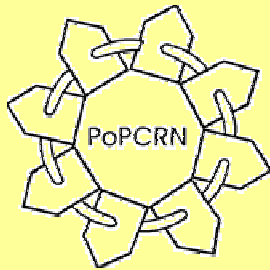


# What's Poppin'?

## Population-Based Palliative Care Research Network

### Kernel's Corner By: Jean S. Kutner, MD, MSPH



#### Highlights

- New newsletter format, new PoPCRN staff, new study funding
- New REST study has 11 participating organizations.
- Clinical Feature: Managing Fatigue at the End-of-Life (Part 2): Making a Difference by Daniel Johnson, MD
- Methylphenidate Treatment for Fatigue at End-of-Life by Daniel Johnson, MD

#### In This Issue:

Kernel's Corner	1
Clinical Feature	2
Research into Practice	3
Special Recognition	4
Current Studies	4
Calendar	5
Recent Publications	5

Welcome to the Fall, 2003 PoPCRN newsletter. This Kernel's Corner focuses on the new – a new newsletter format, new PoPCRN staff, and new study funding.

#### 1) The new newsletter format:

Those of you who have seen previous editions of "What's Poppin'" will note some changes and, I hope, improvements to the newsletter's format and contents. Our goal is to make the newsletter more relevant and more readable for its diverse audience. The changes are the direct result of YOUR feedback and suggestions. The PoPCRN team had been considering changes to "What's Poppin'" in Spring, 2003, when we set a record for length of the publication (16 pages). These considerations coincided with feedback that we received during the first PoPCRN Convocation, held in April 2003. We heard about the format (font too small), the content (too much) and about distribution (not getting to everyone at participating sites who might be interested). This feedback motivated the PoPCRN team to reconsider the intended audience and purpose of the newsletter. We solicited additional input from John Beilenson, President and CEO of Strategic

Communications and Planning, and the PoPCRN Advisory Committee – and are most grateful for their constructive criticism and creative ideas. What we quickly realized is that we were trying to reach many audiences (i.e., front line clinical staff, administrators, research and academic colleagues, potential and current funders) and therefore had quite varied messages – thus the extensive length of previous newsletters. The new approach, debuting in this newsletter, is to focus the newsletter on the clinical applicability of PoPCRN-based studies, reserving more detailed information for the PoPCRN web site ([www.uchsc.edu/popcrn](http://www.uchsc.edu/popcrn)), balancing the length of the newsletter with sufficient, relevant, topical and interesting information. What we haven't yet solved, despite conversations with a number of you, is how to best facilitate distribution of the newsletter to everyone within each of your organizations who may be interested in the newsletter's contents. We send the newsletter electronically to everyone on our mailing list for whom we have an email address, and by hard copy to those

without email. Thus, YOU are the key link to distributing the newsletter within your organization. We encourage you to distribute the newsletter within your organization via email, posting and/or distributing copies. I hope that you enjoy the new format, and certainly welcome your feedback, comments and suggestions.

2) New PoPCRN staff: I am incredibly fortunate to have added 2 new highly qualified individuals to the PoPCRN team. Please join me in welcoming:

**Anne Jordan, PhD:** PoPCRN Project Manager. Anne is responsible for oversight of all PoPCRN activities. Anne has a background in sociology, particularly related to aging. Anne previously worked at the Center for Health Services Research in Denver, focusing particularly on the Medicare Home Health Practice Variations, the Project to Develop a Core Comprehensive Assessment Instrument for PACE, and the Assisting Home Care Providers in Effectively Monitoring and Using Patient Outcomes projects. (continued on page 5)

#### **Mission Statement:**

*The population-based Palliative Care Research Network (PoPCRN) is committed to enhancing the care of persons at the end of life and their families through the conduct and dissemination of high-quality research in palliative care settings.*

**Clinical Feature: Managing Fatigue at the End-of-Life (Part 2): Making a Difference by Daniel Johnson MD, UCHSC, Denver, CO.**

**Case Scenario:**

*Ms. J is a 67y/o Holocaust survivor with a history of Parkinson's disease, diabetes, iron deficiency anemia and depression. Although Ms. J has lived independently with home hospice for 8 weeks, she now requires inpatient hospice services due to progressive functional losses in the context of limited home support. During her assessment at the time of transfer you inquire about the most difficult aspect of her illness: she replies "I'm just so tired all the time".*

**Table 1: Summary of Part 1**

An Approach to Fatigue	The case of Ms. J: What We Know (Part 1)
<b>Step 1:</b> Understanding the patient's meaning	Ms. J's "tiredness" included: physical weakness without sleepiness; increasing episodes of breathlessness with activity; frustration with her inability to care for herself; sadness over missed visits with her grandchildren; and a growing sense of apathy and helplessness.
<b>Step 2:</b> Understanding the patient's expectations and preferences for treatment	Ms. J clearly identified fatigue as the symptom that most disrupted her quality of life and explicitly stated her desire for relief. She was willing to "try anything", but did not want any further testing: "I'm through with all that."
<b>Step 3:</b> Identifying potential sources or contributing factors	Potential sources of Ms. J's fatigue included: Parkinson's disease and progressive deconditioning (weakness); anemia (breathlessness with activity); psychological distress from her loss of independence (frustration); social distress from growing isolation (missed visits); and depression (sadness w/ apathy and helplessness). Ms. J's fatigue worsens with activity or episodes of pain, and abates somewhat during time spent with family and grandchildren ("rallying").

Part 1 of this review – “Managing Fatigue at the End of Life: Challenging the Paradigm” (Spring, 2003 Newsletter) – outlines an approach to fatigue, the most prevalent symptom in terminally ill patients. Table 1 summarizes Part 1, with specific reference to the case of Ms. J. Part 2 builds upon this information to briefly highlight Steps 4 and 5: Developing and implementing a care plan; and reassessing the intervention.

**Developing and Implementing a Care Plan:** An integrated fatigue care plan might be formulated first at the interdisciplinary team (IDT) meeting. The care plan should target potentially remediable sources of fatigue within the framework of an individual's goals and expectations. For example, Ms. J suffers from depression and social

isolation, suggesting that effective interventions might include a trial of an antidepressant and increased family and pastoral care visits. Additional relief might be achieved through improved breakthrough pain control and gentle bedside strengthening (see Table 3). While Ms. J's anemia is likely contributing to her fatigue (pre-hospice Hct=26), Ms J is clear that she does not want blood products or further testing.

At times the primary source(s) of fatigue may not be readily apparent and/ or remediable. In such instances, pharmacological and non-pharmacological symptomatic treatments may help to minimize patient distress (see Table 2). Unlike pain, few symptomatic interventions for fatigue have been rigorously studied in terminally ill patients. In the following section, I

review methylphenidate – one pharmacologic agent with good potential to reduce some types of fatigue in advanced illness.

**Table 2: Potential Fatigue Interventions**

<p><b>Non-Pharmacologic</b></p> <ul style="list-style-type: none"> <li>Exercise rehabilitation</li> <li>Psychological and behavioral counseling</li> <li>Coping techniques</li> <li>Energy conservation</li> <li>Transcutaneous nerve Stimulation</li> <li>Relaxation therapy</li> <li>Massage therapy</li> <li>Herbal therapy</li> <li>Aroma therapy</li> </ul>
<p><b>Pharmacologic</b></p> <ul style="list-style-type: none"> <li>Epoetin</li> <li>Psychostimulants:                             <ul style="list-style-type: none"> <li>Methylphenidate</li> <li>Dextroamphetamine</li> <li>Pemoline</li> <li>Modafinil</li> </ul> </li> <li>Corticosteroids</li> <li>Megesterol acetate</li> <li>Donepezil</li> </ul>

(continued from p. 2)

**Reassessing the intervention:** The hospice team should frequently re-evaluate the fatigue care plan to determine effectiveness, modify

interventions as needed and ensure that treatments remain consistent with patients' goals. Ms. J's integrated care plan provided immediate relief, with reduced fatigue ("tolerable") and improved

well being. Further discussion with Ms. J led to the discontinuation of bedside strengthening (after 1 week) and modifications to her methylphenidate regimen (see Table 3).

**Table 3: Summary of Part 2**

An Approach to Fatigue	The Case of Ms. J: Possible Interventions (Part 2)
<b>Step 4:</b> Developing and implementing a care plan	Family meeting arranged – results in increase family visits; increase pastoral care support; trial of methylphenidate (5 mg QAM + Q Noon) for depression and somnolence; pre-treat incident pain/ dyspnea with roxanol 10 mg prn; initiate bedside resistance therapy to maintain strength.
<b>Step 5:</b> Reassessing the intervention	Reassessment reveals reduced fatigue and improved well-being; Ms. J opts to discontinue strengthening after 1 week ("I don't think I can be strong anymore"); increased methylphenidate to 10 mg QAM and Qnoon + 5 mg Q2 hr PRN; family maintains more frequent contact until death.

## Translating Research into Practice: Methylphenidate for Fatigue

by Daniel Johnson MD, UCHSC, Denver, CO.

**What is methylphenidate?** Known more commonly as Ritalin, methylphenidate is a psychostimulant used in the treatment of attention deficit disorder, geriatric depression, cognitive disorders and more recently, fatigue and somnolence.<sup>1</sup> Methylphenidate acts within the central nervous system to enhance alertness, attention and vigilance.<sup>2</sup> Methylphenidate's rapid onset of action makes this drug particularly attractive for patients who may have only a few weeks to live.

**Is there evidence that methylphenidate is effective for fatigue in terminally ill patients?** Yes, though these data are limited. Three controlled studies have examined the effects of

methylphenidate for the specific treatment of fatigue in advanced illness: two in patients with cancer<sup>3,4</sup> and one in HIV patients.<sup>5</sup> In each of the studies, methylphenidate was effective in reducing distress from fatigue with minimal side effects. Whether similar positive effects would be seen in less-ambulatory, elderly and terminally ill patients remains unknown.

**Which patients are most likely to respond to methylphenidate?** In theory, methylphenidate might be particularly effective for certain subgroups of fatigued patients. Methylphenidate appears to benefit patients with psychomotor slowing,<sup>6</sup> cognitive impairment<sup>7</sup> and/or dysphoric mood.<sup>8</sup> While

methylphenidate has been shown to be a rapid and effective intervention for elderly depressed patients,<sup>9,10</sup> its efficacy for "terminal depression" remains less clear.<sup>11</sup> In one randomized, double blind, crossover trial in 32 cancer patients,<sup>12</sup> methylphenidate therapy decreased pain intensity. Patients receiving methylphenidate also reported a significant increase in physical activity, likely reflecting the effect of methylphenidate on opioid-induced sedation. Collectively, preliminary data appear to provide a rationale toward targeting methylphenidate in fatigued patients with concomitant depressed mood, cognitive impairment, pain and/ or drug-associated somnolence.

---

*"Methylphenidate 2.5-5.0 mg BID... is a common starting regimen.*

*Clinical response to methylphenidate is rapid, usually in 2-3 days."*

(continued from p. 3)

**How should methylphenidate be dosed for fatigue?**

Although little data exist in terminally ill patients, a conservative “start low and go slow” approach is typically advocated. Methylphenidate 2.5-5.0 mg BID (AM and noon) is a common starting regimen. Clinical response to methylphenidate is rapid, usually in 2-3 days. Bruera et. al have recently reported on the effects of patient controlled methylphenidate (PCM) on fatigue in patients with advanced cancer.<sup>13</sup> In this

prospective open study, 25 patients with advanced cancer and moderate or severe fatigue (>3/10 fatigue) received methylphenidate 5 mg every 2 hours as needed for 7 days (max 20 mg/day). Overall day 7 assessment (better, same, worse) was better in 24/24 patients (100%, p<0.0001), with improvements in physical function and overall well being. Interestingly, even patients who chose to take evening doses of methylphenidate reported improved sleep. No serious side effects were reported and all patients chose to continue PCM.

**Does methylphenidate have significant adverse effects?** Adverse effects of methylphenidate include nervousness, over-stimulation, insomnia, mild increase in heart rate and blood pressure, tremor and confusion.<sup>14</sup> While methylphenidate is safe and well-tolerated in elderly patients<sup>15</sup> and patients with advanced illness, this drug should be used with caution in patients with life-threatening cardiac arrhythmias, known bipolar disease or patients at high risk for agitated delirium.

---

For references please see the unabridged version of this article on the PoPCRN webpage.

## New Study: Reducing End-of-life Symptoms with Touch (“REST”)

The PoPCRN team is pleased to announce the initiation of its first multi-site randomized clinical trial – “Reducing End-of-life Symptoms with Touch” (REST). Funding for the study is provided by the Mendel-Asarch Lung Cancer Family Foundation and the National Center for Complementary and Alternative Medicine (NCCAM), a National Institutes of Health (NIH) institute. The study will evaluate how well two

different touch therapies, “moving touch” (aka massage therapy) and “non-moving touch” (control exposure – provides touch and attention without pressure) work to decrease pain and other symptoms and improve quality of life for persons with advanced cancer. The study will be conducted at ten PoPCRN hospices nationwide (see list below) and the University of Colorado Cancer Center. PoPCRN

hosted training for study site personnel in July and October 2003. Study enrollment began in late October and will continue through December 2005. For more information, please see the PoPCRN webpage, the NIH clinical trials web site ([clinicaltrials.gov](http://clinicaltrials.gov)), or contact Jean Kutner, Anne Jordan or Jennifer McLean.

---

PoPCRN recognizes eleven sites participating in the new REST study.

- Hope Hospice and Palliative Care, Ft. Myers, Florida
- Hospice and Palliative Care Center, Winston Salem, North Carolina
- Hospice and Palliative Care of Cape Cod, Hyannis, Massachusetts
- Hospice at Charlotte, Charlotte, North Carolina
- Hospice of St. John, Lakewood, Colorado
- HospiceCare in the Berkshires, Inc., Pittsfield, Massachusetts
- LifePath Hospice and Palliative Care, Inc., Tampa, Florida
- Palliative Care Center-Hospice of the North Shore, Evanston, Illinois
- Pikes Peak Hospice and Palliative Care, Colorado Springs, Colorado
- San Diego Hospice, San Diego, California
- University of Colorado Cancer Center lung cancer clinic, Denver, Colorado

## Kernel's Corner (continued from page 1)

*Jennifer McLean, MSPH:* PoPCRN Research Assistant. Jennifer's primary responsibilities are with the "REST" study (see below and separate feature). Jennifer is completing the requirements for an MSPH degree in November, focusing on barriers to physical activity for people 65 years of age and older in the San Luis Valley region of south central Colorado.

In addition, I am extremely grateful to *Robin Rawlings, MA*, who has volunteered her time with the PoPCRN team for the past several years. Robin, who was previously employed as a counselor at Pikes Peak Hospice and Palliative

Care (Colorado Springs, Colorado), and is currently working towards her PhD in psychology, has recently taken on a more active role with PoPCRN. She redesigned and produces this newsletter and is in the process of revamping the PoPCRN website (watch for upcoming "new and improved" announcements). She also is presenting a PoPCRN-focused workshop at the November Ohio Hospice and Palliative Care Organization statewide meeting.

3) New study funding: Elsewhere in this newsletter you'll read about PoPCRN's new study – "Reducing End-of-

life Symptoms with Touch" (REST). This study moves PoPCRN into a research realm where few other practice-based research networks have ventured – the multi-site randomized clinical trial. This study provides an added dimension to PoPCRN's contributions to furthering end-of-life knowledge and evidence.

I'm excited about PoPCRN's new directions. Enjoy this edition of "What's Poppin'" – and do contact me with comments, questions, or for further information at [jean.kutner@uchsc.edu](mailto:jean.kutner@uchsc.edu).

---

*Please give us feedback on our new newsletter format!*

*Contact us at:  
[jean.kutner@uchsc.edu](mailto:jean.kutner@uchsc.edu)*

## Presentations and Publications

- Ohio Hospice and Palliative Care Organization's Annual Conference: "The Fabric of Caring: Hospice and Palliative Care in Ohio," Nov 11-13, 2003
- American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative-care Nurses Association (HPNA) Annual Meeting, January 2004. Presenting workshops on practice-based research networks for palliative care research and on palliation for congestive heart failure.
- Kutner JS, Nowels DE, Kassner CT, Houser J, Bryant LL, Main DS. Confirmation of the "Disability Paradox" Among Hospice Patients: Preservation of Quality of Life Despite Physical Ailments and Psychosocial Concerns. *Palliative & Supportive Care*. In press, 2003.
- Kutner, JS, Meyer SA, Beaty B, Kassner CT, Nowels D, Beehler C. Outcomes and Characteristics of Patients Discharged Alive From Hospice. *Journal of the American Geriatrics Society*. In press, 2003.
- Johnson DF, Kassner CT, Kutner JS. Current Use of Guidelines, Protocols or Care Pathways for Symptom Management in Hospice. *American Journal of Hospice and Palliative Care*. In press, 2003.
- Johnson DJ, Kutner JS, Armstrong JD. Would you be Surprised if this Patient Died?: Preliminary exploration of first and second year residents' approach to care decisions in critically ill patients. *BMC Palliative Care*, 2003; 2:1.