Developing Interventions to Improve Function in African Americans with Pain

April Hazard Vallerand, PhD, RN, FAAN
Associate Dean for Research
PhD Program Director
Distinguished Professor
College of Nursing Alumni Endowed Professor

Conflict of Interest Disclosure

• Author’s conflicts of interest:
  • April Hazard Vallerand, no conflict of interest

Conflict of Interest Disclosure Information

• Conflicts of interest listed for ALL contributors
  • None

A conflict of interest is a particular financial or non-financial circumstance that might compromise or appear to compromise, professional judgment. Anything that fits this should be included. Examples are owning stock in a company whose product is being evaluated, being a consultant or employee of a company whose product is being evaluated, etc.
• Taken in part from “On Being a Scientist: Responsible Conduct in Research”, National Academies Press. 1995.
Pain is the most common and distressing symptom experienced by cancer patients and often lowers functional status. Pain is experienced by 70-90% of cancer patients, and upwards of 70% die with unrelieved pain. With shorter hospital stays, patients and their caregivers are more than ever responsible for daily pain and symptom management. Unfortunately, they are not typically prepared for this responsibility.

Treatment of Pain

- Pain is a common complaint in 50-70% of all primary care visits
- The prevalence of chronic pain in the general population has been found to be 10% to 40%
- Affects over 116 million Americans
- People at highest risk for inadequate pain control include people who are non-Caucasian, particularly African American and those living in poverty
- Surveys of pharmacies in urban areas, found access to opioid analgesic medications was limited in communities with a high proportion of minority inhabitants
- Inadequate pain control can lead to depression, difficulty with coping, reduced quality of life, an inability to concentrate and decreased socialization

Functional Status

- Functional status, or the ability to carry out meaningful activities, is affected by pain intensity and the patient’s belief that they can control the pain to an extent that allows them to participate in those activities.
Assessment & Intervention

- With proper pain assessment and appropriate therapy based on the World Health Organization analgesic ladder, cancer pain can be controlled in about 90% of cancer patients.
- Much of chronic noncancer pain can be decreased.
- Lack of a proven intervention to address patient/caregiver beliefs and enhance the effectiveness of pain management has been a barrier to progress in the field.

Improving Cancer Pain in the Home

Funded by the National Cancer Institute
#1 K22 CA87713-01

Purpose

- Randomized control trial
- To determine the effect of programs of structured educational interventions directed at nurses, and at patients and their caregivers on the management of pain and opioid-related symptoms in home care patients with cancer.
- Sample
  - Home care nurses caring for patients with cancer-related pain
  - Patients with cancer-related pain
  - Caregivers of patients with cancer-related pain
Requirements to Affect Change

Nurses must be:
- Expert in the content area
- Able to communicate expertise to:
  - physicians
  - pharmacists
  - patients
  - caregivers

The Educational Intervention

Power Over Pain (POP)
- Nurses
  - Basic pain management & communication skills
  - Advanced pain management & assertiveness skills
- Patients & Caregivers
  - Pain management & communication

Conclusions

- Home care nurses receiving the educational intervention demonstrated
- Improved knowledge and attitudes following the beginning and advanced interventions, without a significant decrease between the two sessions
- Decreased barriers following both beginning and advanced interventions
- Increased perceived control over pain following both beginning and advanced interventions

Cancer-Related Pain in the Outpatient Clinic Population

Funded by Detroit Medical Center/College of Nursing Scholar Award

Study Aims

- To investigate the degree to which outpatients with cancer-related pain believe their pain is controllable
- To determine the current level of pain control that these patients are experiencing
- To investigate the relationship between pain and symptom distress, perception of control over pain, and functional status in this patient population.

Sample

- 304 patients
- Gender
  - 119 male (38%)
  - 185 female (61%)
- Age – mean 55 years
- Married – 165 (54%)
- Employed full time – 82 (27%)
Sample

- Ethnicity
  - Caucasian 183 (60.2%)
  - African American 98 (32.1%)
  - Hispanic 5 (1.6%)
  - Other 18 (6.1%)
- Education - mean = 13.11 years

Cancer

- Months since diagnosis
  - Mean 20 months
  - (0.2 – 300)
- Metastasis
  - Yes 130 (42.8%)
  - No 147 (48.4%)
  - Unknown 27 (8.9%)

Pain in the Past 2 weeks

- Worst – 6.67 (SD=2.60)
- Least – 3.74 (SD=2.95)
- Average – 4.69 (SD=2.37)
- Current – 3.89 (SD=2.92)
- Amount of relief achieved from current pain regimen 56%
- Mean number of pain sites = 3.25
Control of Pain

- 90% believed their pain was controllable
- 76% believed their pain was controlled

Perceived Control

- The mean level of perceived control for the patients was 5.03 (SD= 1.01) on a 0 to 7 point scale, with lower scores indicating more control.
- The mean score indicates that patients had only a low to moderate perception of control of their cancer related pain.

Symptom Distress

- Mean score for pain-related distress was 3.76 (SD=1.68) on a scale of 0-4
- Symptom distress related to symptoms other than pain was reported at a low level with a mean of 1.27 (SD = .72).
- This suggests that pain-related distress has a greater influence on symptom distress than other symptoms in patients with cancer-related pain.
Functional Status

- Measured by the Interference Scale of the BPI.
- Mean 4.73 (SD=2.78) on a 0-10 scale
- Participants reported interference by pain with all activities at a moderate level.
- The activities that pain interfered with the most were work, sleep, enjoyment of life, mood, and general activities.


Disparities Between Black and White Patients with Cancer Pain: The Effect of Perception of Control Over Pain
The purpose of this study was to examine disparities in pain intensities, symptom distress, and functional status between White and Black patients with cancer pain and to examine the effect perceived control over pain had on these outcomes.

**Study Aim**

Central element – the perception that one has the ability to affect outcomes

“The perception that one has a way of gaining and/or maintaining control over an adverse event, such as pain.” (Pellino & Ward, 1998, p.111)

**Perceived Control**

- Central element – the perception that one has the ability to affect outcomes
- “The perception that one has a way of gaining and/or maintaining control over an adverse event, such as pain.” (Pellino & Ward, 1998, p.111)

**Sample**

- 281 adult patients, 18 years and older
- Cognitively intact
- English speaking
- Receiving treatment at a large urban cancer center
- Experienced cancer-related pain within the month prior to participation
Results

**Pain Scales** - Median value higher for Black patients than for White patients. While worst pain rating was not significant (p=.09), least, average and pain now values were significantly higher (p<.01) in Black patients than in White.

**Pain Related Distress** - Median values for all three measures were significantly higher (P<.01, .04, <.01) for Black patients than for White patients.
Functional Status - Median values were higher for Black patients than for White patients for all seven measurement activities with four of the items showing significant interference with function (General activities and Mood p=.01, Work p=.04, Relationships p=.02).

Perceived control over pain was the only predictor of disparity identified. When perceived control over pain was controlled statistically, the disparities between Black and White patients in the outcomes of pain-related distress and functional status were diminished to a level no longer significant.

The Effect of Perceived Control Over Pain on Ethnic Disparities

- Perceived control over pain was the only predictor of disparity identified.
- When perceived control over pain was controlled statistically, the disparities between Black and White patients in the outcomes of pain-related distress and functional status were diminished to a level no longer significant.

Clinical Implications

These results exemplify the importance of perceived control over pain, especially in Black patients, and may provide a means of decreasing disparities and improving functional status.
Potential Methods for Increasing Perceived Control Over Pain

- Educating patients about pain management modalities
- Individualizing therapy to meet patient’s needs including acceptable modifications of pharmacological regimen
- Providing options for patients to manage episodes of breakthrough pain
- Teaching patients how to use nonpharmacological modalities
- Educating patients about when to call the clinician if pain is not controlled

Conclusions

- Increasing perceived control over pain results in a decrease in pain-related distress, and an increase in the functional status of the patient.
- Factors that increase perceived control over pain include:
  - Increasing the patient’s knowledge of pain management strategies
  - Identifying and correcting pre-existing misconceptions
  - Reducing barriers to adequate pain management


PAIN AND FUNCTIONAL STATUS IN A PRIMARY CARE CLINIC FOR INDIGENT ADULTS

Funded by a DMC Faculty Scholar Award
Purpose

- Describe the characteristics of pain and its relation to
  - Functional status
  - Perception of control
  - Coping
  - Depression
  - Self-treatment of pain

in patients seen in an urban primary care clinic for low income adults.

Eligibility Requirements

- 18 yrs or older
- Receiving treatment at the clinic
- Cognitively intact
- Not pregnant
- Income of $250/month or less
- Pain in the past 2 weeks

Participant Characteristics (n=301)

- Age: Mean 48 yrs (SD=8)
  Range 22-64
- Gender: Male 159 (53%) Female 142 (47%)
- Race: Black 278 (92%)
  White 16 (5%)
  Hispanic 2 (+1%)
  Asian 1 (+1%)
  Native American 1 (+1%)
  Other Race 6 (2%)
Participant Characteristics \((n=301)\)

- **Education**
  - Less than HS gradation – 90 (30%)
  - GED or HS graduate – 93 (31%)
  - Trade, technical training, college – 118 (39%)

- **Marital Status & Living Situation**
  - Single/never married - 159 (53%)
  - Lived in own home or apt – 189 (63%)

- **Hours Worked/Week**
  - 0 hours – 220 (73%)
  - 40 hours – 25 (8%)

Methods & Procedures

- Exploratory cross-sectional design
- Data were collected during clinic hours, with RAs in clinic every day to obtain a representative sample
- Interview rooms were provided by the clinic
- Instruments were read to participants to prevent problems with literacy
- Interviews lasted 20-60 minutes

Self-reported Health Conditions

- Hypertension – 61%
- Arthritis – 54%
- Breathing problems – 33%
- Mental illness – 31%
- Leg ulcers - 23%
- Neuropathies – 23%

- Self-rated health mean score – 5.5 (SD=2.3); range 1-10
Sites of Pain (n = 301)

<table>
<thead>
<tr>
<th>Site</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legs</td>
<td>230</td>
<td>76%</td>
</tr>
<tr>
<td>Back</td>
<td>143</td>
<td>48%</td>
</tr>
<tr>
<td>Feet</td>
<td>131</td>
<td>44%</td>
</tr>
<tr>
<td>Pelvis</td>
<td>128</td>
<td>43%</td>
</tr>
<tr>
<td>Arms</td>
<td>118</td>
<td>39%</td>
</tr>
<tr>
<td>Hand</td>
<td>93</td>
<td>31%</td>
</tr>
<tr>
<td>Hands</td>
<td>68</td>
<td>23%</td>
</tr>
<tr>
<td>Chest</td>
<td>46</td>
<td>15%</td>
</tr>
</tbody>
</table>

Pain Characteristics

- Mean number of pain sites = 4 ± 2 sites
- 80% take prescription pain medication
- Worst pain in past 2 weeks = 8.4 (0 to 10)
- Least pain in past 2 weeks = 4.2 (0 to 10)
- Average pain = 6.5 (0 to 10)
- Pain now = 5.8 (0 to 10)
- Pain relief from current treatment = 46.2%
- Disabled due to pain = 48%

Effects of Pain on Function
SEM results showing that Perceived Control Over Pain mediated the relationship between Pain and Functional Status. Standardized path coefficients, factor loadings, and correlations among measurement errors are shown. All coefficients were significant, $p < .05$.

Study Conclusions

- Pain is a significant problem for indigent patients in primary care
- Mediation by Perceived Control Over Pain was partial but strong, accounting for a reduction of 29% in the effect of pain on functional status.
- Improving Perceived Control Over Pain has the potential for improving patients’ feelings of life control and purpose or meaning in life, and psychological and physical functioning for adults living with pain.

Implications

- The primary care setting is particularly vulnerable to unmanaged and ineffective pain care across socioeconomic status and racial groups
- Primary care providers, as the gatekeepers, must recognize the existence and effects of pain-related disparities in these populations

Pain
- The number one reason people seek healthcare
- We have the technology to manage/relieve 90% of the pain we see today
  - Why don’t we use it?
  - Relieve vs manage
- Many barriers to the management of pain
  - Lack of assessment
  - Lack of knowledge
- Who manages pain?
- How do we identify problems and know what to do?

Clinicians
- Identify problems
- Attempt to solve problems
  - Limited resources
  - Limited time
  - Limited knowledge?
- Know what needs to be done
- Collaboration between clinicians and researchers is the ideal way to investigate and “solve” a problem

Improving Functional Status in African Americans with Cancer Pain
- Funded by the National Cancer Institute
  - R01 CA154032-01A1
- Power Over Pain – Coaching (POP-C)
- Randomized clinical trial
- Two-group randomized design with repeated measures
- Primary outcomes
  - Patient’s pain, pain-related distress & functional status collected at enrollment, weekly during the 5-week intervention, and at 7 and 12 weeks
- Intermediate measures
  - Beliefs and perceived control over pain collected at baseline, 7 and 12 weeks
Sample

- 256 patient/caregiver dyads
  (128/group)
- Inclusion criteria
  - Self-identified as African American
  - 18 years or older
  - Cognitively intact
  - English speaking
  - Report cancer-related pain in the past week of ≥4 on a 0-10 scale
  - Caregivers identified by the patient as the person who helps most with their care

Caregivers

Concerns & beliefs may discourage patient from adherence to pain plan

- See if congruent beliefs exist, whether congruency changes during the study, & effects of congruency on study outcomes.
- Caregiver Outcomes
  - Knowledge, attitudes, & barriers
  - Perceived control over pain
  - Distress over patient’s pain

Sequence of visits and content for patients and caregivers in each group

<table>
<thead>
<tr>
<th>Week</th>
<th>Type of Visit</th>
<th>Content/Focus</th>
<th>Patient Measure</th>
<th>Caregiver Measure</th>
<th>Patient Group</th>
<th>Caregiver Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Home</td>
<td>Enrollment and Demographics</td>
<td>Primary and Intermediate Outcomes</td>
<td>Program Module Evaluation</td>
<td>175</td>
<td>95</td>
</tr>
<tr>
<td>2</td>
<td>Home</td>
<td>Intervention focus: Medical Management</td>
<td>Primary Outcomes</td>
<td>Side Effect Diary</td>
<td>37</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>Phone</td>
<td>Support/Boost</td>
<td>Primary Outcomes</td>
<td>Side Effect Diary</td>
<td>37</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>Home</td>
<td>Intervention focus: Pain Advocacy</td>
<td>Primary Outcomes</td>
<td>Side Effect Diary</td>
<td>37</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>Phone</td>
<td>Support/Boost</td>
<td>Primary Outcomes</td>
<td>Side Effect Diary</td>
<td>37</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>Home</td>
<td>Effectiveness of Intervention Program</td>
<td>Primary and Intermediate Outcomes</td>
<td>Program Module Evaluation</td>
<td>167</td>
<td>92</td>
</tr>
<tr>
<td>7</td>
<td>Home</td>
<td>Durability of Intervention Program</td>
<td>Primary and Intermediate Outcomes</td>
<td>Program Module Evaluation</td>
<td>159</td>
<td>84</td>
</tr>
</tbody>
</table>
**Power over Pain - Coaching (POP-C)**

This intervention focuses on medication management, pain advocacy, and living with pain. The aim of the intervention is to decrease pain and distress, increase the patient’s perceived control over pain, and enhance functional status. The intervention is specifically tailored to African Americans and individualized to specific patient/caregiver needs.

---

**Medication Management**

- Importance of pain management
- Misconceptions
- Types of analgesics
- Side effect management
- Effective use of analgesics
- Untried analgesic and adjuvant options
- More effective administration of prescribed Rx
- Changes in Rx to ↓ pain or side effects
- Community & economic barriers
- Community resources for prescriptions
- Safe-keeping of medications

---

**Pain Advocacy**

- Communication skills
- Role playing
- Advocacy training
- Suggestions for ↑ communication with health care providers
- Advocating for effective pain management
- Overcoming fear and mistrust
- Transcultural communication
Living with Pain

- Modifying patient’s & caregiver’s responses to pain
- ↓ pain-related distress
- Positive reactions to increased self-efficacy
- Remaining functional with pain under control
- Building confidence to manage pain
- Coping with changes in health status
- Acceptance of pain
- Spiritual / religious resources
- Use of nonpharmacologic modalities
- Use of complementary/alternative therapies

Fidelity

- Monitored by tape recording the first three interventions of each nurse and a session from every 5th patient thereafter.
- Tapes were reviewed by the research team and inconsistencies and modifications were discussed with the Intervention Nurse.
- To ensure standardization, a protocol manual were developed outlining specific interventions for each home visit and telephone session.
- Checklist format allowing the Intervention Nurse to indicate when each topic is covered.
- Ensures that POP-C covers the core content but also allows flexibility to address specific concerns of individual dyads as they arise.
- Intervention Nurses met with the research team at regular intervals for debriefing, problem solving, teaching reinforcement, and to address questions.

Results

- Enrolled - 472 participants
- Completed: 236 with 106 Control and 130 Intervention
- Gender: Female 60%   Male 40%
- Age: 20 to 87; mean age 55 years
- Education:
  - Grade School – 6  (3%)
  - High School – 131 (58%)
  - College – 79  (35%)
  - Grad School – 9  (4%)
- Marital Status
  - Married – 51 (23%)
  - Single 112 (48%), Separated 8 (4%), Divorced 35 (15%), Widowed 21 (9%)
- Alone – 77%
Education & Age

- Diversity of education
- Some college educated & professional
- Many low education levels
- Younger than expected
  - Median age of diagnosis of cancer all races nationally = 66 years
  - Our population mean < 56 years (range 20-87)

Family Support

- Few have families that are local
  - Limited available time
  - Transportation issues
  - Income / work time loss
  - Other responsibilities
- Caregiver
  - Who do you call?
- Round-robin caregivers

Faith Community Support

- Most have a church affiliation
  - Try to attend
  - Little evidence of church support
- SOCIAL ISOLATION
Cancer Demographics

- **Sites**
  - Breast: 48 (21%)
  - GI: 34 (15%)
  - Lung: 34 (15%)
  - GU: 31 (14%)
  - Oral: 24 (11%)
- **Months since diagnosis** - range 0-193; Mean = 30
- **Metastasized**
  - No: 139 (61%)
  - Yes: 82 (36%)

Pain Ratings

- **Worst pain** - mean = 7.59 (0-10 scale)
- **Average pain** - mean = 5.89 (0-10 scale)
- **Least pain** - mean = 3.55 (0-10 scale)

Patients experience moderate levels of pain most of the time.

On good days, their pain drops to a low to moderate level.

On bad days, their pain is severe.
Results
Effect of intervention for different measures of perceived control

<table>
<thead>
<tr>
<th></th>
<th>Estimate</th>
<th>S.E.</th>
<th>C.R.</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Control</td>
<td>.252</td>
<td>.084</td>
<td>2.981</td>
<td>.003</td>
</tr>
<tr>
<td>Function</td>
<td>.339</td>
<td>.060</td>
<td>5.678</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Pain</td>
<td>.476</td>
<td>.073</td>
<td>6.522</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Distress</td>
<td>.400</td>
<td>.068</td>
<td>5.889</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Results (cont.)

In these tests, all structural parameters were significant.
Conclusions and Implications

- These results support the POP-C intervention and the model it is based on, validating the effects of the POP-C intervention for African Americans with cancer pain.

- Interventions to increase perceived control over pain have the potential to improve functional status by decreasing pain and pain-related distress.
The importance of function

What does this pain keep you from doing?

Functional status, or the ability to carry out meaningful activities, is affected by pain intensity and the patient’s belief that they can control the pain to an extent that allows them to participate in those activities.

Taking Pain Medications Correctly

Many patients wait until they cannot stand the pain before taking meds

Many patients are concerned about addiction

Concerns about the cause of pain are also common

Misunderstandings about medications may cause patients to resort to potentially dangerous ways of controlling pain

A little information may cause patients not to take medications at all

Many of our patients have access to insurance

Often Medicaid, some VA

Limited choices of meds

Difficulty accessing meds, frequent delays in getting meds

Inadequate numbers of units

Leads to choice of when and how to take meds
Research Informs Clinical Practice - Lessons Learned

- 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
- Nurses made the difference in this study!
  - Were honored to be invited into the home
  - Went above and beyond to meet patients’ needs
    - Advocated for patients with physicians and pharmacists
    - Bought needed items for patients and gave them rides
    - It’s the little things that count!
  - Respected and cared about the patients and caregivers

Research Informs Clinical Practice - Lessons Learned

- The importance of perceived control over pain
  - African American patients suffer higher levels of pain, more pain-related distress, and poorer function than their Caucasian counterparts
  - Patients often feel they have no control over their disease, their treatment, or their symptoms
  - Empowering patients with education, advocacy, and encouragement with interventions such as the Power Over Pain - Coaching (POP-C) intervention can improve their lack of power and help them become a partner in controlling their pain

Research Team

- April Hazard Vallerand, PhD, RN, FAAN – PI
- Tom Templin, PhD – Co-I
- Stephanie Schim, PhD, RN, FAAN – Co-I
- Sue Hasenau, PhD, RN – Project Director
- Lisa Campbell, PhD – Consultant
- Tamara Baker, PhD - Consultant
- Linda Vanni, MSN, RN, ACNS-BC, NP – Consultant
- Feleta Wilson, PhD, RN, FAAN – Consultant
- Sheria Robinson, MSN, RN - GRA
### Research Assistants

- Mary Czajka
- Cynthia Evison
- Bradley Hornsby
- Mark Hamung
- Mary Verbrugge
- Anna Bechtel
- Josey Rege
- Louie Fra
- Jennifer Lanese
- Angela Klop
- Paula Liebes
- Karen Wohlgemuth
- Heidi Breese
- Garth Terwilliger
- Kelly Long
- Susan Hanson
- Ken Barlow
- Tim Senning
- Alex Taya
- Carla Ainsworth
- Emily Salvatori
- Kathy Zona
- Vicki Tapan

### Intervention Nurses

- Mary Zugcic
- Cynthia Couture
- Debbie Hasenau
- Carol Strong
- Patti Petroulias
- Janna Roop
- Lisa Norris
- Jordana Latozas
- Angelka Maly
- Paula Gaines
- Karin Wilkinson
- Wendy Brunson
- Katie Kessler
- Claire Michelini
- Kathleen Szkutnicki
- Cathy Chiu
- Susan Musto
- Vicki Speyer
- Tim Sparling

### Data Collection Nurses

- Ann Yeaman
- Antonia Bamishe
- Jacqui Khan
- Sarita Rao
- Brian Phillips
- Marcia Andrews
- Darlene Blair
- Gail Soderling
- Karen Olsen
- Deborah Collins-Bohler
- Chontay Stanley
- Tarrie Franke
- Chanta Stanley
- Tarrie Thornton
- Lee Ann Horn
- JoAnn Knasiak
- Maha Albdour
- Vivian Murphy
- Nancy Hauff
- Jacqueline Katin

### Recruiters

- Diane Sobecki-Ryniak
- Angela Recchia
- Ann Collins
- Samantha Strassburg
- Brenda Lawrence
- Shoniqwa Russell
- Venita Thornton
- Leilani Triplett
- Christine Driscoll
- Sylvia Scott

### Research Assistants

- Amanda Baumbach
- Tarra Bae
- Kaven Jackson
- Gail Underwood
- Gail Tucker
- Lisa Beno
- Mela Olszewski
- Nancy Shaw
- Jacqueline Katin

### Research Study

**Power Over Pain**

Wayne State University
College of Nursing

- Pop C Nurses - July 2011