Power Over Pain: Improving Function in African Americans with Cancer Pain

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Cancer Pain

- 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, 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

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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

April Hazard Vallerand, PhD, RN, FAAN
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%)
Measures

- Pain Rating Scales (4 items)
- Symptom Distress Scale (13 items)
- Pain Interference Scale (7 items)
- Knowledge and Attitudes (9 items)
- Perceived Control (7 items)
- Barriers (17 items)
Pain in the Past 2 weeks

- Worst – 6.67 (SD=2.60)
- Least – 3.74 (SD=2.96)
- 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
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=1.88) 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.

Fit Statistics:
Chi Square (105.04) / df (57) = 1.84, p=.00
Comparative Fit Index (CFI) = 96
Root Mean Square Error of Approximation (RMSEA) = .05

Original conceptual model of factors affecting pain-related functional status
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.
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 adversive 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 \( p = .02 \))
The Effect of Perceived Control Over Pain on Ethnic Disparities

- Perception of 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 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 patient about when to call the clinician if pain is not controlled
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

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Funded by a DMC Faculty Scholar Award
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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
Measures

- **Pain & Pain-related function** - Brief Pain Inventory (BPI)
- **Depression** - Center for Epidemiological Studies Depression Scale (CESD)
- **Perception of control over pain** - Survey of Pain Attitudes Control Scale (SOPA) & Life Control Scale of the Multidimensional Pain Inventory (MPI)
- **Coping** - Pain Catastrophizing Scale
- **Purpose in Life** – Purpose In Life Questionnaire
- **Self-Treatment of Pain** – Self-Treatment of Pain Questionnaire
- **Demographic Data**
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>Pelvic</td>
<td>128</td>
<td>43%</td>
</tr>
<tr>
<td>Arms</td>
<td>118</td>
<td>39%</td>
</tr>
<tr>
<td>Head</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

![Bar Chart: Interference by Pain]

- General
- Mood
- Walking
- Work
- Relationships
- Sleep
- Enjoyment

0 1 2 3 4 5 6 7 8 9 10
### Questionnaires Scores

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>CES-Depression</td>
<td>27.0</td>
<td>9.6</td>
<td>9 to 60</td>
</tr>
<tr>
<td>Purpose in Life</td>
<td>97.8</td>
<td>21.0</td>
<td>23 to 139</td>
</tr>
<tr>
<td>Brief Pain Inventory (Functioning)</td>
<td>6.5</td>
<td>2.5</td>
<td>0 to 10</td>
</tr>
<tr>
<td>Perception of Control</td>
<td>13.8</td>
<td>8.5</td>
<td>0 to 40</td>
</tr>
<tr>
<td>Life Control</td>
<td>13.0</td>
<td>5.8</td>
<td>0 to 24</td>
</tr>
<tr>
<td>Pain Catastrophizing</td>
<td>43.7</td>
<td>12.3</td>
<td>18 to 65</td>
</tr>
</tbody>
</table>
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 CA149432-01A1
- 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 $\geq 4$ 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
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 \( \uparrow \) 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
Results

- Enrolled - 472 participants
- Completed: 239 with 108 Control and 131 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  (49%), 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 = 66 years
  - Our population mean = 55 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
Research Informs Clinical Practice - Lessons Learned

- 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.
Research Informs Clinical Practice-
Lessons Learned

- 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
Research Informs Clinical Practice—Lessons Learned

- 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
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.
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POP- C Nurses - July 2011
POWER OVER Pain

Research Study
Wayne State University
College of Nursing