

# ‘Seeing is Believing’: Pictures of Chronic Pain

JAMIE CRAWLEY, PhD, RN  
Faculty of Nursing - University of Windsor

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# Objectives

- Identify the influence on society of untreated and undertreated chronic pain
- Describe how chronic pain produces challenges in the lives of African Americans/patients living in poverty
- Distinguish how patients' home environments may produce barriers for effective pain management
- Discuss strategies to improve chronic pain care for African Americans living in poverty and for other chronic pain patients

# Background

- Pain can be debilitating, with patients often facing significant barriers in the diagnosis, treatment, and management of their pain (National Pain Foundation, 2009a)
- People at highest risk for inadequate pain control include people who are non-Caucasian, (particularly African American) and those living in **poverty** (American Pain Society, 2004; Benkert & Peters, 2005; Green, Baker, Sato, Washington & Smith, 2003; Pieper, Vallerand, Nordstrom & DiNardo, 2009).
- Chronic pain - defined as pain or discomfort that persisted continuously or intermittently for longer than 3 months (Elliott, Smith, Penny, Smith & Chambers, 1999)

# Background

- Pain is a common complaint in 50-70% of all primary care visits (Sullivan & Egel, 2005)
- Providers might have their decisions for treatment influenced by “moral rationing,” meaning a practitioner judges whether a person is “more or less deserving of treatment” (Van Ryn & Fu, 2003 p. 251)
- Inadequate pain control can lead to depression, difficulty with coping, reduced quality of life, an inability to concentrate and decreased **socialization** (American Pain Society and Janssen Pharmaceutica, 1999; Block & Brock, 2008; Green, Baker, Sato et al., 2003; Gureje, Von Korff, Simon & Gater, 1998; National Pain Foundation, 2009b; Pieper, Szcsepaniak & Templin, 2000; Vallerand, Saunders & Anthony, 2007)

# Methods

- Purpose - the purpose of this study was to examine the experiences of chronic pain as described by African American male and female indigent adults (adults living in poverty), attending an urban, primary care clinic
- Qualitative, focused ethnography (Muecke, 1994; Speziale & Carpenter, 2003)
- Interview questions, photovoice and field notes
- Photovoice: (Baker & Wang, 2006; Photovoice, 2006; Wang & Burris, 1997)
  - Is a participatory action strategy that enables those taking photographs to record through images, the chronic pain experience
  - It evokes dialogue about important issues and engages policy makers
  - Empowering to people, gives participants control over representation of their world



“I would amputate my own legs if I could.” (P-4, I-1)



“That is the first set of stairs that I have to climb before I can even attempt to go inside the house. And although there’s not many there, but they are horrible. They are horrible. And this little rail over here. O.k. not too sturdy. Not too sturdy at all. And I was in pain and I was trying to hold onto it and it started wobbling. And I almost fell down the stairs.” (P-7, I-2, PV-1)

# Setting and Inclusion Criteria

- Setting – urban, primary care clinic caring for indigent population
  - Patients earn < \$250/month
- Criterion- based selection (Schensul, Schensul & LeCompte, 1999)
- Inclusion criteria
  - Women and men – self-identified as African American
  - Registered at the clinic (indigent)
  - No obvious signs of cognitive impairment
  - Experienced moderate to severe pain >3 months
  - Spoke English and denied current use of illicit drugs

# Data Collection

- Protection of Human Subjects
  - IRB-HIC/REB/DMC/clinic approval
- Data Collection
  - After signing informed consent participants completed:
  - Brief Pain Inventory (Short Form) (Cleeland, 1991) , interviews and given camera to complete photovoice
  - Trustworthiness was maintained
- Data Analysis
  - Descriptive stats for Brief Pain Inventory (Short Form) (Cleeland, 1991)
  - Interviews transcribed verbatim

# Findings

- 13 participants (7 men/6 women)
- 31 interviews and 18 photovoice sessions
- More than 2000 pages of transcripts and 400+ photos reviewed – Five themes and multiple subthemes

# Findings

- Demographic:
  - Ages - ranged from 40-57 years; one female 22 years
  - All were unemployed due to pain
  - With every visit participants said they spoke about their pain with health care provider
- Brief Pain Inventory (Short Form):
  - Participants experienced pain in 3-9 different places on the body with the back, sacral, hips and leg areas being the most common locations for their chronic pain
  - Chronic pain at its worst in the last 24-hours – average of 9.3 (*on a scale of 0-10, where 0 was no pain and 10 would be the worst pain they could imagine*)
  - Average pain score – 7.4

# Theme - Waiting on Pain

“Are these pills ever going to work? How long is it going to take?” (P-4, I-3)

## Waiting on pain – Her front porch



“My street I live on goes this way, this is the other street. This is from the kitchen window. ...passin’ the time by watchin’ the people and traffic pass by...” (P-2, I-3, PV-2)

## Waiting on pain - Working elevators



“Now this here is the elevator that they just fixed. This is the one that was down for three weeks. They just fixed it. We have to have elevators, I’m on the 8<sup>th</sup> floor.” (P-2, I-3, PV-2)

## Waiting on pain – Comfort food



“This is my candy bar. This is what I eat for pain, chocolate, Snickers. It helps, believe it or not that Snickers chocolate helps. This is what I eat that’s why I took a picture. It relaxes me, I don’t know why but it does and this is my chair” (B-4, L2, PV-1)

# Theme – Coping with Pain

“I don’t want to be high, I just want to be pain free.”

(P-5, I-1)

## Coping with chronic pain – Cane, “my buddy”



“Oh that’s my buddy. Yeah, he support me. That’s my cane, he supports me. ‘Cause first I was embarrassed to have it you know. And then seem like I seen more since I have my cane. I seen so many people, more people with the cane this year than I ever seen in my life.” (P-9, I-2, PV-1)

## Coping with chronic pain - Running boards on truck



“The next picture is his truck. Now that’s very helpful this running board when I get into his truck. It’s very helpful ‘cause a lot of trucks don’t have these. So if I got to get up there [without one] and that’s kind of painful.” (P-13, I-2, PV-1)

## Coping with chronic pain - Neighbor's pets



“That’s a little barkin’ dog. He just irritates me and he barks all night. I be cussin’ at him at night. I forget about the pain. I be in the window, he be next door, he just irritates me and you know I cussin’ at him so much until I get sleepy and my pain, I forgets about that you know ‘cause he be barkin’ and I be cussin’ him, he be barkin’ and I be cussin’. And we carry on then, this puppy will carry on a couple of hours a night. I mean every night and he helps me. That little puppy helps me.” (P-4, I-3, PV-2)

# Theme – Challenges with Chronic Pain

“You don’t look like you’re in pain.” (P-8, I-2)

## Challenges and chronic pain - Walking



“This is the bus stop, nowhere to sit. Yeah lean on a pole or stand there and just take it... that’s the same corner. Just showing you how wide it is and the traffic. And they want you to walk across the street in 10 seconds.” (P-13, I-2, PV-1)

# Challenges with chronic pain and preparing food



“O.k. this is my microwave that I use to prepare my frozen meals. I put them in the microwave to prepare my frozen meals. And the cereal. It’s something fast that I don’t have to be standin’, cookin’. This is my fast meals. So this is how I prepare my frozen meals in the microwave.” (P-9, I-2, PV-1)

## Challenges with chronic pain – Manual locks in cars



“Oh this is just showing that I have manual locks, manual windows and that makes it harder too. Well especially without the AC. I can’t reach the other side...I come in here on the freeway with my window rolled all the way down. ...the manual roll down window ‘cause everybody assumes everything is automatic and it isn’t.” (P-10, I-2, PV-1)

# Theme – Negotiating Pain in a Vulnerable Environment

“I’ve missed so many appointments because I don’t have the transportation. No bus fare ‘cause I don’t have income.” (P-2, I-1)

# Negotiating pain in a vulnerable environment - View when cannot get out of bed



“This is a personal picture. This is one of those days where pain was there and I didn’t clean up that day. It’s like if I woulda cleaned up last night I wouldn’t have to look at this. I can’t go anywhere. My stomach is still sore, I can’t get out of bed and this is what I have to look at. It’s kinda depressing it’s almost like yeah this is adding to the situation.” (P-7, I-2, PV-1)



## Negotiating Pain in a Vulnerable Environment – Drive-by shooting



“Oh no this what that is. This is where the girl got killed... A week or so ago, the 13 year old girl that got shot...between the eyes. That was right here. That was right here and my house is the 1<sup>st</sup>, 2nd house and this is where we clean the blood up. You know what there was so much down there, we clean it up.” (P-4, I-3, PV-2)

# Negotiating pain in a vulnerable environment - Income limiting safety



“But this is actually the first flight and I don’t know if you can tell but these are steeper. But there’s not a light on the stairs. So if I don’t leave my room door open. With the light on. I have to feel my way down the stairs and they’re so steep that when you step out and try to feel for the next one you gotta almost commit to going down without even seeing the stair. I hate those stairs. Absolutely hate em.” (P-7, I-2, PV-1)

# Theme – Sharing Wisdom about Chronic Pain

“...try to put their selves in our situation.” (P-9, I-2)

# Sharing Wisdom about Chronic Pain - Listen to patients

“I think they should be a little more compassionate and realize that people need this medication instead of formin’ these opinions that everybody sellin’ them or just tryin’ to get high or somethin’. You know, it’s not like that. I’m not sayin’ that’s not being done. I’m just sayin’ not everybody do that.”

(P-13, I-2)

# Discussion

- Chronic pain influences all aspects of people's lives
- Aspects of people's lives may influence their chronic pain
  
- Clock time versus subjective time
- Dependency on others
- Lack of transportation
- Poverty, loss, violence
- Patients have strengths and resilience

# Discussion

- Determining and acknowledging the challenges patients experience and methods of coping will assist health care providers to understand chronic pain patients more completely
- Building trusting relationships with patients improves chronic pain care
- Patient-centered pain care improves health and reduces health care disparities

# Limitations and Strengths

- Limitations:
  - Participants were selected based on ‘reliability’
  - Sample limited to urban, primary care clinic
  - Did not include those admitting to current illicit drug use
- Strengths of study:
  - Participants described the important experiences in their lives related to their chronic pain
  - Cultural patterns and the artifacts, people, and rituals that were meaningful to the participants as related to their chronic pain were identified

# Recommendations/Reflections

- Importance of trust and communication to strengthen the patient-health care provider relationship
  - Patients feel valued when someone listens to their concerns about chronic pain
  - Patients who follow up with care – improved management of co-morbidities
  - Various coping methods, feel judged if have history of illicit drug use
  - Difficult to maintain sobriety when experiencing severe chronic pain
  - Severe chronic pain may decrease patients' ability to understand health teaching and treatment instructions

# Recommendations

- Care for African American indigent adults will be improved with:
  - Continued advocacy for clients and for health care policies that reduce inequities and chronic pain care disparities
  - Recognition of the costs of untreated and under-treated chronic pain – decreased quality of life, increased visits to ER, exacerbation of other existing co-morbidities, increased use of health care resources

# Conclusion

“You got people that need it [pain medications]...that’s the worse thing in the world to be walkin’ around hurtin’ every day, sufferin’...at least try to understand that, we tryin’ to do better for ourselves. If we wouldn’t, we wouldn’t be up here, we’d be down on the street. There are people goin’ down the street...they don’t care, they not tryin’ to get healed. Here we comin’ up here and we tryin’, real hard, real hard.” (P-12, I-2)

# Thank you

Special thanks to:

- The participants of this study
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