in research, only one participant in the PROMIS cognitive interviews was homeless. Based on the feedback from this participant who found many items irrelevant to his experience and had difficulties answering questions about how pain impacts his functioning, investigators decided to conduct an additional study focused solely on the homeless.

Methods

Study sample

A convenience sample of homeless individuals was recruited through posting flyers at Seattle area shelters, transitional housing programs, and public agencies. In order to recruit a sample as diverse as possible, flyers were posted at organizations that targeted their services to specific subpopulations (e.g., women, men age 50 and older, homeless people with health problems). Study inclusion criteria were (1) 18 years or older, (2) diagnosed with a disability or chronic health condition typically associated with pain, and (3) spent most of the past 3 months in nonpermanent living options. Demographics and primary health conditions were collected from participants as well as self-reported average levels of pain, fatigue, and difficulty with physical function over the past 7 days.

Study design

Face-to-face cognitive interviews were conducted to gather data for this study. The primary purpose of the cognitive interviewing process was to explore how homeless individuals thought about and experienced pain and learn about cognitive processes they used when responding to questions about pain interfering in their lives. Cognitive interviewing is frequently used to identify problems (e.g., irrelevant items) with questionnaires by examining the cognitive processes that participants use to answer questions [30-32]. Research protocols developed by PROMIS for cognitive interviews were modified and implemented for this study. The protocol

for the pain banks can be found on the website at <http://www.nihpromis.org/Web%20Pages/Bank%20Construction.aspx>.

Interviews lasted between 45 min and 2 h and took place in a private meeting room at the Seattle Central Public Library in downtown Seattle. Interviews were lead by a primary interviewer. An additional research staff member attended the interviews and took detailed field notes. All interviews were audio recorded to corroborate and complete field notes as needed.

Before beginning the interview, each participant completed a consent form, demographic form, and the wide range achievement test (WRAT3) [33]. The WRAT3 has been used as a quick assessment of literacy level in research studies [34]. Reading level was assessed because the ability of respondents to understand the questions is essential for validation of paper-and-pencil instruments. The interview and subsequent analyses were structured into two parts: (1) *pain measurement* and (2) *pain experience*.

Pain measurement—Fifty-six pain items that were included in the PROMIS preliminary pain impact bank were selected to be tested within the homeless population to ensure relevance. These items were selected because they targeted measurement of the impact of pain on the lives and lifestyles of participants. In addition, nine ‘global’ items that asked about overall health and quality of life were included in the study, such as “In general, would you say your quality of life is” with response options “Excellent, Very good, Good, Fair, Poor.” Six pain intensity items that measured worst, average, least, and current pain were also administered, for a total of 72 items. All 72 items were developed and tested as part of the PROMIS [35]. We decided to test the pain items in the homeless group because of prevalence of pain in this population and lack of existing research.

All of the pain impact items followed the same format of *item context*, *item stem*, *response scale*. For example, a standardized item read as follows: “In the past 7 days, overall how much did pain interfere with your daily activities? Not at all, A little bit, Somewhat, Quite a bit, Very much.” The item context is the time frame: “In the past 7 days,” the item stem is “overall how much did pain interfere with your daily activities,” and the response scale is “Not at all, A little bit, Somewhat, Quite a bit, Very much.”

The 72 items were divided into 4 sets of 18 items each, and each set was administered to three to five participants. Each participant was asked to respond to the set of candidate items in paper-and-pencil format “as if you were filling out the form at a doctor’s office.” After the participant completed the set of items, the primary interviewer used a list of questions and follow-up probes to encourage the participant to verbalize his or her thought process in answering the items. The questions and probes addressed four main areas: *item clarity*, *timeframe*, *item content*, and *response format*. To gauge *item clarity*, the interviewer asked whether the question was clear to the participant. For *timeframe*, participants were asked what timeframe they considered when responding to the questions. We used the 7-day timeframe in this study because of the PROMIS pain banks used this timeframe in the testing. Questions regarding *item content* focused on participants’ understandings of the item and challenges encountered in answering the item. Participants were asked, “Was this question easy or hard to answer” and “What comes to mind when you think about this question.” For the final topic, *response format*, participants were asked, “Were the response options appropriate? Were there too many or too few options?” Participants were also asked for suggestions about how to improve each of the items.

To analyze the data, we used a modified version of the questionnaire appraisal system (QAS) [36] as described in Table 1. In preparation for analysis, researchers summarized field notes for each of the four sets of pain measurement items into one single text document. Audio

recordings were referenced as needed to supplement field notes. For coding purposes, the first two categories within the QAS (Problems with Reading the Question and Problems with Instructions) and the Open-Ended Question subcategory were excluded from the coding scheme, because they did not apply. The remaining five categories and 20 subcategories were used for coding.

Two coders trained in the modified-QAS system, independently coded each of the four sets. Coders reviewed the summaries of feedback for each set of 18 items, and an item was coded as having a specific QAS problem if the problem was identified as such by at least one of the three to five participants. Disagreements between the two coders were resolved by consensus. Coders were encouraged to identify additional item problems that were not captured by the QAS.

Pain experience—After providing feedback about each item, respondents were invited to provide additional information about their experience living with and managing pain. At the end of the interview, they were asked, “Have you sought treatment for your pain?” If they responded “Yes,” they were requested to describe their experience seeking treatment for pain. These qualitative data were organized into main themes and summarized. This study was approved by the University of Washington’s Institutional Review Board and informed consent was obtained from all participants.

Results

Sample characteristics

Tables 2 and 3 display participant demographic characteristics. The mean age of participants was 50.5 years (range = 39-75). The majority of participants were male (77%), from racial groups other than white (59%), were unemployed or disabled (88%), and reported some posthigh school education (65%). The WRAT3 test identified 58.8% with a post-high school education reading level. When asked to identify places where they stayed for at least one night over the past 3 months, the two most common responses were ‘shelter/transitional housing/tent city’ (77%) and ‘public parks/streets/under a bridge’ (35%).

The most frequently reported health condition was arthritis (47%). Other chronic health conditions reported by participants included back pain, diabetes, multiple sclerosis, AIDS, and lupus. Nearly half of the participants (47%) reported their average level of pain and fatigue over the past 7 days as severe or very severe, while the remainder (53%) reported mild or moderate pain and fatigue. While substance abuse and mental health status questions were not systematically asked, many participants volunteered information, indicating they had substance abuse (36%) and mental health (29%) issues. Other health characteristics are presented in Table 4.

Pain impact items

Coders using the modified-QAS coding method agreed between 91.2 and 96.9% of the time, with Cohen’s kappa ranging from 0.61 to 0.82 indicating substantial agreement [37]. Table 5 displays problems identified with the 56 impact items. QAS categories that had no identified problems were removed from Table 5. The analysis of the remaining 15 pain intensity and global items was limited by the small number of items tested, and thus were not included in results.

Based on the QAS coding system, four problems were identified in at least 20% of the tested pain impact items. These were issues related to lack of clarity regarding timeframe referenced

when responding to items, vagueness of item content, inappropriate assumptions made by items, and vagueness of item response categories.

Items that were unclear, irrelevant and/or had other identified problems made it difficult for participants to respond with certainty and accuracy. Table 6 presents the common issues that participants experienced when responding to items and provides specific examples of words and phrases that were problematic or a description of the problem.

Difficulties with accuracy—In addition to the common problems identified through the QAS coding, participants had difficulty in honing in on the specifics of what some items were asking. For example, when asked *‘How much did pain make it difficult to fall asleep?’* one participant responded about his ability to sleep, not focusing specifically on falling asleep. Another recurrent issue was the difficulty participants had in isolating the impact of pain as a contributor to an outcome. For example, when asked *‘How often did pain make you feel depressed?’* one participant proceeded to tell stories about his multiple sources of depression such as lack of money, dealing with the threat of physical violence when living on the streets, and physical pain and was not able to consider only the impact of his pain on depression. Other examples of confounding factors include the impact of medication or uncomfortable sleeping conditions and pain on ability to sleep.

Ways of responding to problematic items—When participants responded to items identified as vague or having inappropriate assumptions, they typically responded in one of four ways: (1) left item blank, (2) selected ‘Not At All’ to signify that the item ‘Does Not Apply’ since there was no ‘Does Not Apply’ option, (3) modified the specific meaning of words/phrases in the item to better reflect their life circumstances (e.g., when a participant was asked, *‘How much did pain interfere with doing your tasks away from home,’* he identified the shelter as his home and described his tasks away from home as going to the library and church), (4) selected a meaning for items that had multiple interpretations (e.g., ‘family life’ means nuclear family), or (5) selected the middle answer as a “safe option.” For example, in reference to an item about pain’s impact on household chores, one participant stated, *“It is not relevant to me. I do not have household chores to do at this time but selected ‘somewhat’ just to answer question.”*

Pain experience in the context of homelessness

To increase understanding among health care providers, researchers, and policy makers about the unique experience of homeless people with pain, we collected and summarized participants’ experiences living with, managing, and seeking treatment for pain. The results are reported in Table 7.

These results describe how conditions of homelessness exacerbate suffering caused by pain and create barriers to pain management and treatment. Participants clearly recognized that their experience living with pain would be improved if they were not homeless. As one participant expressed, *“If I had a home, I would be able to soak in a hot tub to relieve some of this, and sleep in a comfortable bed I could take care of myself better—but I’m not. I have to stand to take a shower and lay on a matt on the floor with all kind of women around me. It’s totally different when you have pain and have a home, or don’t have a home.”*

The majority of participants expressed dissatisfaction, and some expressed extreme frustration with their experiences seeking and receiving treatment for pain. They reported numerous examples of inappropriate and poor quality care, specifically not receiving proper assessments of pain or only being offered ibuprofen instead of more effective longer-term treatment regimens. Consequently, many participants found other ways to deal with pain such as learning to tolerate the pain and self-medicating with legal or illegal substances. Only a few participants

reported being able to access quality care, because they had insurance through the VA or located a health care provider at a community clinic.

Discussion

Measuring pain

Cognitive interviewing was found to be an effective method for testing items and yielded useful information. Data analyses suggest that substantial modifications are required to make pain impact items clear and relevant to the experience of pain in the homeless population. For development of future pain item banks, we recommend that developers examine, modify, and test terminology used in items and response categories to increase clarity and address inappropriate assumptions. Researchers and clinicians should also be aware of the tendency for individuals to disregard the 7-day timeframe.

It is notable that item stems that were identified as being ‘vague’ or having ‘inappropriate assumptions’ often were those associated with a domiciled and typical life such as having relationships, a family, a home, a job, comfortable sleeping conditions, and the ability to participate in leisure/recreational activities. Items pertaining to socializing and relationships were challenging for participants to answer because they had a very small or no social network of friends, family, and/or co-workers; and because they did not engage in normal social activities such as going out to a restaurant or movie. As one participant stated, *“I did not become homeless until I was 50...There are two Seattles I know of. There is the Seattle that gets up and goes to work every day, watches TV, goes on vacations; and there is the homeless side where there is treachery, thievery, and BO....They sleep on mats, it’s horrible. You don’t cultivate relationships.”*

Some of our findings parallel to those obtained in research with domiciled populations, suggesting that some item problems are not unique to the homeless population. Specifically, retrospective reporting is difficult and particularly complicated when those reports are related to pain [38]. In addition, the term ‘interfere’ was found to be problematic in other research on pain items [39].

Pain experience

Physical pain is challenging to address even in populations with stable homes and employment, health insurance, and access to quality health care. The physical discomforts and stressors of homelessness exacerbate suffering caused by pain, create multiple obstacles to pain management, and barriers to accessing quality treatment. The majority of study participants had sought treatment from the same local urgent care center and expressed dissatisfaction and frustration with the health care received. While the high level of use at this urgent care center can be partially attributed to location, the over-utilization of urgent care centers by homeless has been thoroughly documented in previous research [40,41].

Recommendations

The following recommendations described in Table 8 aim to improve pain items and reduce health disparities in research and clinical practice that impact homeless individuals.

Best practices: conducting research with the homeless—The lack of consideration by researchers for participants other than those with typical middle class living arrangements reflects that these populations are more difficult for researchers to reach, recruit, and retain. As found in recent health disparities research, overcoming recruitment barriers is critical to addressing health disparities [42]. Here, we provide best practices in conducting research with homeless individuals and other diverse populations.

We found that a discussion with key individuals at agencies that serve homeless persons was very helpful in establishing trust and identifying the most appropriate mechanisms for recruitment. Procedures and personnel vary from place to place, and persons who know the institution or agency and the persons served can best advise what strategies are likely to be successful. Also, because of the lack of predictable structure in the lives of persons who are homeless, it is important not to schedule interviews too far in advance. The further from the initial contact date the interviews are scheduled, the less likely the participant will be to make the scheduled interview. Similarly, it is important upon initial contact with a participant to identify multiple ways to reach the participant (phone number at shelter, leaving message with a friend) if participant fails to show up. In our study, we did not encounter any situations that presented a danger to the interviewers, but it was important that the safety of interviewers be considered and addressed. We implemented a safety plan for safely exiting the interview and getting help if the participant arrived inebriated or became hostile. Finally, it is critical that the interviewer remain flexible in his or her approach to the interview in order to address the diversities of issues that challenge participants who are homeless. Participants may have low levels of literacy and/or distrust of health professionals (including researchers). On the other hand, they may want to share personal stories and have difficulty attending to the interviewers' questions. Substance abuse issues, cultural differences, and mental health issues may insinuate themselves on the interview process. All of these potential issues underscore the need for creativity and flexibility on the part of the interviewer.

Limitations

A number of limitations should be noted. First, the small sample size ($N = 17$) limits the generalizability of findings, especially considering the diversity of the homeless population. Second, some participants were reluctant to critique the items. For example, when asked for suggestions as to how to improve a question, one participant responded, *'you guys are way smarter about wording stuff than me.'* Finally, participants received a \$25 honorarium for completing the interview, and this incentive may have attracted some participants who did not legitimately meet study inclusion criteria. In response to this concern, researchers conducting interviews probed for sufficient detail about their experience of pain. In addition, participants were carefully screened and turned away when they reported finding out about the study through a friend instead of the posted flyer, and/or were unable to identify their chronic health condition.

Conclusions

The homeless population experiences a high prevalence and severity level of physical pain that is complicated by conditions of homelessness and lack of access to appropriate care. This topic has received inadequate attention both in clinical research and practice standards, and thus this underserved population is excluded from the benefits these efforts might yield. This study suggested that including homeless people in clinical research (i.e., pain measurement tool validation) is not only feasible, but it also yields useful results. By making item banks more appropriate for homeless populations, clinical research and subsequent clinical policies and practices will be more relevant and useful to this population.

While this study focuses on the homeless population, the recruitment approach and research methods employed may be applicable to other diverse populations that are typically excluded from clinical research and over-represented in clinical practice. Health disparities research shows that we, institutional decision-makers, do not understand the unique needs or experience of underserved subgroups [43]. Cognitive interviewing may be an effective method in bridging this knowledge gap.

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Table 1

QAS coding definitions

Categories	Definition
1. Clarity	<i>Identify problems related to communicating the intent or meaning of the question to the respondent</i>
1a. Wording	Question is lengthy, awkward, ungrammatical, or contains complicated syntax
1b. Technical terms	Terms are undefined, unclear, or complex
1c. Vague	There are multiple ways to interpret the question or to decide what is to be included or excluded
1d. Reference periods	Time periods are missing, not well specified, or problematic
2. Assumptions	<i>Determine whether there are problems with assumptions made or the underlying logic of the question</i>
2a. Inappropriate assumptions	Belief or idea in question is inaccurate regarding the respondent or his/her situation
2b. Assumes constant behavior	Question fails to account for situations when behaviors or experiences vary
2c. Double-barreled	Contains more than one implicit question
3. Knowledge/memory	<i>Check whether respondents are likely to not know or have trouble remembering information</i>
3a. Knowledge	Respondent is unlikely to know the answer to a factual question
3b. Attitude	Respondent is unlikely to have formed the attitude being asked about
3c. Recall	Respondent may not remember the information asked for
3d. Computation	The question requires a difficult mental calculation
4. Sensitivity/bias	<i>Assess questions for sensitive nature or wording, and for bias</i>
4a. Sensitive content	The question asks about a topic that is embarrassing, very private, or that involves illegal behavior
4b. Sensitive wording	Given that the general topic is sensitive, the wording should be improved to minimize sensitivity
4c. Socially acceptable	A socially acceptable response is implied by the question
5. Response categories	<i>Assess the adequacy of the range of responses to be recorded</i>
5a. Mismatch	There is a mismatch between question and response categories
5b. Technical terms	Terms are undefined, unclear, or complex
5c. Vague	Response categories are subject to multiple interpretations
5d. Overlapping	Response categories are overlapping
5e. Missing	Eligible responses are missing in response categories
5f. Illogical order	Response categories are in an illogical order

Table 2Participant characteristics ($N = 17$). Mean age 50.5, range 39-75

	N
Gender	
Female	4
Male	13
Race/ethnicity	
White	7
Black or African-American	2
American Indian/Alaska native	1
Hispanic	3
Multi-racial	4
Relationship status	
Never married	6
Married	3
Separated/divorced	8
Highest grade level	
Some high school	3
High school grade/GED	3
Some college/technical degree/AA	9
College degree	2
Employment status	
Unemployed	9
Retired	1
Disabled	6
Full-time student	1
Annual income	
Less than \$20,000	17
Veteran	3
Places stayed for at least one night in the past three months	
Vehicle	2
Shelter/transitional housing/tent city	13
Public park/streets/under a bridge	6
Friend's/relative's home	2
Motel/hotel	3
Other (own apt)	1
Indicated substance abuse issue	6
Indicated mental health issue	5

Table 3

Reading level (WRAT3)—grade level

	N
Post-high school	10
High school	4
Eighth grade	2
Sixth grade	1

Table 4**Health characteristics**

			N	
<i>Chronic health condition or disability</i>				
Arthritis/osteoarthritis/joint disease			8	
Back pain			4	
Other musculoskeletal (e.g., scoliosis)			4	
Diabetes			4	
AIDS/HIV			2	
Multiple sclerosis			1	
Lupus			1	
Pain			Fatigue	Physical function difficulty
<i>In the past 7 days, average level of pain (N)</i>				
Mild	2	1	3	
Moderate	7	8	4	
Severe/very severe	8	8	10	

Table 5

Problems with pain impact items

QAS categories	Subcategories	N	%
1. Clarity	1a. Wording	1	2
	1c. Vague	32	55
	1d. Reference periods	43	75
2. Assumptions	2a. Inappropriate assumptions	18	32
	2b. Assumes constant behavior	1	2
	2c. Double-barreled	2	4
3. Knowledge/memory	3d. Computation	1	2
4. Sensitivity/bias	4a. Sensitive content	2	4
5. Response categories	5a. Mismatch	7	13
	5c. Vague	11	20
	5d. Overlapping	2	4
	5e. Missing	6	11
	5f. Illogical order	3	5

Table 6

Types of item problems

Types of problems	Examples/description
Vague (unclear meaning)	<ul style="list-style-type: none">• 'day to day activities'• 'social activities and relationships'• 'emotionally tense'• 'discouraged'
Vague (multiple interpretations)	<ul style="list-style-type: none">• 'close personal relationships' = romantic relationships or friends and family• 'family life' = nuclear family or extended family• 'long distances' = down the hallway or 2 miles• 'fatigue' = tired or depressed• 'interference' = prevented from engaging or engaging made more difficult
Inappropriate assumptions (irrelevant to life circumstances in multiple domains)	<ul style="list-style-type: none">• Social: 'recreational activities,' 'leisure activities'• Relationships: 'family life,' 'close personal relationships'• Domestic: 'work around home,' 'tasks away from home'• Employment: 'work,' 'ability to work'
Lack of adherence to 7-day timeframe	<ul style="list-style-type: none">• Referring to shorter or longer timeframes• Referring to salient event [36] such as a life changing event (e.g. becoming homeless, loosing job, having an accident) instead of the 7-day timeframe
Vague response options	<ul style="list-style-type: none">• Subjective terms: 'poor,' 'fair,' 'somewhat'

Table 7

Pain experience

<i>Living with and managing pain</i>
<ul style="list-style-type: none">• Poor weather conditions increase pain level, specifically for participants with arthritis• Poor sleeping conditions exacerbate suffering caused by pain such as sleeping on streets, in shelters, or in vehicles• Grogginess caused by pain medications is a challenging side effect because of lack of safety living on streets (<i>'I need to keep my wits about me to protect myself'</i>)• Self-medicating with marijuana or other illegal substances to alleviate pain and promote a restless sleep• Lack of treatment options result in homeless people developing a high tolerance for pain (<i>'I guess you get used to it'</i>)• Health problems, many associated with pain, begin with or are intensified by homelessness (<i>'Most people I know did not have pain before they came to the shelter, at the shelter they come down with a lot of stuff.'</i>)• Participants fear of becoming addicted to pain medication (i.e., methadone, morphine)
<i>Accessing quality treatment</i>
<ul style="list-style-type: none">• Lack of health insurance and primary care provider contributes to high use of urgent care centers• It can take many months to locate and get an appointment with a health care provider who will accept medical coupons (<i>'Doctors are overloaded'</i>)• Discriminatory and poor treatment of homeless by health care providers and staff at local urgent care centers due to status of clients (i.e., homeless, poor physical appearance, and lack of insurance). Participants stated that they were not taken seriously, not trusted, not listened to, and not provided a proper diagnosis (<i>'... being homeless, doctors don't care. If I had job and a place, insurance —they would be going out of their way to take care of me'</i>)• Assumption on behalf of health care providers that all homeless are drug-seeking (<i>'... if you are homeless they automatically think you are a drug addict'</i>)• Common treatment at local urgent care centers is to provide ibuprofen• Health care providers' liability and concern of overmedicating or contributing to drug-seeking behaviors inhibits proper treatment (<i>'Doctors are constrained to give out meds because they might get in trouble'</i>)

Table 8

Recommendations

<i>Researchers</i>	
<ul style="list-style-type: none">• Examine, modify, and test terminology used in items and response categories to increase clarity, and address inappropriate assumptions by rewording terms to be more inclusive of diverse life circumstances (e.g., change 'home' to 'where you are living')• Employ cognitive interviewing to identify item problems and ensure item clarity, relevance, and overall functionality• Conduct future research on the topic of pain and homelessness to determine pain prevalence, characteristics of pain (i.e., associated prevalent health conditions), and complexities of pain that are unique to homeless individuals• Include persons who are homeless in instrument development and validation studies as well as other clinical research to ensure study outcomes will be relevant and applicable to their atypical life conditions	
<i>Health care providers</i>	
<ul style="list-style-type: none">• Administer valid standardized pain assessment measures in clinical practice to help determine legitimacy or intensity of a homeless individual's pain• Develop and employ clinical guidelines that address health care provider concerns regarding prescribing pain medication to individuals with or potentially with substance abuse problems• Employ guidelines and establish institutional policies to ensure homeless persons are treated in a non-discriminatory manner by health care staff and professionals	
<i>Advocates and policy makers</i>	
<ul style="list-style-type: none">• Increase awareness among health care professionals and advocates that serve homeless clients about the unique experience of pain among homeless population• Develop community health care services that target homeless individuals suffering from chronic pain	