



University of California
San Francisco

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Pain Control Program Intervention for Patients and Their Family Caregivers

**8th Annual Pain Consortium Symposium: Advances in
Pain Research**

Integrated Self-Management Strategies for Chronic Pain

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Theoretical Foundations for the **PRO-SELF© Pain Control Program 1 (PPCP1)**

- **Work by Dodd and colleagues who tested the PRO-SELF© Program with other cancer-related symptoms**
 - Knowledge
 - Skills training
 - Nursing support
- **Additions to the original PRO-SELF© Program that were used in PPCP1**
 - “Academic detailing” (Soumerai & Avorn, 1990)
 - Nurse coaching (Gortner et al., 1988)

Effectiveness of the PRO-SELF Pain Control Program

- RCT of a psychoeducational intervention compared to standard care
- Oncology outpatients with pain from bone metastasis (homogeneous sample)
- Primary outcomes
 - Changes in knowledge scores
 - Changes in pain intensity scores over time (average and worst pain)
 - Changes in opioid analgesic prescriptions
 - Changes in opioid analgesic intake (total opioid dose and ATC opioid dose)

Details of the PPCP1 Intervention

- **Time and duration**
 - 6 weeks
 - Three face-to-face home visits
 - Three phone calls
 - ~4.5 hours
- **Psychoeducational intervention involved both patients and their family caregivers (FCs)**
- **Academic detailing session**
 - Focus on knowledge deficits
 - Resolve any conflicts between patients and FCs
- **Skills training**
 - Educational booklet
 - Use of a pillbox
 - Pain management diary
 - Script to speak with MD/nurse
- **Major foci for the intervention**
 - Change in analgesic prescription
 - Administration of medication around the clock

Pain Experience Scale Score

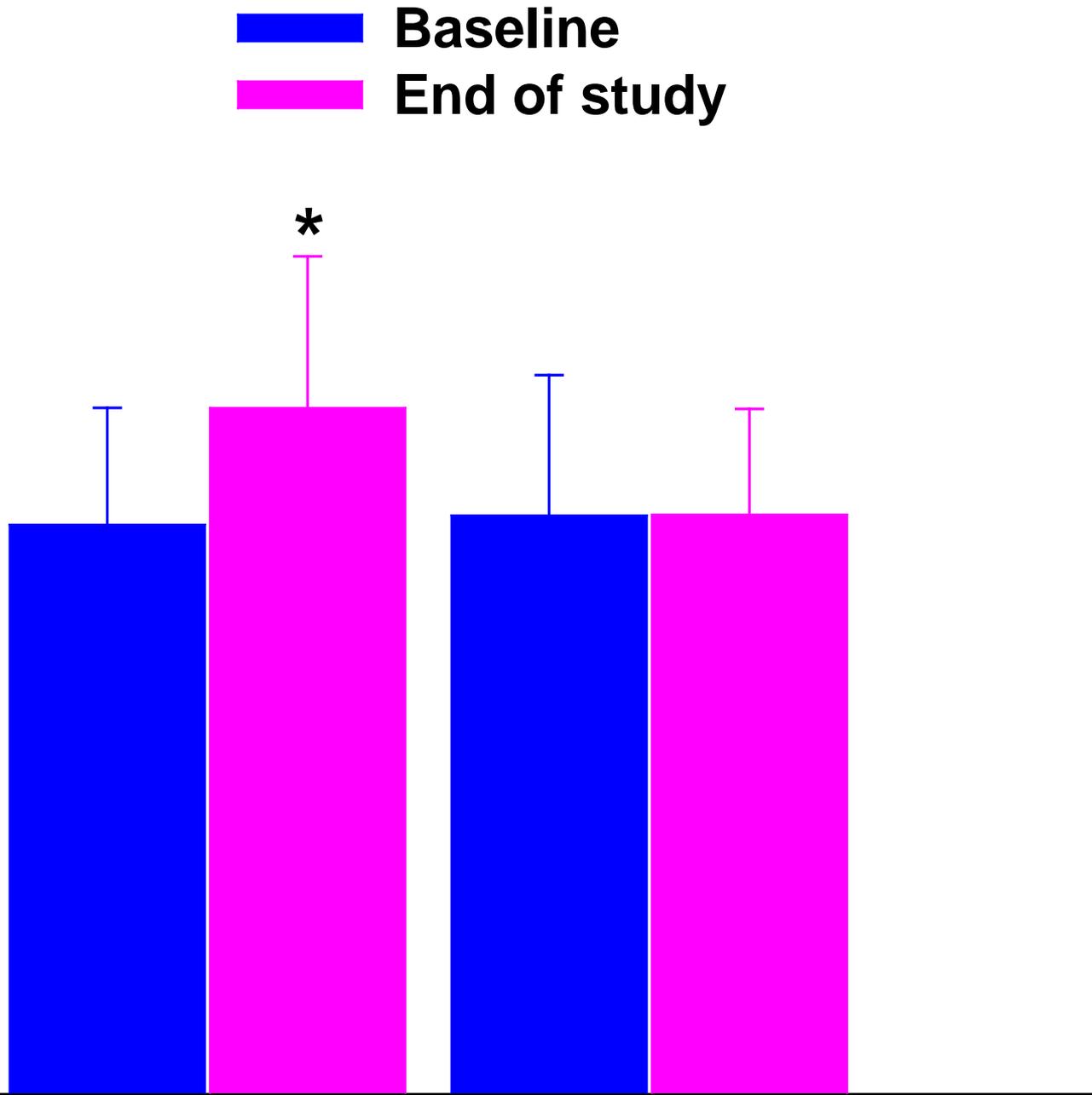
100
80
60
40
20
0

Baseline
End of study

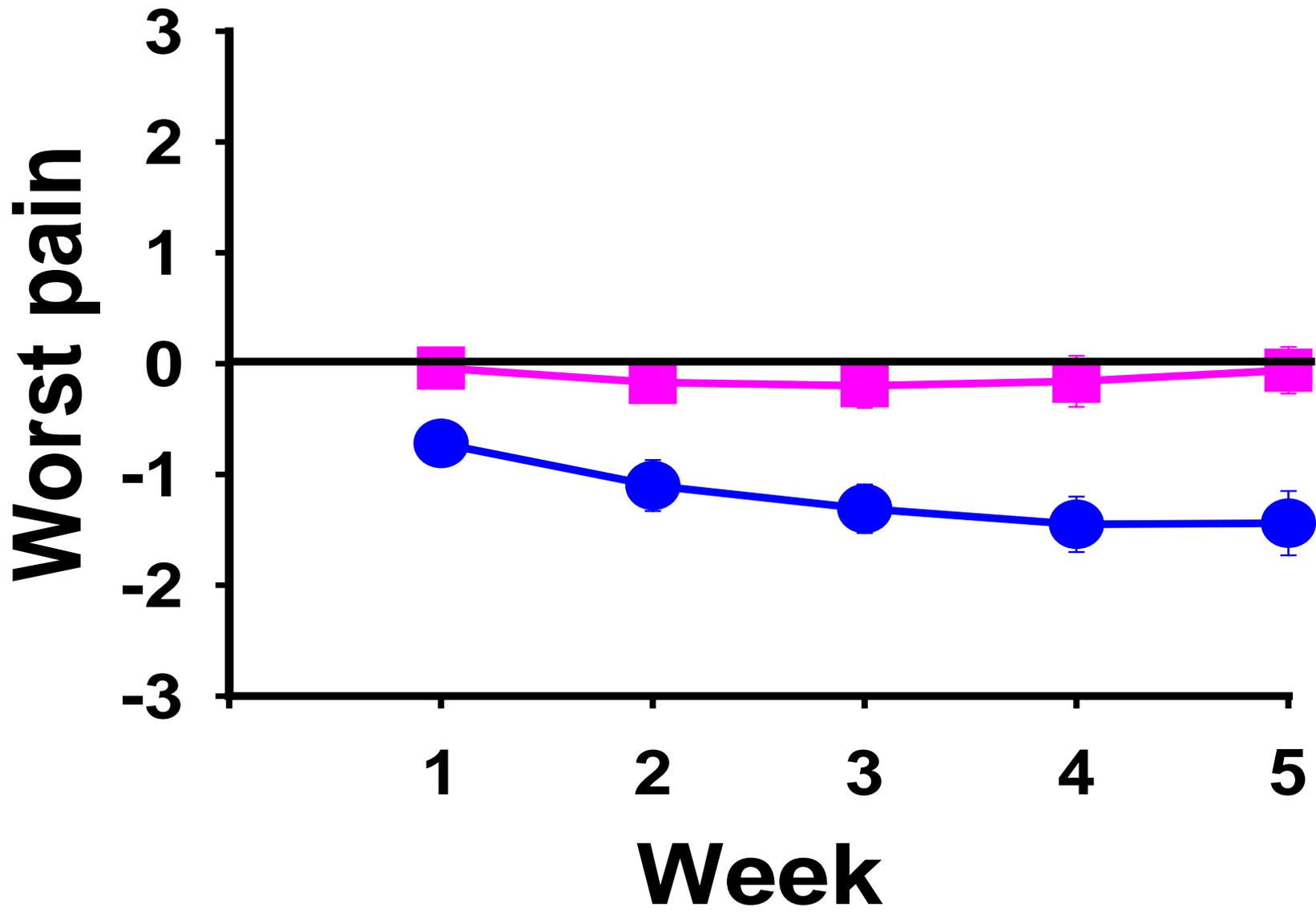
PRO-SELF

Standard care

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PRO-SELF
Standard care



Responder Analysis

- **Categorized patients in the PRO-SELF© group based on change in mean of average and worst pain intensity scores**
 - Responders = $\geq 30\%$ decrease in pain
 - Partial responders = 1% to 29% decrease in pain
 - Non-responders = 0% or increase in pain
- **Results of responder analysis**
 - 49.4% (n=44) – complete responders
 - 24.7% (n=22) – partial responders
 - 25.8% (n=23) – non-responders
- **No significant differences were found among the three responder groups in:**
 - Demographic characteristics
 - Disease characteristics
 - Treatment characteristics
 - Baseline pain scores

QUALITATIVE ANALYSES - 1

- **Evaluation of the fidelity of the intervention**
 - Audio-taped the clinical interactions
 - Administrative supplement for qualitative analyses
- **Characteristics of non-responders**
 - Previous stigmatizing pain experiences
 - Bad experiences with cancer pain management
 - Severe constipation
 - Strongly held convictions about analgesics
 - Toxins to be avoided
- **Conclusion that PPCP1 was not the appropriate intervention for this subgroup of patients**



QUALITATIVE ANALYSES -2

- **Second qualitative analysis focused on an evaluation of difficulties and challenges that patients in the intervention group faced with self-management of cancer pain**
- **Goal of this analysis was to determine how to revise the psychoeducational intervention**
- **Determined that the intervention nurses identified many of these difficulties and challenges during the last intervention session**
 - Need for a longer intervention period

Difficulties with Pain Management Regimen

1. Obtaining prescribed medication

- Reimbursement barriers
- Lack of availability of analgesics at pharmacies

2. Difficulty accessing information

- Basic information
- Practical information about the use of analgesics

3. Difficulty tailoring prescribed medications to meet individual needs

- Optimal combination of medications
- Optimal dose of medications
- Optimal timing for medications

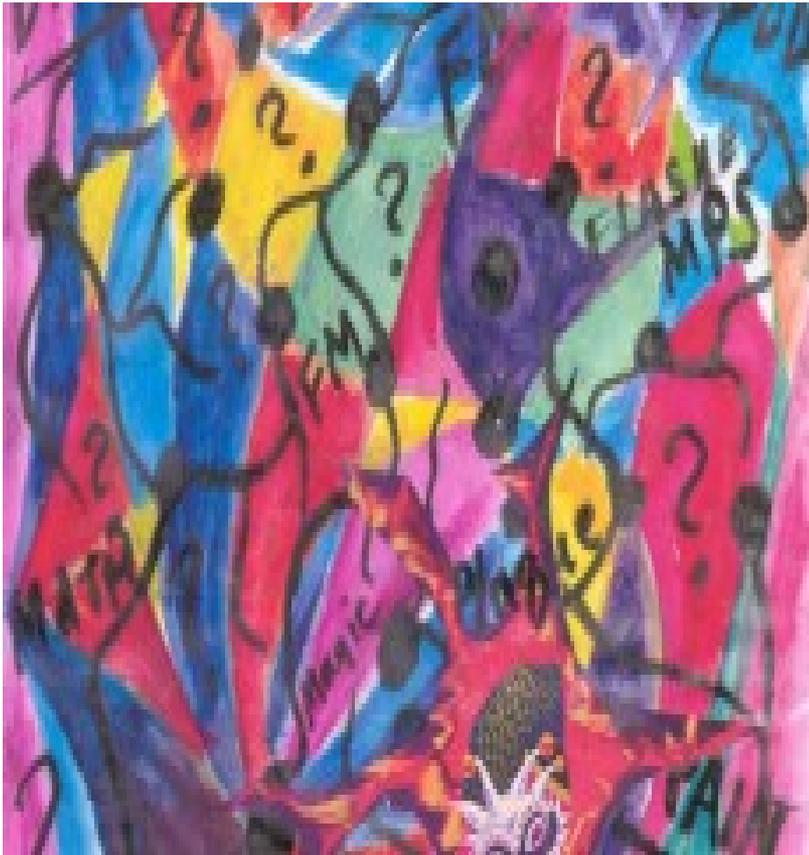
Difficulties with Pain Management Regimen

- 4. Difficulty managing side effects**
 - Constipation
 - Cascade of side effects
- 5. Difficulty with cognitively processing complex information**
- 6. Difficulty managing new or unusual pain**
- 7. Difficulty managing multiple symptoms simultaneously**
- **Used this information to guide the development of PRO-SELF© Plus (funded by NCI and NINR)**
 - Dose response intervention study
 - Mixed methods study

Details of the PRO-SELF[®] PLUS

- **Time and duration**
 - 10 week intervention
 - Low dose = 8 hours
 - High dose = 12 hours
- **Psychoeducational intervention involved both patients and their family caregivers (FCs)**
- **Academic detailing session**
 - Focus on knowledge deficits
 - Resolve any conflicts between patients and FCs
- **Skills training**
 - Comprehensive initial evaluation of difficulties
 - Educational booklet
 - Use of a pillbox and adherence with the analgesic regimen
 - How to use the pain management diary to monitor the effectiveness of the pain management plan
 - Aggressive management of constipation
 - Script to speak with MD/nurse
- **Major foci for the intervention**
 - Ongoing evaluation of the management of specific difficulties

PRO-SELF© PLUS



Gerald Becker
Inside My Brain
Painexhibit.org

Patient Characteristics	
Age	59.8 (12.3)
Education	15.5 (2.8)
Female	54%
Non-white	24%
Married/partnered	66%
Lives alone	21%
Karnofsky score	70.0 (12.1)
Average pain	4.5 (2.0)
Worst pain	7.5 (2.1)
Days per week	5.2 (2.2)
Number of symptoms	15.6 (6.0)

PRO-SELF© PLUS



Rosemary Boehm
Colors of Pain
Painexhibit.org

- Imagine being a patient with the characteristics described in the previous slide
- Self-care activities needed for **pain medication management**
 - Complex health care systems
 - Home and lifestyle contexts

Pain Medication Management Processes in the Context of **Complex Health Systems**

1. Getting prescriptions

- Multiple clinicians involved in pain management
- Clinicians were located in different health care networks and different geographic areas
- Difficulty obtaining a new prescription or refill
 - Timing of the refills

2. Obtaining medications

- Insurance policies dictated where prescriptions could be filled
- Pharmacies do not stock the opioid or dose of opioid
 - Need to find a pharmacy to meet needs
- Use of mail order pharmacies resulted in significant delays
 - Requirement to be at home to sign

Pain Medication Management Processes in the Context of **Complex Health Systems**

2. Obtaining medications (continued)

- Some insurance companies place limits on the amount of medication a patient could receive
- Some insurance companies would not provide new prescriptions for analgesic medications
- Public assistance programs limited the amount of analgesic as well as the number of prescriptions covered
 - Patient needed to coordinate communication between the MD and insurance company
- Receipt of incorrect medications

Pain Medication Management Processes in the Context of **Home and Lifestyle Contexts**

- **Home environment**
 - Other individuals lived in patients' homes
 - Visitors to patients' homes
 - Children, friends
- **Lifestyle contexts**
 - Pain management at work
 - Pain management during leisure activities and vacations
 - Pain management during medical appointments and errands

Pain Medication Management Processes in the Context of **Home and Lifestyle Contexts**

1. Lack of understanding

- “Take as directed”
- Keeping purposes and names of the different medications straight
 - Patients developed their own nomenclature
- Lack of understanding of maximum daily doses
 - Acetaminophen
- Information on pill bottles too small to read
- Written information was difficult to understand

Pain Medication Management Processes in the Context of **Home and Lifestyle Contexts**

2. Organization of medications at home

- Large number and various forms of medication
 - Pain medications
 - Treatments for cancer and other conditions
- Separate system for organizing pain medications when away from home
- Lack of organization was associated with safety risks
 - A container, envelope, or plastic bag for medications
- Multiple analgesic formulations (e.g., pills, liquids, patches) posed organizational challenges
- Idiosyncratic approaches to the organization of analgesic medications
 - Pill boxes were not effective
 - Use of zip lock bags
 - Placing pills for the day in a glass

Pain Medication Management Processes in the Context of **Home and Lifestyle Contexts**

3. Storage of medications at home in a safe manner

- Medications left on the kitchen counter
- Storage of out of date prescriptions
- Need to hide analgesic medications from other family members
 - Patient who was confused
 - Need to account for children, visitors, pets
 - Individuals with history of substance misuse

4. Scheduling medication administration

- Finding the optimal schedule for the most effective pain management
- Scheduling analgesic intake in relation to lifestyle
 - Optimal timing of analgesics when working

Pain Medication Management Processes in the Context of **Home and Lifestyle Contexts**

5. Remembering to take medications

- Remembering to take medications when routines changed
- Difficulty remembering due to cognitive impairment, fatigue, or overload

6. Taking medications

- Difficulty swallowing large pills
- CTX-neuropathy posed challenges for patients in handling pills
- Cutting sustained release capsules in half
- Cognitive decline associated with errors in analgesic administration

Conclusions

- **Self-management of cancer pain is extremely complex**
 - Knowledge
 - Ongoing skills training
 - Ongoing coaching
- **Comprehensive, multidimensional assessment**
 - Pain problem
 - Demographic, clinical, and social characteristics of the patient
 - Home environment
 - Health care system
- **Requires TIME for ongoing education and coaching**



Marilyn Dodd



Karen Schumacher



Debu Tripathy



Claudia West



Brad Aouizerat



Chris Miaskowski



Bruce Cooper & Steven Paul