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*New CME Requirement:
1 Credit on Prescription Opioid Drugs, including Responsible Prescribing Practices, Alternatives to Opioids for Managing and Treating Pain, and the Risks and Signs of Opioid Abuse, Addiction, and Diversion
2019 NEW JERSEY

01 NONPHARMACOLOGIC, NONOPIOID, AND OPIOID TREATMENT OPTIONS IN CHRONIC PAIN THERAPY
COURSE ONE | 1 CREDIT*
*Satisfies 1 Credit Hour Requirement on Opioids

23 END-OF-LIFE: DOMAINS AND COMMUNICATIONS
COURSE TWO | 2 CREDITS+
+Satisfies 2 Credit Hour Requirement on End-of-Life Care

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Unless exempt, a licensee applying for biennial license renewal shall complete 100 continuing medical education credits in Category I or Category II courses, of which at least 40 of such credits shall be in Category I.

MANDATORY CME REQUIREMENT ON OPIOIDS (NEW)

PHYSICIANS (MD/DO) & PODIATRISTS
The State Board of Medical Examiners shall require that the number of credits of continuing medical education required of each person licensed as a physician, as a condition of biennial registration pursuant to section 1 of P.L.1971, c.236 (C.45:9-6.1), include one credit of educational programs or topics concerning prescription opioid drugs, including responsible prescribing practices, alternatives to opioids for managing and treating pain, and the risks and signs of opioid abuse, addiction, and diversion. The continuing medical education requirement in this subsection shall be subject to the provisions of section 10 of P.L.2001, c.307 (C.45:9-7.1).

PHYSICIAN ASSISTANTS
The State Board of Medical Examiners shall require that the number of credits of continuing medical education required of each person licensed as a physician assistant, as a condition of biennial renewal pursuant to section 4 of P.L.1991, c.378 (C.45:9-27.13), include one credit of educational programs or topics concerning prescription opioid drugs, including responsible prescribing practices, alternatives to opioids for managing and treating pain, and the risks and signs of opioid abuse, addiction, and diversion. The continuing medical education requirement in this subsection shall be subject to the provisions of section 16 of P.L.1991, c.378 (C.45:9-27.25).

MANDATORY CME REQUIREMENT ON END-OF-LIFE CARE

PHYSICIANS (MD/DO) & PODIATRISTS
The State Board of Medical Examiners requires that the number of credits of continuing medical education required of each person licensed as a physician or podiatrist include two (2) credits of educational programs or topics related to end-of-life care as a condition of biennial renewal.

What This Means For You:
Licensed physicians (MD/DO), podiatrists and physician assistants (PA) are now required to complete one (1) credit of continuing medical education relative to opioids as a condition of biennial renewal. Additionally, licensed physicians (MD/DO) and podiatrists must complete two (2) credits of CME related to end-of-life care for biennial renewal, unless exempt.

RENUEWAL DEADLINES:
MD/DO: 6/30/2019
PA: 8/31/2019
DPM: 10/31/2019

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Disclaimer: The above information is provided by InforMed and is intended to summarize state CE/CME license requirements for informational purposes only. This is not intended as a comprehensive statement of the law on this topic, nor to be relied upon as authoritative. All information should be verified independently.
Dear New Jersey Medical Professionals,

InforMed is pleased to offer this collection of CME activities for healthcare professionals in the state of New Jersey. The uniquely tailored curriculum is customized to the educational needs of the New Jersey medical professional. Participants earn *AMA PRA Category 1 Credit™* through these self-directed, on-demand courses.

The CME series is designed to streamline the education requirements of the New Jersey Board of Medical Examiners. Licensees who complete this program satisfy the new one (1) credit requirement on Opioids. Additionally, physicians (MD/DO) and podiatrists satisfy the two (2) credit requirement on End-Of-Life Care for license renewal. All activities are independently sponsored by InforMed Continuing Medical Education without commercial support.

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-InforMed CME Team

For more than 45 years InforMed has been providing high level education activities to physicians and other healthcare professionals. Through our level of engagement with a wide variety of stakeholders, including our physician association, we have become the foremost public health policy continuing medical education organization in the United States. We are recognized as the leading provider of mandatory CME activities to physicians as a means of updating knowledge, improving competencies and fulfilling requirements for federal, state, regulatory and license renewal.
NONPHARMACOLOGIC, NONOPIOID, AND OPIOID TREATMENT OPTIONS IN CHRONIC PAIN THERAPY

TARGET AUDIENCE

This course is designed for all physicians (MD/DO), physician assistants, nurse practitioners and other healthcare professionals who seek to successfully manage pain.

COURSE OBJECTIVE

The clinical challenge of pain management is further complicated by the public health crisis related to illicit and prescribed opioids. This educational activity will discuss alternative therapeutic options and managing pain with opioid analgesics.

LEARNING OBJECTIVES

Completion of this course will better enable the course participant to:

1. Identify evidence based nonpharmacologic treatment options for the treatment of various chronic, non-cancer pain conditions in the context of a comprehensive treatment plan
2. Identify evidence based non-opioid medications and some chronic pain types for which they may be beneficial, and common risks and side effects
3. Explain when a trial of opioids may be beneficial and describe components of risk evaluation and mitigation
4. Apply a patient-centered approach to pain management by use of various communication and listening techniques

ACCREDITATION STATEMENT:

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DESIGNATION STATEMENT:

InforMed designates this enduring material for maximum of 1 AMA PRA Category 1 Credit™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

COURSE DATES: 
Release Date: 10/2018
Exp. Date: 09/2021

MAXIMUM CREDITS:
1 AMA PRA Category 1 Credit™

FORMAT:
Enduring Material (Self Study)

HOW TO RECEIVE CREDIT:

- Read the course materials
- Complete the self-assessment questions at the end. A score of 70% is required.
- Return your customer information/answer sheet, evaluation, and payment to InforMed by mail, phone, fax or complete online at course website under NETPASS.

NONPHARMACOLOGIC, NONOPIOID, AND OPIOID TREATMENT OPTIONS IN CHRONIC PAIN THERAPY

Release Date: 10/2018
Exp. Date: 09/2021

Enduring Material (Self Study)

LEARNING OBJECTIVES

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DESIGNATION STATEMENT:

InforMed designates this enduring material for maximum of 1 AMA PRA Category 1 Credit™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.
SPECIAL DESIGNATION
The New Jersey State Board of Medical Examiners requires one (1) credit hour of educational programs or topics concerning prescription opioid drugs, including responsible prescribing practices, alternatives to opioids for managing treatment of pain, and the risks and signs of opioid abuse, addiction, and diversion as a condition of biennial renewal.

This course satisfies one (1) credit hour relative to opioids.

FACULTY
Melissa B. Weimer, DO, MCR, FASAM
Chief of Behavioral Health and Addiction Medicine
Saint Peter’s Health Partners
Clinical Assistant Professor of Medicine
Oregon Health and Science University

Beth Dove
Medical Writer
Dove Medical Communications

ACTIVITY PLANNER
Joseph J. McGurrin

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- Beth Dove
- Joseph J. McGurrin
- Melissa B. Weimer, DO, MCR

STAFF AND CONTENT REVIEWERS:
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Nonpharmacologic, Nonopioid, and Opioid Treatment Options in Chronic Pain Therapy

Overview

Pain is a major public health problem that is expected to worsen as the population ages. Prevalence of pain estimates vary, but a self-reported population-level survey found 11.2 percent of US adults (25.3 million people) experience chronic pain, defined in the report as pain every day for the past 3 months. The National Pain Strategy (NPS), which outlines the federal government's first coordinated plan for reducing the burden of chronic pain, further describes a sub-category of high-impact chronic pain, which is associated with substantial restriction of participation in work, social, and self-care activities for 6 months or more. This term will allow more detailed study on the degree to which pain interferes with people's lives.

In addition to the human suffering it brings, the burden of chronic pain exacts significant economic costs in productivity loss and use of healthcare resources. The burden is expected to grow in the future due to a number of contributors, including:

- Increasing obesity with associated risk of diabetes, neuropathy, and orthopedic problems
- Inadequate post-surgical pain management strategies for the growing number of surgeries
- A cohort of people living with chronic pain after surviving life-threatening injury, cancer, or other illness

Chronic pain is complex with medical, social, psychological, and spiritual manifestations, making it a difficult condition to assess and treat. Opioids are frequently prescribed for pain but are associated with significant risks to patients that include but are not limited to respiratory depression that may be fatal (unintentional opioid overdose), opioid-use disorder (OUD), endocrine system disruption, and opioid-induced hyperalgesia (potentiated pain response). Furthermore, opioid and other sedating medications are frequently combined to treat comorbid conditions, raising risk for drug-drug interactions and potentiating sedating, cognitive, and respiratory-depressant effects.

The clinical challenge of pain management is further complicated by a public health crisis related to the use of illicit and prescribed opioids. It is estimated that at least 2 million Americans have an opioid-use disorder (OUD) involving prescribed opioids and nearly 600,000 have an OUD involving heroin. In all, about 90 Americans die every day from overdoses that involve an opioid. Although opioids have a role in pain management, they should be considered 1 option in a comprehensive pain management plan that includes multiple disciplines and treatment options rather than a single-modality treatment.

Although numerous nonopioid medications and nonpharmacologic treatment options are available, and more effectiveness and safety data are coming to light, nonpharmacologic therapies are understudied in clinical practice, in part, because evidence is poorly disseminated and both training and reimbursement are lacking. This educational activity summarizes evidence and practice recommendations for evidence-based alternatives to opioids for chronic pain treatment and the risk mitigation strategies that are necessary when opioids are prescribed. On completion, clinicians should be better prepared to consider all available treatment options as part of comprehensive pain management and to describe appropriate assessment and monitoring measures when opioids are prescribed.

Recommendations: Nonpharmacologic and Nonopioid Pharmacologic Pain Treatment Options

Calls are increasing to integrate pain care into a comprehensive model that makes use of multidisciplinary and multimodal care that is delivered in an interdisciplinary, team-based approach wherever available, using and combining, when appropriate, the range of available treatment options. Box 1 lists some common definitions used to describe delivery of pain care. A number of governmental, professional, and academic sources have issued publications encouraging the use of nonpharmacologic and nonopioid pharmacologic treatment options as part of a comprehensive, multidisciplinary model of pain care.

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**Box 1. Frequently Used Definitions in Delivery of Pain Care**

- **Biopsychosocial** refers to a medical problem or intervention that combines biological, psychological, and social elements or aspects.
- **Complementary health** approaches are mind and body practices and natural products of non-mainstream origin, including chiropractic and osteopathic manipulation, meditation, massage, relaxation, yoga, acupuncture, naturopathic medicine.
- **Integrated care** is the systematic coordination of medical, psychological, and social aspects of health care and includes primary care, mental health care, and, when needed, specialist services.
- **Integrative health** care incorporates complementary approaches into mainstream health care.
- **Interdisciplinary care** is provided by a team of health professionals from diverse fields who coordinate their skills and resources to meet patient goals.

**Levels of care:**
- **Primary care** practitioners offer routine screenings and assessment, management of common pain conditions, including pain from headache, diabetes, arthritis, and low back pain.
- **Pain medicine** specialists provide secondary-level consultations (may include multidisciplinary team-based care); some provide procedures to address pain.
- **Interdisciplinary pain** centers provide tertiary care through advanced pain medicine diagnostics and interventions, including rehabilitation therapy and behavioral health care.

**Multidisciplinary care** involves a variety of disciplines that work independently and in parallel to accomplish therapeutic goals. A typical multidisciplinary team to address pain might include a medical provider, social worker, pain psychologist, physical therapist, occupational therapist, and recreational therapist.

**Multimodal pain treatment** addresses the full range of an individual patient’s biopsychosocial challenges by providing a range of multiple and different types of therapies that may include medical, surgical, psychological, behavioral, and integrative approaches as needed.

**Pain self-management** programs address the systematic provision of education and supportive interventions by health care providers to strengthen patients' skills and confidence in medical management, role management, and emotional management of their health problems, including regular assessment of progress and problems, decision making, goal setting, self-monitoring, and problem solving.
Specifically:

- National Academy of Medicine calls for improved medical education and reimbursement models for comprehensive pain management that encompasses pharmacologic and nonpharmacologic modalities.
- National Institutes of Health (NIH) endorses comprehensive pain prevention and management in recognition of pain's biological, psychological, and social contributing factors.
- Centers for Disease Control and Prevention (CDC) specifies that nonpharmacologic therapy and nonopioid pharmacologic therapy are preferred for chronic pain outside of cancer, palliative, and end-of-life care.
- The Consortium Pain Task Force (PTF), made up of 72 academic medical centers and health systems, recommends evidence-based nonpharmacologic pain therapies as part of comprehensive pain care for patients with acute, chronic, and cancer pain.
- The American College of Physicians (ACP) presents evidence and clinical recommendations to guide noninvasive pharmacologic and nonpharmacologic treatment of low back pain.
- US Food and Drug Administration (FDA) calls for development of new and nonaddictive pain treatment options, including opioids with abuse-deterrent properties, and announced an Opioid Analgesic Risk Mitigation and Education Strategy blueprint containing information on nonpharmacologic and pharmacologic (opioid and nonopioid) treatments.
- The Joint Commission requires nonpharmacologic pain treatment options as a scored element in a revised pain standard for its accredited hospitals effective January 1, 2018.

However, some call for the terms “alternative” and “complementary” to be replaced with a strategy that evaluates all pharmacologic and nonpharmacologic treatments on evidence of effectiveness and risk.

Nonpharmacologic Therapies: Indications, Evidence, and Risks

Nonpharmacologic therapies should be considered first-line options for chronic pain and may be used alone or combination with each other, medication treatments, surgeries, or other procedures. Their benefits in addition to pain control include:

- Reduced anxiety
- Reduced depression
- Reduced nausea and vomiting
- Improved sleep quality
- Increased patient wellbeing
- Increased functional gains and reduced debility

The CDC recommends the following nonpharmacologic therapies as posing less risk to patients than opioids while, in some instances, resulting in better outcomes, include:

- Exercise therapy
- Weight loss
- Psychological therapies such as cognitive behavioral therapy (CBT)
- Interventions to improve sleep
- Certain procedures

Additional benefits of nonmedication therapeutic approaches are that patient education and other lifestyle modifications, such as dietary improvements, stress management, mindfulness and other meditation techniques, sleep hygiene, and some movement therapies are low cost and generally acceptable to patients. Along with an increase in self-efficacy may come healthier choices and reductions in disease, such as obesity and diabetes, that contribute to pain.

One recent report detailed the results of a systematic comparative effectiveness review conducted using methods set by the Agency for Healthcare Research and Quality (AHRQ). Key findings showed that the following noninvasive nonpharmacologic treatments improved pain or function or both for at least 1 month for the following common chronic pain conditions:

- Chronic low back pain: Exercise, psychological therapies (primarily CBT), spinal manipulation, low-level laser therapy, massage, mindfulness-based stress reduction, yoga, acupuncture, multidisciplinary rehabilitation (MDR)
- Chronic neck pain: Exercise, low-level laser, Alexander Technique, acupuncture
- Knee osteoarthritis: Exercise, ultrasound
- Hip osteoarthritis: Exercise, manual therapies
- Fibromyalgia: Exercise, CBT, myofascial release massage, tai chi, gong, acupuncture, MDR
- Chronic tension headache: Spinal manipulation

Most effects were small, and long-term evidence was sparse. Evidence of harms was limited but suggested no serious harms from any of the interventions studied.

In still another recent report, the Consortium PTF examined systematic reviews and meta-analyses to assess nonpharmacologic interventions with an emphasis on safety, effectiveness (both short and long term), and economic impact. Most effectiveness evidence for nonpharmacologic interventions applied to chronic pain (Table 1). However, somatic interventions that were found to reduce postop pain and some cases of acute, nonsurgical pain include acupuncture and massage therapy. Findings indicated advantages in terms of being opioid sparing, having high levels of safety, and increasing patient self-efficacy and engagement in the treatment plan. Therapeutic options not covered in the Consortium PTF evidence review because they are already recognized conventional care options (although still underutilized) include:

- CBT
- Physical therapy
- Exercise therapy
- Electrical stimulation (E-Stim), various types of electrical stimulation often used in physical therapy

More in-depth discussion of some of these therapies follows.

**Acupuncture**

Acupuncture has the most evidence for chronic pain and has been found to effectively treat a number of painful conditions, including musculoskeletal pain (e.g., neck, shoulder, and low back pain), headache, migraine, and osteoarthritis pain; furthermore, benefits persist over time. More rigorous study is needed in the area of acupuncture for the treatment of neuropathic pain, although acupuncture has demonstrated some benefit for peripheral neuropathies.

It is important that professionals who deliver acupuncture have the training necessary to provide correct needling techniques. Treatment frequency should be individualized to the patient and the pain type and severity. In trials for osteoarthritis and musculoskeletal pain, average frequency was 8-15 treatments over 10-12 weeks. Weekly treatment is common for tension headache and migraine. In a military population, treatments at least 4 times a year were associated with improved symptoms and reduced medication use.

**Spinal Manipulation Therapy**

These treatments of the spine and pelvic joints are most often delivered by osteopathic doctors and chiropractors to improve pain and function. Techniques vary but systematic reviews have found benefits for neck pain, cervicogenic headache, low back pain (with benefits sustained for up to 6 weeks), and migraine as a prophylactic treatment.
<table>
<thead>
<tr>
<th>Intervention</th>
<th>Chronic Pain Conditions</th>
<th>Study Specifics</th>
<th>Outcomes, Comparators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acupuncture</td>
<td>Musculoskeletal (neck, shoulder, low back pain)</td>
<td>MA of 29 RCTs with 17,922 patients; Updated MA of 39 RCTs with total of 20,827 patients; Multi-center trial with 14 161 patients: acupuncture added to routine care</td>
<td>Significantly better pain relief than sham, no acupuncture; greater, immediate pain relief than sham or analgesic injection; superior to routine care alone for neck pain and disability</td>
</tr>
<tr>
<td></td>
<td>Headache</td>
<td></td>
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<tr>
<td></td>
<td>Migraine</td>
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<tr>
<td></td>
<td>OA</td>
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<td></td>
<td>Knee OA</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Migraine, tension headache</td>
<td>SR and MA: 2349 patients; 4985 patients</td>
<td>Effective for reducing headache frequency compared to no or sham acupuncture, other prophylactic</td>
</tr>
<tr>
<td></td>
<td>Disease-related pain</td>
<td>SR with MA: evaluating pain relief within 30 minutes of first treatment</td>
<td>Greater immediate pain relief than sham or analgesic injection</td>
</tr>
<tr>
<td></td>
<td>Musculoskeletal (low back, neck, shoulder), knee OA</td>
<td>MA</td>
<td>Effect persistence: 90% of benefit persisted at 12 months compared to wait list or usual care; 50 persistence of benefit at 12 months compared to sham</td>
</tr>
<tr>
<td></td>
<td>Peripheral neuropathy, Bell’s palsy, carpal tunnel syndrome</td>
<td>SR with MA: Differing study methodologies</td>
<td>Benefit over controls</td>
</tr>
<tr>
<td>Biofeedback</td>
<td>Low back pain</td>
<td>MA: 23 treatment conditions and 1062 patients;</td>
<td>Improvements in pain, depression, disability, muscle tension, coping</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SR</td>
<td>ACP recommendation</td>
</tr>
<tr>
<td></td>
<td>Tension headache</td>
<td>MA of trials</td>
<td>Effective with stable benefit up to 15 months compared to headache monitoring, placebo, relaxation therapies</td>
</tr>
<tr>
<td></td>
<td>Fibromyalgia</td>
<td>SR and MA: 7 studies with 321 patients; MA of RCTs of mind-body interventions</td>
<td>Significant pain reduction compared to controls; less effect due to variability of measures</td>
</tr>
<tr>
<td>Manipulative or manual therapy</td>
<td>Knee OA</td>
<td>SR and MA: 14 studies with 841 patients; 12 studies, 4 with low risk of bias</td>
<td>Significant improvements in pain, function, stiffness (stiffness, physical function not significant &lt; 4 weeks treatment); effective for function compared to no treatment and for pain and function when added to comparator</td>
</tr>
<tr>
<td>(non-spinal joint manipulation)</td>
<td></td>
<td>SR</td>
<td>Fair evidence for short-term, limited evidence for long-term treatment</td>
</tr>
<tr>
<td></td>
<td>Lower extremity: Hip OA, patellofemoral syndrome, ankle inversion sprain, plantar fasciitis</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shoulder disorders</td>
<td>SR: 35 studies</td>
<td>Fair evidence for treating a variety of disorders, alone or in combination with exercise, multimodal; limited/insufficient evidence for minor neurogenic shoulder pain/shoulder</td>
</tr>
<tr>
<td></td>
<td>Lateral epicondylitis, carpal tunnel syndrome, temporomandibular disorders</td>
<td>SR: 129 studies</td>
<td>Effective when combined with exercise, multimodal</td>
</tr>
</tbody>
</table>
Table 1. Consortium PTF: Select Evidence for Nonpharmacologic Treatments in Chronic Noncancer Pain* (Continued)

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Chronic Pain Conditions</th>
<th>Study Specifics</th>
<th>Outcomes, Comparators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Massage therapy</td>
<td>All pain populations, chronic pain examples: musculoskeletal, headache, visceral, fibromyalgia, spinal cord, venous insufficiency</td>
<td>SR and MA: 60 high quality, 7 low-quality studies[29]</td>
<td>Improved pain, function, mood, QOL over sham, no treatment, active comparators</td>
</tr>
<tr>
<td>Low back pain</td>
<td>SR review[7]</td>
<td></td>
<td>ACP recommendation</td>
</tr>
<tr>
<td>Neck pain</td>
<td>NIH review limited to RCTs[50]</td>
<td></td>
<td>NIH recommendation</td>
</tr>
<tr>
<td>Knee OA</td>
<td>SR with MA: 14 studies with 841 patients</td>
<td></td>
<td>Manual therapy, including massage, significantly improved pain, stiffness, function at 4 weeks</td>
</tr>
<tr>
<td>Knee OA</td>
<td>RCT: 125 patients[31]</td>
<td></td>
<td>Optimal dose at 8 weekly 1-hour sessions; benefits persisted at least 8 weeks compared to usual care</td>
</tr>
<tr>
<td>Mind-body directed therapies:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mindfulness-based stress reduction</td>
<td>Low back pain</td>
<td>SR and MA: 7 RCTs with 864 patients[32]</td>
<td>Short-term improvements in pain intensity and physical functioning compared to usual care</td>
</tr>
<tr>
<td>Low back pain</td>
<td>SR review[7]</td>
<td></td>
<td>ACP recommendation</td>
</tr>
<tr>
<td>Headache, fibromyalgia, irritable bowel syndrome, other chronic pain</td>
<td>SR: 17 studies with 1855 patients of mindfulness and relaxation-based eHealth interventions[13]</td>
<td>Positive health outcomes</td>
<td></td>
</tr>
<tr>
<td>Tension and migraine headache</td>
<td>RCT with 40 patients: 8-week program[15]</td>
<td></td>
<td>Significant improvement of pain and QOL compared to controls</td>
</tr>
<tr>
<td>Pain-coping skills training</td>
<td>Knee pain</td>
<td>150 patients ≥age 50 combined with physiotherapist-prescribed home exercise[16]</td>
<td>Clinically meaningful improvements in pain and function, sustained for ≥6 months</td>
</tr>
<tr>
<td>OA, RA</td>
<td>MA: 27 RCTs of psychological interventions for arthritis pain[37]</td>
<td></td>
<td>Significant benefits for pain and psychological, physical, and biological function</td>
</tr>
<tr>
<td>Hip OA, Knee OA</td>
<td>133 patients, 8-week Internet-based program[18]</td>
<td></td>
<td>Significant benefits for pain in women compared to controls</td>
</tr>
<tr>
<td>Music Therapy</td>
<td>Various pain types</td>
<td>MA: 97 RCTs[19]</td>
<td>Significant reduction in pain, pain-related emotional distress, small but significant reduction in opioid and nonopioid intake</td>
</tr>
<tr>
<td>Progressive relaxation</td>
<td>Low back pain</td>
<td>SR[7]</td>
<td>ACP recommendation</td>
</tr>
<tr>
<td>Relaxation and autonomic regulatory approaches</td>
<td>Fibromyalgia</td>
<td>NIH review limited to RCTs[50]</td>
<td>NIH recommendation</td>
</tr>
<tr>
<td>Intervention</td>
<td>Chronic Pain Conditions</td>
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</tr>
<tr>
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</tr>
<tr>
<td>Movement therapies: Yoga</td>
<td>Nonspecific low back pain</td>
<td>Cochrane review: 9 studies with 810 subjects&lt;sup&gt;50&lt;/sup&gt;</td>
<td>Slight improvements in pain and function, little effect on QOL or depression compared to no exercise</td>
</tr>
<tr>
<td></td>
<td>Low back pain</td>
<td>SR&lt;sup&gt;7&lt;/sup&gt;</td>
<td>ACP recommendation</td>
</tr>
<tr>
<td></td>
<td>Low back pain</td>
<td>AHRQ: SR of RCTs of noninvasive treatments&lt;sup&gt;41&lt;/sup&gt;</td>
<td>Effective compared to placebo, sham, no treatment, usual care, wait list</td>
</tr>
<tr>
<td></td>
<td>Low back pain</td>
<td>NIH review limited to RCTs&lt;sup&gt;30&lt;/sup&gt;</td>
<td>NIH recommendation</td>
</tr>
<tr>
<td>Various pain types</td>
<td>SR: 10 RCTs&lt;sup&gt;62&lt;/sup&gt;</td>
<td>Significant pain reduction in 9 trials, various comparators, including standard care, self-care, therapeutic exercises, no intervention</td>
<td></td>
</tr>
<tr>
<td>Low back pain, OA, RA, kyphosis, fibromyalgia</td>
<td>SRs with MA: 17 studies with 1626 participants&lt;sup&gt;43&lt;/sup&gt;</td>
<td>Moderate treatment effect for functional and pain outcomes</td>
<td></td>
</tr>
<tr>
<td>Knee OA</td>
<td>SR: 6 studies with 372 patients&lt;sup&gt;64&lt;/sup&gt;</td>
<td>Possible positive effects on pain and mobility, unclear effects on QOL</td>
<td></td>
</tr>
<tr>
<td>Neck pain</td>
<td>SR of RCTs: 3 studies with high risk of bias&lt;sup&gt;65&lt;/sup&gt;</td>
<td>May be beneficial</td>
<td></td>
</tr>
<tr>
<td>Back pain, RA, headache/migraine, other</td>
<td>MA&lt;sup&gt;4&lt;/sup&gt;</td>
<td>Positive effects for pain and related disability</td>
<td></td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>SR with MA of meditative movement therapies (qigong tai chi, yoga): 7 studies with 362 subjects&lt;sup&gt;67&lt;/sup&gt;</td>
<td>Only yoga had significant effects on pain, fatigue, depression, health-related QOL (subgroup analysis)</td>
<td></td>
</tr>
<tr>
<td>OA</td>
<td>SRs with MA: 18 RCTs&lt;sup&gt;48&lt;/sup&gt;</td>
<td>Effective</td>
<td></td>
</tr>
<tr>
<td>OA, back pain, headache</td>
<td>SR with MA&lt;sup&gt;49&lt;/sup&gt;</td>
<td>Moderate-quality evidence more effective at short term for pain and disability than usual care or no treatment</td>
<td></td>
</tr>
<tr>
<td>Low back pain</td>
<td>SR&lt;sup&gt;7&lt;/sup&gt;</td>
<td>ACP recommendation</td>
<td></td>
</tr>
<tr>
<td>Low back pain</td>
<td>AHRQ: SR of RCTs of noninvasive treatments&lt;sup&gt;41&lt;/sup&gt;</td>
<td>Effective compared to placebo, sham, no treatment, usual care, wait list</td>
<td></td>
</tr>
<tr>
<td>Tai chi</td>
<td>Knee OA, fibromyalgia</td>
<td>NIH review limited to RCTs&lt;sup&gt;50&lt;/sup&gt;</td>
<td>NIH recommendation</td>
</tr>
<tr>
<td>OA</td>
<td>Evidence map of 107 SRs on health outcomes: 8 SRs addressed OA&lt;sup&gt;50&lt;/sup&gt;</td>
<td>Positive effects compared to controls on pain, physical function, joint stiffness (all results short term)</td>
<td></td>
</tr>
<tr>
<td>Alexander Technique</td>
<td>Back pain</td>
<td>SR with 18 studies&lt;sup&gt;51&lt;/sup&gt;</td>
<td>Significant long-term pain and incapacity reductions</td>
</tr>
<tr>
<td></td>
<td>Neck pain</td>
<td>3-arm RCT (Alexander Technique, acupuncture, usual care) with 517 patients&lt;sup&gt;52&lt;/sup&gt;</td>
<td>Both active arms led to significant reduction in pain and pain-related disability persisting at 12 months compared to usual care</td>
</tr>
</tbody>
</table>
Chronic Pain Conditions

Nonspecific low back pain
RCT with 61 patients with
Improvements in pain and functional ability in the short term over usual care and physical activity (equivalent to massage and other forms of exercise)

Low back pain
SR with MA

Low back pain
RCT with 101 postmenopausal patients
Significantly better pain and disability results at 6 weeks and 1 year for Pilates + physical therapy over physical therapy alone

Neck and scapular pain

Low back pain
SR with MA

Neck, cervicogenic headache, migraine prophylaxis
SRs
Beneficial, results with comparators limited

Feldenkrais

Neck and scapular pain
RCT with 61 patients with visual impairment
Significantly less pain post-treatment and at 1-year follow-up compared to no treatment

Spinal manipulation therapy

Low back pain
SR with MA

Neck pain, cervicogenic headache, migraine prophylaxis

Another modality, manipulative therapy, which refers to treating other joints in the upper and lower extremities, has been investigated and found to be beneficial for knee and hip osteoarthritis, common shoulder disorders, and other painful conditions.

Exercise Therapy

Choices in exercise therapy include walking, swimming or water aerobics, yoga, and free weights. Exercise therapy may be self or professionally directed, though patients with extreme debility from pain probably benefit from professionally-directed exercise. The opportunity for gains is many and include active patient engagement in the treatment plan, better posture, improved weakness, improved core strength, and the addressing of repetitive motions that contribute to musculoskeletal pain. Exercise treatments may be most appropriate when paired with self-management techniques to match exercise type and length of activity to the patient's level of conditioning. Conditions that may improve with exercise therapy include chronic low back pain, chronic neck pain, hip and knee osteoarthritis, pain, fibromyalgia, and migraine (as a preventative treatment).

Cognitive Behavioral Therapy

CBT trains patients in behavioral techniques to help modify situational factors and cognitive processes that exacerbate pain or contribute to the pain experience. Accordingly, CBT addresses psychosocial contributors to pain, including fear, avoidance, distress, and anxiety. Treatment involves teaching patients coping strategies and relaxation techniques and encouraging them to be active rather than passive in managing their chronic pain. There is evidence that CBT has small-to-modest positive effects on pain, disability, mood, and catastrophic thinking. It is one of the most frequently recommended modalities for chronic pain treatment and is increasingly covered by insurance reimbursement schemes. An advantage of CBT is the lack of associated risks. Unfortunately, there is a workforce shortage of pain psychologists or counselors trained in CBT for chronic pain, so accessing this treatment may be limited in most communities.

Mindfulness-Based Stress Reduction, Relaxation Therapies

Mindfulness-based stress reduction (MBSR) is a meditation technique that, along with CBT, is recommended for the treatment of chronic low back pain by the ACP. Other conditions that have demonstrated improvement with MBSR and internet-delivered interventions are headache, fibromyalgia, and irritable bowel syndrome. Furthermore, MBSR has been associated with less pain and improved quality of life in adults with headache and has demonstrated benefits for depression, quality of life, and acceptance of pain in adolescents with recurrent headache.

Pain-coping skills training (PCST) is a mind-body therapy that targets psychological factors common in chronic pain, such as poor pain coping and pain catastrophizing, an exaggerated negative orientation by the person in pain toward actual or anticipated pain. It has shown particular benefit for arthritis pain and can be delivered through Internet programs.

Other relaxation therapies that help patients reduce stress and muscle tension and address shallow breathing, among other benefits, include guided imagery, hypnosis, acceptance and commitment therapy (ACT), and music therapy. ACT has similar benefits as CBT for chronic pain, and 2 studies have shown higher satisfaction and better response from older adults, respectively.

Yoga, Tai Chi, Other Movement Therapies

Yoga is a discipline combining physical postural, breathing, and attention techniques. A number of guidelines recommend yoga for the treatment of low back pain. Other conditions with evidence of benefit include osteoarthritis, rheumatoid arthritis, kyphosis, and fibromyalgia.

It is difficult to rigorously evaluate the effectiveness of yoga for pain because of the variety of yoga styles and the heterogeneity in the delivery of the intervention. Yet several relatively high-quality randomized clinical trials (RCTs) indicate yoga’s benefits for mental health and disability associated with pain. There is some evidence that even short-term interventions may be effective for pain and pain-related disability. There are indications that interactive telehealth delivery options provide comparable benefits, including pain improvement, to in-person yoga.
The choice of yoga styles should be individualized to patient preference and availability, there being no strong evidence of advantage in any particular style. It should be noted that the NIH recommends hatha yoga, iyengar, and viniyoga for chronic low back pain.

Tai chi originated as a martial art and is taught as a series of slow, low-impact movements that integrate breath, mind, and physical activity. Tai chi is recommended for chronic low back pain by the ACP and has been shown in systematic reviews to be effective for osteoarthritis pain. Tai chi is specifically recommended for knee osteoarthritis and fibromyalgia. It has been proposed that the treatment duration for osteoarthritis may be greater than 5 weeks. Because sample sizes are small and study methodology is lacking in rigor, more high-quality trials are needed to assess the effects of tai chi on pain in the short term and long term. These limitations, however, are common in movement therapies and not unique to tai chi.

Other movement therapies that are useful in managing chronic pain include Pilates, Alexander Technique, and Feldenkrais. All movement therapies share features of touch, direct exercise, strengthening, and awareness of posture and muscle utilization. Personal preferences play a role in which therapies patients may find beneficial. Consider that Pilates showed significant improvement in pain relief and functional enhancement in a systematic review of effects on nonspecific chronic low back pain, but other exercises that involved torso movement showed similar effects if the exercises were performed for 20 cumulative hours.

**Lifestyle Changes, Self-Efficacy**

The term, self-efficacy, comes from social cognitive theory and is the goal in programs aimed at bettering choices in healthy nutrition, activities, emotional disposition, and outlook. Numerous studies link healthy behaviors, such as dietary changes, stress and sleep management, exercise, smoking cessation, and engagement in supportive relationships, to overall improved health and reduction of diseases that include diabetes, atherosclerosis, and obesity. Such improvements have potential to improve pain and function. In one study, overweight patients who reduced weight by at least 20% showed improvements in pain relief, function, walk distance, physical and mental health-related quality of life, joint compression force, and levels of IL-6, an inflammatory marker. The more weight was lost, the greater the improvements. As patients’ engagement with healthy behaviors increases, so does their confidence, leading to continued performance of the behaviors.

**Nonpharmacologic Treatment Harms and Risk**

Adverse events are considered less with nonpharmacologic than pharmacologic therapies and are frequently poorly reported in studies. Exercise therapy risks include injury and should be considered in the context of the patient’s existing conditions. Harms reported with most exercise therapies are generally limited to increased pain and muscle soreness with no serious harms reported. No harms or serious adverse events were associated with tai chi, psychological interventions, multidisciplinary rehabilitation, ultrasound, acupuncture, lumbar support, or traction. Yoga for chronic low back pain had mild-moderate harms, such as self-limiting joint and back pain comparable to physical therapy.

Acupuncture and massage therapy have a low risk of adverse events when provided by qualified, trained practitioners. Adverse events with spinal manipulation include increases in pain and muscle soreness but may, in rare cases, include serious events such as cerebral artery dissection, stroke, and neck injury. Various mindfulness-based and suggestive practices as well as psychological therapies are safe, although rare adverse reactions are possible in people with epilepsy, psychiatric patients, or trauma survivors who experience a paradoxical reaction. Biofeedback has a low risk of harms with rare side effects, such as headache, fatigue, or sleep difficulties.

**Interventional pain management**

Interventional pain management is the use of invasive and non-invasive techniques, including joint injections, nerve blocks, tissue ablations, spinal cord stimulation, pain pumps, and other procedures, to reduce pain. Conditions that may be treated using interventional techniques include rheumatoid arthritis, osteoarthritis, rotator cuff disease, and some radiculopathies. Practice guidelines are not uniform for most interventional techniques in chronic pain, although such techniques may be helpful for select patients. Injections of corticosteroids are frequently given but have not been found to be effective in the long term for low back pain with or without radicular symptoms. Benefit to pain and function of systemic corticosteroids is uncertain and may be short lived.

There are harms and risks to consider with interventional procedures. Epidural injections can cause articular cartilage changes in osteoarthritis, joint infection, and sepsis and are associated with rare but serious adverse events, including loss of vision, stroke, paralysis, and death. Interventional techniques, including various surgeries, should not be considered ahead of more conservative care.

A consideration with interventional procedures is that financial incentives may be tied to specific procedures or other specialty care without sufficient regard to best practices.

**Nonopioid Medication Therapies: Indications, Evidence, and Risks**

Although less associated with overdose, toxicity, drug-drug interactions, physical dependency, and substance-use disorder than opioids, nonopioid drug treatments do have risks and potential side effects. Before initiating any pharmacologic treatment, clinicians should review FDA-approved labeling, including boxed warnings. Particular care is necessary in certain populations, including older patient, pregnant patients, and patients with medical comorbidities, including cardiovascular, renal, gastrointestinal, pulmonary, and liver compromise.

**Acetaminophen (APAP)**

Pain conditions for which APAP are used include osteoarthritis, chronic lower back pain, migraine. Although useful for mild pain without inflammation, APAP may be less effective than other medications.

A principal risk with APAP is hepatotoxicity at doses >3-4 grams per day and in patients with chronic alcohol use or liver disease at lower daily doses. An FDA black box warning highlights risk for severe liver damage and the necessity to evaluate all dose levels from all medications (including opioid-combination products) to avoid exceeding the daily dosage level. Aside from risk for liver complications, APAP has fewer adverse events than other medications.

**Nonsteroidal Anti-Inflammatory Drugs (NSAIDs) and Selective Cyclooxygenase-2 (COX-2) Selective Inhibitors**

Examples of multiple indications are localized osteoarthritis, acute and chronic low back pain without sciatica, and headache. Many guidelines recommend the use of NSAIDs for various common chronic pain conditions before considering less conservative treatment options. However, NSAIDs are associated with significant morbidity and mortality. New FDA warnings emphasize chance of stroke or heart attack. Additional risks of harm include delayed healing, gastrointestinal bleeding or perforation, hepatic risks, and renal failure. Risks with NSAIDs are increased at high doses or longer use. Careful consideration and control of daily dosage is important with NSAID usage.
**Skeletal Muscle Relaxants**

Muscle relaxants are prescribed short term for relief of pain and muscle spasm. Examples include tizanidine, cyclobenzaprine, and methocarbamol. These medications are associated with central nervous system (CNS) adverse effects, principally sedation. Skeletal muscle relaxants may also increase the CNS-depressant effects of opioids, and careful weighing of risks versus benefits should occur before co-prescribing these medications.4 Certain muscle relaxants, such as carisoprodol, have no evidence for their use and can be easily misused. Heightened risks for toxicity and respiratory depression leading to overdose are also notable with carisoprodol and benzodiazepines when combined with opioids, and these combinations should be avoided.5

**Anticonvulsants**

Examples of anticonvulsants used for pain management are pregabalin, gabapentin, and carbamazepine, which are principally used to treat neuropathic pain, including diabetic neuropathy, postherpetic neuralgia, and fibromyalgia.6,2 Topiramate and valproate are commonly used to treat headache.5 Analgesic benefit is generally mild to moderate.5

The adverse effects with this class of medications may limit treatment and include sedation, dizziness, cognitive slowing, and ataxia; furthermore, some anticonvulsants appear to have abuse potential.5,6,2 Widely prescribed off-label for pain, gabapentin misuse has been reported to be 1% in the general population, 40-65% among people with prescriptions, and between 15% and 22% in the population of people who abuse opioids.7

**Antidepressants**

Tricyclic antidepressants (TCAs) and serotonin and norepinephrine reuptake inhibitors (SNRIs) are prescribed for the treatment of neuropathic pain (e.g., diabetic neuropathy, postherpetic neuralgia), migraine, and amplified pain disorders such as fibromyalgia and complex regional pain syndrome.5,6,2 There is moderate-quality evidence from 8 manufacturer studies that duloxetine is effective at reducing pain in diabetic peripheral neuropathy pain at 60 and 120 mg daily doses and lower quality evidence for effectiveness in fibromyalgia pain at similar doses.7 In a small number of studies, tricyclic and tetracyclic antidepressants produced moderate improvements in chronic low back pain.7,4

Depending on class, risks include anticholinergic effects, vasomotor symptoms, sexual dysfunction, weight gain, emotional blunting, and suicidal thoughts.5 SNRIs are often better tolerated than TCAs.6,2 The class of TCAs is relatively contraindicated in severe cardiac disease, particularly in conduction disturbances or in patients with prolonged QTc.6 In addition, TCAs have heightened anticholinergic properties.5,6 TCAs should be started at low doses, titrated as needed and tolerated, and may be most beneficial at bedtime due to sedating effects.6,2 Antidepressant therapy for pain is chosen carefully after consideration of individual risk profile and comorbidities.5

**Topical Agents**

Topical medications are used to treat localized neuropathic pain, osteoarthritis, and other localized musculoskeletal pain.5,6,2 Examples of topical agents include TCAs, SNRIs, lidocaine (for localized neuropathic pain), capsaicin (for musculoskeletal and neuropathic pain), ketamine, baclofen, and topical NSAIDs such as ketoprofen and diclofenac.5,6,2 The strongest evidence for benefit is for anti-inflammatory in musculoskeletal pain and capsaicin in neuropathic pain.5

Topical agents provide options that may be safer than systemic medications.6,2 In patients older than 75 years, topical NSAIDs may be particularly useful to minimize common risks of oral NSAIDs.6,2 Common adverse effects of topical treatments include initial flare or burning sensation and irritation of mucous membranes.5,6

**Screening Candidates for Pain, Selecting Therapies**

Chronic pain, lasting longer than 3 months, may have many causes, such as injury or chronic disease, or may lack a clear connection to an identifiable cause.5 One should seek an underlying cause and treat it as well as managing the pain. Clinicians should conduct a thorough medical history, physical exam and appropriate testing, and review of prior medical records.6 Pain scales, like the numeric visual analog scale, are useful but do not capture important functional or quality of life measures. The PEG is a brief, 3-item scale that is more useful because it includes these important measures.7,5

Bear in mind patients with chronic pain are at risk for comorbid depression, anxiety, post-traumatic stress disorder (PTSD), and insomnia that may be severe and exacerbate pain.6,2 Be aware, also, that patients with mental health disorders are more likely to be prescribed opioids7,6 and monitor that pain therapies are not causing more harm than good.

**Opioid Therapy**

If patients have not responded to treatment with nonopioid and nonpharmacologic treatment, a trial of opioid therapy may be warranted in select patients if the expected benefits for both pain and function are anticipated to outweigh the risk.4 Examples of opioids include fentanyl, hydrocodone, hydromorphone, methadone, morphine, oxycodone, and tramadol. Opioids, when used, are to be part of a comprehensive pain program, and yet the correct balance for achieving optimal pain relief while alleviating opioid-related adverse effects is still a subject for investigation.1

Guidelines are not conclusive on when a trial of long-term opioid therapy (LTOT) is warranted, but consideration may be given when there is severe ongoing pain with an adverse impact on function and quality of life despite optimization of other therapies. A benefit-to-harm evaluation should be performed, documented, and updated throughout the course of LTOT.4

A 2016 CDC guideline for prescribing opioids for the treatment of chronic pain specifies that:4

- Opioids are not first line therapeutics for chronic pain outside of active cancer, palliative, or end-of-life care.
- Opioids should be reserved for when expected benefits to pain and function outweigh known and substantial risks.
- Opioids, when used, should be combined with nonpharmacologic and nonopioid pharmacologic therapies, as appropriate.

Furthermore, the guideline recommends that LTOT be considered in context with a broader pain management strategy with the goal of improving patient outcomes for pain reduction and function while reducing risk for opioid-related adverse outcomes. An evidence review from the CDC found that opioids were not superior in effectiveness to NSAIDs for low back pain or antidepressants for neuropathic pain.10

The role of opioids in chronic pain management is unclear, but select individuals may benefit.7,2 Careful candidate selection, prescribing, and documentation are critical to lessening overdose and opioid use disorder (OUD) risks.

**Opioid Risk Mitigation**

Patients who are initiated or continued on opioid therapy should be assessed and monitored for risks that contribute to OUD, misuse, or diversion. Some definitions related to problematic opioid usage are shown in Table 2.

**Screening for Risk in Opioid Therapy**

Screening for the risk of an OUD may be aided by the use of several available tools, some of which are shown in Table 3.82-85 The Current Opioid Misuse Measure (COMM) is an assessment for patients already on ongoing opioid therapy.46
### Table 2. Definitions Related to Opioid Use and Misuse

| Tolerance⁷⁸ | A physiologic state of adaptation in which exposure to the opioid results in diminution of its effects over time. In patients with “analgesic tolerance,” increased doses of opioid are needed to maintain pain relief. |
| Physical dependence⁷⁸ | A physiologic state characterized by abstinence syndrome (withdrawal) if treatment with an opioid is stopped or decreased abruptly, or if an antagonist is administered. |
| Nonmedical use (also known as abuse)⁷⁹ | The intentional, non-therapeutic use of a drug product or substance, even once, to achieve a desirable psychological or physiological effect. |
| Misuse⁷⁹ | The intentional therapeutic use of a drug product in an inappropriate way and specifically excludes the definition of abuse. |
| Addiction⁸⁰ | Chronic disease characterized by compulsive, or uncontrollable, drug seeking and use despite harmful consequences and long-lasting changes in the brain. |

Criteria for Opioid-Use Disorders from the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition⁸¹

1. Opioid taken in larger amounts or over a longer period than intended.
2. Persistent desire or unsuccessful efforts to cut down or control opioid use.
3. A lot of time spent obtaining, using, or recovering from the effects of the opioid.
4. Craving or a strong desire to use opioids.
5. Recurrent opioid use resulting in a failure to fulfill major role obligations at work, school, or home.
6. Continued use despite persistent or recurring social or interpersonal problems caused or exacerbated by opioid use.
7. Stopping or reducing important social, occupational, or recreational activities due to opioid use.
8. Recurrent use of opioids in physically hazardous situations.
9. Continued use despite knowledge of having persistent or recurrent physical or psychological problems caused or worsened by opioid use.
10. Tolerance as defined by either a need for markedly increased amounts to achieve intoxication or desired effect or by markedly diminished effect with continued use of the same amount. (Does not apply when used appropriately, as directed, under medical supervision.)
11. Withdrawal manifesting as either characteristic syndrome or the substance is used to avoid withdrawal. (Does not apply when used appropriately, as directed, under medical supervision.)

“The disease of OUD is diagnosed using DSM-5 criteria: A minimum of 2–3 criteria are required for a mild substance-use disorder (SUD) diagnosis, while 4–5 is moderate, and 6–7 is severe; OUD is specified instead of SUD, if opioids are the drugs of abuse. Addiction, while not a DSM-5 diagnosis, is still a term that is used and generally describes a severe OUD. The presence of tolerance and physical dependence are not in themselves indicators that an OUD has developed. Tolerance and physical dependence are expected, known side effects of long term use of opioids.

### Table 3. Examples of Opioid-Use Disorder Risk Assessment Tools

<table>
<thead>
<tr>
<th>Tool</th>
<th># of items</th>
<th>Administered</th>
<th>Approximate Time to Complete</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Initial Screen Prior to Initiating Opioid Therapy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opioid Risk Tool (ORT)⁸³</td>
<td>5</td>
<td>Patient</td>
<td>1 min</td>
</tr>
<tr>
<td>Revised Screener and Opioid Assessment for Patients with Pain (SOAPP-R)⁸²</td>
<td>24*</td>
<td>Patient</td>
<td>5 min</td>
</tr>
<tr>
<td>Diagnosis, Intractability, Risk, Efficacy (DIRE)⁸⁴</td>
<td>7</td>
<td>Clinician</td>
<td>2 min</td>
</tr>
<tr>
<td>Pain Medication Questionnaire (PMQ)⁸⁷</td>
<td>26</td>
<td>Patient</td>
<td>10 min</td>
</tr>
<tr>
<td><strong>For Use During Opioid Therapy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current Opioid Misuse Measure (COMM)⁹⁶</td>
<td>17</td>
<td>Patient</td>
<td>10 min</td>
</tr>
<tr>
<td>Patient Version Prescription Drug Use Questionnaire (PDUQp)⁹⁸</td>
<td>31</td>
<td>Patient</td>
<td>20 min</td>
</tr>
<tr>
<td><strong>Brief Initial Drug Screening Not Specific to Pain Population</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CAGE-AID (Adapted to Include Drugs)⁹⁹</td>
<td>4</td>
<td>Clinician</td>
<td>1 min</td>
</tr>
<tr>
<td>Single-Question Screening Test⁹⁰ (followed by 10-item Drug Abuse Screening Test⁹¹ if positive)</td>
<td>1</td>
<td>Clinician</td>
<td>1 min</td>
</tr>
</tbody>
</table>

*4- and 12-item SOAPP formats are available.
None have been fully validated in a variety of clinical settings but are generally chosen by evaluating length, time available, and expertise within the clinic. The screening tools assess for the risk that patients will display aberrant drug-related behaviors during the course of opioid therapy in order to determine the type and frequency of clinical monitoring measures. Aberrant drug-related behaviors include requests for early refills, self-escalation of opioid doses, and attempts to obtain opioids from unauthorized sources.

Patient risk factors for problematic opioid use form the basis of most risk assessment tools and are important for clinicians to know. They include:

- Nonfunctional status due to pain
- Exaggeration of pain
- Unclear etiology for pain
- History of rapid opioid dose escalation
- High dose opioid use (>90 mg of morphine equivalents)
- Young age
- Tobacco use
- Poor social support
- Personal history of substance abuse
- Family history of substance abuse
- Psychological stress
- Psychological trauma
- Psychological disease
- Psychotropic substance use
- Focus on opioids
- History of sexual abuse
- History of legal problems
- History of substance-abuse treatment
- Craving for prescription drugs
- Mood swings
- Adverse childhood experience
- Social environments that encourage illicit substance use

Overdose risk is a critical area for extra clinical vigilance, and clinicians should be aware of opioid-related overdose risk factors that include:

- Middle age
- History of substance abuse
- Comorbid mental and medical disorders
- Higher daily opioid dose: ≥50 morphine milligram equivalents (MME)
- Use of multiple prescribers
- Recent upward titration
- Recent opioid rotation
- Methadone use
- Concomitant benzodiazepine use
- Concomitant alcohol use
- Concomitant antidepressant use
- Unemployment
- Polysubstance abuse

- Recent release from prison
- Recent release from abstinence-based addiction treatment
- Sleep apnea
- Heart or pulmonary complications (e.g., respiratory infections, asthma)
- Pain intensity

Bear in mind prescription opioid-related overdose deaths often involve benzodiazepines (examples are alprazolam, diazepam, and lorazepam) and avoid this combination whenever possible. In addition to benzodiazepines, other substances that may heighten opioid respiratory-depressant effects include alcohol, carisoprodol, any sedatives or hypnotics, and tricyclic antidepressants.

Informed consent of the risks and expected benefits of opioid therapy should be obtained and documented. Patient and prescriber roles and responsibilities should be clearly described, discussed with the patient, and documented in the patient record. A formal agreement to be signed by the clinician and the patient and retained in the record should be considered. Goal setting is important, and patients should be involved in the process of setting expectations for LTOT and counseled to understand that initial treatment with opioids is to be considered a trial.

Opioid selection, dosing, and titration are individualized according to health status, previous opioid exposure, therapeutic goals, and risk for harm. When prescribing opioids, the rule is to “start low and go slow,” initiating at the lowest effective dose and titrating slowly to effect. Clinicians should reassess risks and benefits of treatment when increasing a dose to 50 MME or more per day; doses of 90 MME or more should be avoided or carefully considered and the rationale documented. Short-acting opioids are recommended for initial dosing. Clinicians are warned that methadone is characterized by complicated and variable pharmacokinetics and pharmacodynamics and requires cautious initiation and titration only by clinicians familiar with its unique properties.

Common opioid side effects that should be anticipated and that may require management include:

- Tolerance (need for more medication to achieve same pain relief)
- Physical dependence (symptoms of withdrawal are expected when the medication is stopped)
- Hyperalgesia
- Constipation
- Nausea or vomiting
- Dry mouth

Clinicians should be alert for initial signs patients may have trouble managing opioid medications. Patients may misuse or abuse medication for various reasons. Some may attempt to self-medicate their own pain, mood, or sleep difficulties with unauthorized escalation of doses. Others may desire to achieve a psychoactive reward or to avoid withdrawal symptoms. Some people will use opioids outside of medical direction compulsively due to OUD. People may pose as patients to seek opioids to divert for financial gain. Milder forms of misuse may stem from a misunderstanding of the clinician’s directions. Aberrant drug-related behaviors may be difficult to interpret. Therefore, it is important to use objective measures in combination with clinical evaluation to track the effect of the therapeutic regimen.

**Urine Drug Testing**

Urine toxicology has limitations but serves several purposes. It can alert clinicians to the presence of unauthorized prescription drugs or illicit drugs. In addition, it can show the absence of prescribed drugs that could be a sign the patient is diverting medication. It is also an important measure to demonstrate to medical boards and other regulators of medical care that the prescribing of controlled substances is done for a legitimate medical purpose in accordance with law.

Initial assessment includes baseline urine drug testing (UDT). Immunoassay testing is usually performed at the point of care (POC) and detects drug classes but typically does not isolate specific opioids. If the POC test indicates unexpected results, the next step is a more specific laboratory test using gas chromatography/mass spectrometry (GC/MS) technology or liquid chromatography dual mass spectrometry (LC/MS/MS), which can detect specific drugs and their metabolites. The usual clinical process is a POC test that is followed by the quantitative evaluation from a laboratory only if the POC test indicates possible deviation from medical direction. Some laboratories offer definitive LC/MS/MS testing that may be given as the initial screen. However, because LC/MS/MS testing can be expensive, many insurance payors still require the two-step process of a POC test first.

Recommended drugs for which to test include:

- Common illegal drugs (e.g., cocaine, amphetamine/ methamphetamine)
- Opioids, including buprenorphine, fentanyl, hydrocodone, hydromorphone, methadone, morphine, oxycodone, and oxymorphone,
Caution is necessary to interpret UDT results, and limitations include:\textsuperscript{108}

- Cross-reactivity with other drugs or substances
- Potential for false positives (e.g., poppy seeds positive for opiates)
- Potential for false negatives
- Variable drug metabolism
- Limited windows of detection
- Laboratory error or test insensitivity

It is recommended to carefully select the laboratory that will perform the quantitative testing and to inform them of relevant pain management goals. To minimize the chance cross-reactivity will affect results, inform the laboratory of all prescribed and over-the-counter drugs the patient is taking. Cutoff points for drug detection should be clinically relevant and the importance of the presence or absence of prescribed drugs emphasized in discussions with laboratory personnel. Laboratories may also test for specific gravity, which — along with measuring the temperature of the sample after the POC test — is a means to guard against tampering. Unexpected UDT results should be discussed with the patient, and the actions taken should be documented in the record.

A value in UDT lies in early identification of patients who may be at risk for OUD, other SUD, diversion or opioid overdose but a conscious choice for patients who demonstrate benefit in pain control, life activities, functional goals, and quality of life. Monitoring should assess the multiple domains of analgesia, activities of daily living, adverse events, aberrant drug-related behaviors, affect, and progress toward goals of therapy.\textsuperscript{4,111}

Periodic monitoring includes ongoing UDT and PDMP checks. Pill counts may also be necessary at times. Guidelines on frequency of UDT vary, but a consensus recommendation is to test every patient at least annually and patients at high risk at least 2 to 3 times per year.\textsuperscript{108} Some clinicians obtain a urine sample at each clinic visit for high-risk patients, though this is probably unnecessary for patients who do not exhibit high-risk behaviors or risk factors.\textsuperscript{4}

Frequency of testing may be intensified if there are clinical signs the patient is having problems managing opioid intake.

The recommended frequency for periodic review of PDMP data ranges from every prescription to every 3 months.\textsuperscript{4} In addition to periodic monitoring, frequency of ongoing PDMP checks may be influenced by various factors that include clinical signs of therapeutic non-adherence and changes in medications or dosages.

Patients who are determined to be at heightened risk for the development of an SUD and for whom alternatives to opioids are not possible may be managed more stringently than other patients. Measures include more frequent clinic visits, shorter intervals between prescriptions, the use of family members or friends to hold and dispense opioids, increased frequency of UDT and PDMP checks, and strong consideration of referrals for management or co-management to pain, addiction, psychiatric, and biobehavioral experts as appropriate. Although patients with histories of SUD, psychiatric illnesses, and family histories of illicit drug, alcohol, and prescription drug use disorders are considered to be at an elevated risk, every patient should receive a level of monitoring in keeping with universal precautions (Box 2).\textsuperscript{111} Bear in mind also that a patient’s level of risk may change due to life stress, progression of disease, relapse to active SUD, and other circumstances.\textsuperscript{111}

### Box 2. Universal Precautions for Opioid Use in the Management of Patients with Chronic Pain

1. Diagnose and treat identifiable pain causes, address pain symptoms, address comorbid substance-use disorders and psychiatric illness.

2. Assess for psychological illness and personal and family substance use disorders, being respectful of a patient’s complaint of pain. Use urine drug testing to aid therapeutic decision making. Refer for assessment of substance use disorders when illicit or unprescribed drug use is found. Patients who refuse such assessment should be considered unsuitable for opioid therapy.

3. Informed Consent should include specifics of substance use disorder, physical dependence, and tolerance, address the patients’ questions about the proposed treatment plan, and cover anticipated benefits and foreseeable risks.

4. Treatment Agreements detail in writing or verbally the expectations and obligations of the patient. May be combined with informed consent.

5. Perform pre- and post-intervention assessments of pain level and function to assess the success of the medication trial in meeting clinical goals. Emphasize that treatment plans are on a trial basis.

6. Select appropriate opioid and adjuvant medications to trial in an individualized regimen, keeping in mind opioids should not be a first choice of treatment.

7. Perform regular reassessment of the patient’s pain level and function, taking input from family and other knowledgeable third parties, and documenting the rationale to continue or change the therapeutic trial.

8. Regularly assess analgesia, activity, adverse effects, aberrant behavior, and affect to direct therapeutic decisions.

9. Perform periodic review of pain diagnosis and comorbid substance use disorders, psychiatric illnesses, and medical comorbidities, changing treatment focus as necessary over time. Success in treating pain with opioids is not likely to be successful in the presence of an untreated opioid use disorder.

10. Perform complete and careful documentation in the medical record of the initial evaluation and each follow-up visit. Remember, if you do not document it, it did not happen.
Difficulties with Opioid Therapy
If patients appear nonadherent to medical direction, intensified monitoring measures may include asking patients to appear for pill counts, greater frequency of UDT and PDMP checks, requiring more frequent clinic visits, or asking family members to take charge of the medications for the patient. Any incidents or unexpected test results should be documented along with the content of patient counseling. If patients show signs of opioid misuse or OUD (dose escalations, frequent losing of prescriptions, ongoing requests for early refills, unauthorized drugs in UDT, obtaining unauthorized prescriptions from multiple providers), the clinician should revisit the treatment plan, refer for specialist management for psychiatric or OUD treatment, and be prepared to humanely and slowly taper opioids, managing any adverse effects and treating pain with nonopioid modalities.112

When prescribing opioids, consider naloxone co-prescription in the presence of certain patient risk factors that include polypharmacy, mental or substance-use disorders, previous overdose, and higher dose (≥50 MME/d).4 If patients experience a nonfatal opioid overdose during pain management, the CDC advises reducing opioid dose and discontinuing opioids whenever possible.4 Clinicians should have in place a plan to discontinue opioids if necessary before beginning an opioid trial.

Documentation with Opioid Therapy
Diligent documentation is essential with opioid therapy to ensure patient safety, show progress toward therapeutic goals, and satisfy relevant medicolegal and regulatory requirements. Some of the recommended items include:109,113

- Medical history
- Results of physical exam, diagnostic, and imaging tests
- Pain intensity and level of functioning
- Results of risk assessment, screening tools
- Description of all treatments provided (date, type, dose, quantity)
- Rationale for opioid therapy (if relevant) and previous treatments
- Informed consent and opioid treatment agreement(s), if relevant
- Prescription of naloxone, if provided, and rationale
- All prescription orders for opioids and other controlled substances
- Record of adverse events
- Results of UDT and PDMP checks
- Instructions to patient, including addressing nonadherence and ongoing discussions of risks vs. benefits
- Assessments of progress toward achieving therapeutic goals

- Notes on consultations with specialists
- Notes on continuing, revising, or terminating treatment
- Authorization for release of information to other treatment providers

Abuse-Deterrent Opioids
The FDA has recognized the development of abuse-deterrent formulations (ADFs) of opioid analgesics as one component of a strategy to combat the opioid crisis while preserving the availability of effective medications for people who require opioids to manage pain.114 Accordingly, the FDA issued guidance to industry to test abuse-deterrent technologies and also announced its intention to scrutinize stringently any proposed opioid products that do not have abuse-deterrent properties.79 At least 10 ADFs have FDA-approved labeling attesting to abuse-deterrent properties:

- OxyContin (oxycodone) from Purdue Pharma
- Targiniq ER (naloxone and oxycodone) from Mundipharma
- Embeda (morphine and naltrexone) from Pfizer
- Hysingla ER (hydrocodone bitartrate) from Purdue Pharma
- MorphaBond (morphine) from Inspiron Delivery Technologies
- Xtampza ER (oxycodone) from Collegium Pharmaceutical
- Troxyca ER (oxycodone and naltrexone) from Pfizer
- Arymo ER (morphine) from Egalet Corp
- Vantrela ER (hydrocodone) from Teva Pharmaceuticals International
- RoxyBond (oxycodone hydrochloride) from Inspiron Delivery Technologies

These formulations incorporate physical barriers designed to deter crushing and chewing, chemical barriers to resist extraction of the opioid in common solvents for injection, or opioid antagonists to block euphoria when a pill is altered. Numerous additional abuse-deterrent technologies are currently in development. In initial postmarketing reports sponsored by drug companies, ADFs appear to be associated with reduced prescription drug abuse; Studies performed to test how much recreational abusers like the drug revealed that lower “drug liking” and “drug high” scores correlated to less abuse and changes in drug-taking behavior.115,116 However, more research is necessary, and the final real-world utility of ADFs is still unknown.

Interdisciplinary, multimodal treatment is well established as superior for pain care over single-modality treatments.14 However, barriers clinicians encounter include:

- Limited time for assessment
- Limited reimbursement for evidence-based therapies and referrals
- Difficulties accessing specialist care

Interdisciplinary pain programs integrate many nonpharmacologic treatments and focus on active management of chronic pain in an opioid-sparing way. The evidence for the programs is good for most pain conditions, but they are not widely available in the United States.117 Nevertheless, resources are available to guide the incorporation of multimodal care in practice, including treatment modules and recommended practices.

ACP Guideline
The ACP graded the evidence from a review of RCTs and systematic reviews and issued the following recommendations to guide treatment of radicular or nonradicular low back pain or spinal stenosis:7

- Recommendation 1 (strong recommendation). For acute (<4 weeks) and subacute (4-12 weeks):
  - Expect improvement over time
  - Nonpharmacologic treatments: superficial heat massage, acupunture, or spinal manipulation
  - Pharmacologic treatment (if desired): NSAIDs or skeletal muscle relaxants

- Recommendation 2 (strong recommendation). For chronic low back pain (>12 weeks), start with nonpharmacologic treatment:
  - Exercise
  - Multidisciplinary rehabilitation
  - Acupuncture
  - Mindfulness-based stress reduction
  - Tai chi
  - Yoga
  - Motor control exercise
  - Progressive relaxation
  - Electromyography biofeedback
  - Low-level laser therapy
  - Operant therapy
  - CBT
  - Spinal manipulation
• Recommendation 3 (weak recommendation, moderate-quality evidence. For chronic low back with inadequate response to nonpharmacologic therapy:
  • First try pharmacologic treatment with NSAIDs (first-line therapy) or tramadol or duloxetine (second-line therapy)
  • If aforementioned treatments fail, consider opioids only if the potential benefits outweigh the risks for individual patients and after a discussion of known risks and realistic benefits with patients

**CDC Guideline**
The CDC states that topical agents are considered first-line, particularly anti-inflammatories for musculoskeletal pain and capsaicin for neuropathic pain. NSAIDs and APAP are among first-line therapies for low back pain and osteoarthritis. First- and second-line therapies for neuropathic pain include anticonvulsants and antidepressants (SNRIs and TCAs). If opioids are used, nonopioid medication and nonpharmacologic treatment should also be prescribed as appropriate.

Multimodal and multidisciplinary therapies combine exercise and related therapies with psychologically-based approaches. These therapies involve coordination of medical, psychological, and social aspects of care and should also be considered for patients not responding to single-modality therapy or those having several functional deficits. Such strategies can reduce long-term pain and disability compared with single-modality care and compared with physical treatments (e.g., exercise) alone.

Disciplines to which clinicians may refer patients for further evaluation and treatment of pain include:
• Board-certified pain specialists for management of complex pain, particularly when medication management is needed
• Physical medicine and rehabilitation specialists
• Sports medicine
• Licensed practitioners acupuncture, massage therapy, osteopathic therapy, and chiropractic care
• Psychologist, psychiatrists, and social workers who specialize in pain care or who can manage comorbid mental health conditions

**The VA Stepped Care Program**
The Department of Veterans Affairs (VA) stepped pain care program is shown in Appendix 1.2. This program demonstrates a levels-of-care approach combining self-management strategies, nonpharmacologic and pharmacologic treatments, and a process for engaging the expertise of other specialties in coordinated care of the patient.

A stepped-care intervention that combined analgesics, self-management strategies, and brief CBT resulted in statistically significant reductions in pain-related disability, pain interference, and pain severity in veterans with chronic musculoskeletal pain.118

**Exercise 1:**

Instructions: Please devote 5 minutes to reading the following clinical scenario then answer the questions that follow.

A 24-year-old man presents in severe pain. Six months ago, while riding his motorcycle, he lost control and ended up in the ditch, injuring his back. Since then, he has experienced severe (7/10) back pain that radiates down his left leg. The patient had an L4/5 microdiscectomy that relieved his radicular symptoms somewhat but only temporarily. His pain is worsened by sitting and is only relieved by lying down. acetaminophen and ibuprofen bring him limited relief, and he has begun to suffer stomach pain from daily doses in excess of 800 mg of ibuprofen. He has a history of panic attacks and tension headaches for which he has never sought treatment. He smokes a pack of cigarettes per day and drinks at least a six-pack of beer every Saturday and Sunday. He says he drinks beer to relieve the stress and pain of working at his call center job, which requires him to sit 8 hours at a time, exacerbating his pain. He admits to illegal drug use (marijuana and cocaine) in college but says he has used neither substance since he left school. His medical exam is normal by cardiopulmonary, gastrointestinal, endocrinologic, and neurologic measures.

1. Would you consider any nonpharmacologic treatment options for this patient? If so, which one(s) and why?

2. Would you consider any nonopioid pharmacologic treatment options for this patient? If so, which one(s) and why?

3. Are referrals necessary and appropriate at this time? Why or why not?

**Patient-Centered Care**

Improving communication between clinicians and patients is critical to safe and effective pain care. Although close to half of all US adults use some form of treatment that could be considered outside of conventional medical care, very few discuss this use with their physicians.119 This lack of communication raises potential problems such as therapeutic interactions and failure to recognize the source of therapeutic benefits or side effects.

A patient-centered approach to structuring pain therapy entails asking patients open-ended questions, listening closely to their responses (including the reasons they express resistance to pain therapy that utilizes nonopioids), and reflecting their concerns back to them using empathic language.2 Treatment combinations should be tailored dependent on patient needs, cost, and convenience, and patients may express much of this during clinic visits, including their financial concerns with paying for treatments. Therefore, necessary clinician knowledge includes how to counsel patients who resist nonopioid therapies in addition to when and how to refer patients for treatment in other specialties. Improving listening and feedback skills will enable clinicians to function in a manner that considers the risks and benefits of all treatment and individualize them to patient need.

**Insurance, Financial Considerations**

The complexity of chronic pain increases difficulty for clinicians, who have limited time with patients, and leads to choices that are most easily prescribed and reimbursed, commonly prescription drugs.4,5 Care provided by physical therapists, psychologists, psychiatrists, and social workers are typically reimbursed by insurance; this would include CBT and other behavioral therapies.5 Care such as acupuncture, massage therapy, and chiropractic service is much less likely to be reimbursed, although this is changing in a few states.5 In addition, 37 US State Attorneys General have petitioned America’s Health Insurance Plans (AHIP) to cover and incentivize nonopioid pain treatments.5 Analyses have shown that nonpharmacologic options such as acupuncture can be cost-effective options in the United States.5,120 In Washington State,
where coverage of licensed providers is mandated, insured patients with back pain, fibromyalgia, and menopause symptoms who used nonpharmacologic therapy providers had lower insurance expenditures than those who did not use them.\textsuperscript{11}

**Exercise 2:**

**Instructions:** Please devote 5 minutes to reading the following clinical scenario then answer the questions that follow.

The patient’s pain has worsened and he has stated nothing works for him except oxycodone ER. His panic attacks have recurred, spiking in frequency to nearly every day. He says his insurance will not cover massage therapy or acupuncture. He claims he has tried yoga at a reduced cost in a local community center, but experienced worsened pain the next day and so stopped classes. He is not open to any forms of relaxation therapy or meditation modalities, as he does not understand how sitting and “doing nothing” will help him. He has begun to call in sick to work at least twice a week, staying home in bed, lying flat, which he says is the only thing that brings him any relief. His most recent UDT is positive for marijuana.

1. What treatments or referrals could be considered for this patient’s panic attacks?

2. Are opioids a viable treatment for this patient? Why or why not?

3. Discuss communication methods and issues in monitoring, following up, and/or referring to other specialists in treating this patient.

**Summary**

Clinical practices in pain management often lack tailoring to the individual patient and over-rely instead on high-risk treatments that include inappropriate prescribing of opioids.\textsuperscript{2} Interdisciplinary and multimodal pain treatment encompasses a broad range of evidence-based nonpharmacologic therapies.\textsuperscript{2} Effective nonpharmacologic therapies are available from licensed professionals in acupuncture therapy, massage therapy, osteopathic manual medicine, chiropractic, physical therapy, and psychology. Other evidence-based modalities that may be directed by instructors or self-engaged include mind-body and movement therapies such as yoga, tai chi, MBSR, stress management, and diet and sleep hygiene changes. When opioids are indicated for chronic pain, stringent risk assessment, monitoring, and documentation processes are necessary. Precise direction on how to structuring delivery of comprehensive pain care has been lacking in medical training. Strategies will be needed to facilitate both access to and coverage of evidence-based nonpharmacologic therapies.
STEP 4
Tertiary, Interdisciplinary Pain Centers
Multidisciplinary Pain Medicine Specialty Teams; Rehabilitation Medicine; Advanced pain medicine diagnostics and interventions;

STEP 3
Secondary Consultation
Multidisciplinary Pain Medicine Specialty Teams; Rehabilitation Medicine; Behavioral Pain Management; Mental Health/Substance-Use Disorder Programs

STEP 2
Patient Centered Medical Home in Primary
Routine screening for presence and severity of pain; Assessment and management of common pain conditions; Support from MH-PC Integration; OEF/OIF, and Post-Deployment Teams; Expanded care management; Pharmacy Pain Care Clinics; Pain Schools

STEP 1
Self-Care
Nutrition/weight management, exercise/conditioning, and sufficient sleep; mindfulness meditation/relaxation techniques; engagement in meaningful activities; family and social support; safe environment/surroundings

CARF International is an independent, nonprofit accreditor of health and human services.
MH-PC = mental health-primary care
OEF/OIF = Operation Enduring Freedom/Operation Iraqi Freedom
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1. Interdisciplinary pain care:
   A. Is reimbursed by most insurances
   B. Is a method using treatment modalities that lie outside conventional medical care
   C. Is team-based delivery of care from multiple disciplines
   D. Is a method of medication management using nonopioid pharmacologic treatments

2. Which of the following medications has gastrointestinal bleeding as a possible side effect?
   A. Duloxetine
   B. Nonsteroidal anti-inflammatory drugs
   C. Oxycodone
   D. Gabapentin

3. A recommended treatment option for localized neuropathic pain is:
   A. Fentanyl patch
   B. Lidocaine patch
   C. Spinal manipulation therapy
   D. Heat packs

4. First-line pain treatment options to suggest for patients who are constrained by costs include:
   A. Spinal cord stimulation
   B. Massage therapy
   C. Weight loss, stress management, mindfulness meditation
   D. Medication management optimizing anticonvulsants

5. An example of a rare serious adverse event with spinal manipulation is:
   A. Muscle soreness
   B. Gastrointestinal perforation
   C. Blurred vision
   D. Stroke

6. When a trial of opioid therapy is under consideration:
   A. It should be combined with nonopioid and nonpharmacologic therapies
   B. It should be optimized prior to NSAIDs therapy to minimize cardiac risks
   C. It should be undertaken primarily in older patients
   D. It is not recommended in combination with movement therapies such as tai chi and yoga

7. Risk mitigation for opioid therapy includes:
   A. Assessing the patient for risk of opioid-use disorder
   B. Co-prescribing an anti-nausea medication
   C. First ensuring that epidural injections are not effective for the patient’s pain
   D. Making opioid therapy contingent on the patient engaging in exercise therapy

8. Which of the following options may be considered as a second-line option for treating chronic low back pain without radicular symptoms?
   A. A long-acting opioid as needed
   B. A thorough psychological evaluation followed by a trial of a spinal cord stimulator
   C. Duloxetine
   D. Low-dose hydrocodone/acetaminophen twice daily

9. When a new patient resists treatment with nonopioid therapies, an appropriate response is to
   A. Refer the patient for psychological evaluation
   B. Explain that treatment may be terminated if parameters of treatment are not met
   C. Listen carefully for reasons the patient is opposed
   D. Initiate a trial of opioid therapy with careful monitoring controls

10. Nonpharmacologic treatments usually reimbursed as part of conventional care include:
    A. Massage and cognitive behavioral therapy
    B. Cognitive behavioral therapy and physical therapy
    C. Guided imagery and progressive relaxation
    D. Yoga and acupuncture
TARGET AUDIENCE

This course is designed for all physicians (MD/DO), physician assistants, nurse practitioners and other healthcare professionals who seek to improve communications and assessment of domains for palliative/end-of-life care.

COURSE OBJECTIVE

Physicians and other healthcare professionals are constantly striving to improve care for patients in their final phase of life. This educational activity reviews areas for improvement in assessment of domains of palliative/end-of-life care and communications between other healthcare providers, patients and families.

LEARNING OBJECTIVES

Completion of this course will better enable the course participant to:

1. Discuss which domains of palliative care can be formally assessed with a validated tool and which domains are not yet covered in assessment tools.
2. Explain the indicators of collaborative and compassionate palliative/end-of-life care and how these factors can be incorporated into these settings.
3. Illustrate the need to incorporate patients’ values into discussions regarding palliative/end-of-life care as patients’ treatment preferences and values can conflict.
4. Summarize the roles specific family members take in end-of-life decisions and the influences of age and gender of members, and family structure and dynamics in this process.
5. Describe the specific barriers physicians face to holding discussions regarding end-of-life care and areas of focus for physician training and other measures to help overcome these barriers.

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Introduction

Over the next two decades, the number of elderly persons (i.e., aged 65 years and older) in the United States is projected to double to 70 million. Although the aging of the baby boomer population will greatly contribute to growth of the elderly population, longer life spans play a key role in this trend. For many persons, this increase in life expectancy is accompanied by the burden of chronic illness(es) in their later years. End of life in this scenario of chronic illness(es) is characterized by progressive physical decline and reduced quality of life.1

Modern end-of-life care can be traced back to the pioneering working work of Dame Cicely Saunders, who established the first hospice, St Christopher’s Hospice in south London. The guiding principle of hospice care is that terminally ill patients receive pain and symptom management and compassionate care. The term “hospice” is now used to refer to the facility providing end-of-life care, to end-of-life care, and the final phase of palliative care.2

The World Health Organization defines palliative care as a comprehensive approach for raising the quality of life for patients with life-threatening illnesses and their families. Inherent in this holistic approach is the treatment of pain and physical symptoms and the provision of support for other aspects of serious illness including psychosocial and spiritual aspects.3

This CME activity has been compiled in alignment with gap areas identified in care at the end-of-life. The following six sections, in aggregate, are to inform clinicians about assessment and indicators of domains of palliative/end-of-life care and to improve discussions about end-of-life care between providers and patients and their family members.

Measurement of the quality palliative care is confounded by the variety of domains that must be assessed.4 The first section covers the Agency for Healthcare Research and Quality (AHRQ) brief that categorizes more than 150 tools for assessing domains of palliative care. Furthermore, the text identifies gaps in assessment tools (eg, spiritual, structure and process, ethical and legal, or cultural domains, patient-reported experience subdomain), and suggests focus for future research.

The multiple domains of palliative/end-of-life care require an interdisciplinary, collaborative approach by healthcare providers and allied professionals.5 Consistent provision of collaborative care in many medical settings remains an elusive goal.6 Delivery of compassionate care also frequently fails to meet patients and providers expectations.7 The second section, Compassionate Collaborative Care, proposes that compassionate care is a necessary component for integrating and maintaining collaborative care in end-of-life care settings.8 This segment reviews indicators of collaborative and compassionate palliative/end-of-life care and provides guidance on how compassion and collaboration can be incorporated in these settings.

A primary-care based survey of elderly patients in the United States found that approximately half had engaged in advance care planning (ACP).9 According to multidisciplinary panel of international ACP experts: “The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.”10 In the third section of this monograph, a study that shows discrepancies between patients’ preferences and values regarding treatment in the end-of-life care setting and the need for greater communication and planning for end-of-life care is described.

The literature on end-of-life decision-making highlights the importance of communication between healthcare providers and family members, but little attention has been paid to the manner in which family members interact and take on roles in this process.11 Providers and care teams need to understand roles family members may play making decisions regarding end-of-life care. The fourth section of this monograph investigates the roles specific family members take in end-of-life decisions including influences of age and gender of members, family structure, and dynamics on who takes on these roles.

Conversations between patients and their healthcare providers regarding end-of-life care can improve patients’ experiences. The Coping with Cancer study - an NCI/NIMH-funded, longitudinal, multi-institutional study of advanced cancer patients showed that patients who had these discussions were more likely to receive hospice care and have longer hospice stay and had less physical distress in the last week of life than patients who did not discuss end-of-life care with their physicians.12 Unfortunately, physicians may not receive adequate training to hold these conversations.13 The last section describes a study of the difficulties providers experience during discussions about end-of-life care with patients, highlights situations of particular challenge such as conversations with patients whose ethnicity differs from their own, and discusses the need for planning and developing tactics to overcome specific types of barriers to effective communication in these situations.
Section 1

Hospices are required by the Center for Medicare and Medicaid Services to participate in the Hospice Quality Reporting Program (HQRIP) and the Hospice Experience of Care Survey. In contrast, there are no requirements for reporting quality of end-of-life care provided by palliative care programs, accountable care organizations, and large medical systems. Measurement of the quality of palliative care is confounded by the multiple, complex domains that must be assessed. This first section reviews assessment tools for measuring the quality of the domains of palliative care.

Assessment Tools for Palliative Care

Background

Palliative care is defined as care that provides relief from pain and other symptoms and supports quality of life for patients with serious advanced illness and their families.1 Over the last decade, a multi-professional group published consensus guidelines that define the domains that palliative care should address (Figure 1).2 Because palliative care is fundamentally concerned with the patient/caregiver experience, the best way to assess these domains involves patient and/or caregiver reports.

Therefore, valid and responsive patient and caregiver assessment tools addressing all domains are essential to measuring the quality and effectiveness of palliative care.

We defined an assessment tool as a data collection instrument (generally a scale, questionnaire or survey) that has been psychometrically evaluated, is completed by or with patients or caregivers, and collects data at the individual patient or caregiver level. Assessment tools may include patient and caregiver reports of physical symptoms (e.g., pain and dyspnea), mental health issues (e.g., depression), caregiver outcomes (e.g., quality of life and burden), and processes of care (e.g., communication and continuity). For conceptual ease, palliative care assessment tools can be categorized by the eight domains defined within the National Consensus Project Guidelines (Figure 1)2 as well as by a ninth domain for palliative care assessment tools that are intrinsically multidimensional (i.e., tools that assess quality of life or patient experience). The multidimensional domain tools include items that cross multiple domains and often address areas such as physical health and functional status, mental health, social and role function, as well as physical and psychological symptoms (i.e., Edmonton Symptom Assessment Score,1 Memorial Symptom Assessment Score,3 etc.).

Each of the domains may also have subdomains, such as the subdomains of pain, dyspnea, or fatigue which are within the overarching physical domain.

Palliative care assessment tools may be used for varying applications within palliative care. Assessment tools may be used by providers in clinical care to directly assess symptoms or other issues with patients or families. Assessment tools may also be used as quality indicators, defined as population-based measures that enable users to quantify the quality of an aspect of care by comparing it to evidence-based criteria.3 Finally, assessment tools may be used in research studies to evaluate the impact of a specific palliative care intervention(s).

Exploration of assessment tools across three applications - clinical, quality indicators, and intervention is important because a tool’s utility may vary by its application. For example, measuring aspects of care important for research-related, academic inquiry may not be important, or even feasible, in clinical care delivery. Assessment tools to be primarily used in clinical care settings are optimally simple and brief to facilitate ease of completion by a seriously ill patient and/or a frequently-overswhelmed family member. In contrast, assessment tools to be used primarily to evaluate interventions may be lengthier and/or specific to

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3. Assessed on December 1, 2018.
targeted intervention related domains of palliative care; when optimal, these tools are both highly responsive (sensitive to change) and reliable to facilitate detection of intervention-related outcome variations.

Ultimately, palliative care assessment tools should be reliable, valid, and responsive assessments of aspects of care that are important to patients and caregivers. These tools should also be particularly responsive to palliative care interventions as well as easily administered in palliative care populations and settings. Given these goals, researchers and others seeking to improve the quality of palliative care face two challenges (1) determining whether there are sufficient tools to address all palliative care domains and applications, and (2) determining, for each domain and application, which tools are the most appropriate for use as determined by reliability, validity, and responsiveness.

Over the past 15 years, various groups have published compilations of palliative care assessment tools to try to address the challenges of measurement. In the mid-1990s, Teno et al. published a Toolkit of Instruments to Measure End-of-Life Care (TIME). In 2004, for the National Institutes of Health State of the Science Conference on Improving End-of-Life Care, the End of Life Care and Outcomes systematic review updated the TIME review and summarized the psychometric properties of 99 additional, relevant assessment tools and their use in assessing palliative care interventions. The PEACE Palliative Care Quality Measures project then updated the End of Life Care and Outcomes review through February 2007 and reported on a select number of tools.

Since the PEACE project in 2007, no reviews have addressed the use of assessment tools across palliative care domains, although additional tools have been developed and applied in these domains. Subsequent systematic reviews have addressed a few individual domains and some multidimensional domains (e.g., quality of life); however, these reviews have not been synthesized into a comprehensive overview of the field.

Given that these tools are frequently used together or overlap in measured concepts, and given the growth of the field of palliative care in clinical scope and research over the past ten years, an integrated overview of assessment tools is valuable. This overview would also: identify domains that lack sufficient assessment tools; highlight areas for future research; and provide a resource for individuals choosing tools for use in clinical care, quality indicators, or intervention settings.

Objectives of This Technical Brief

Our objectives are to provide a comprehensive overview of palliative care assessment tools that could be used by stakeholders interested in the use of palliative care assessment tools for application in clinical care, as quality indicators, or for evaluation of interventions.

We also sought to identify evidence gaps and suggest next steps for future research about palliative care assessment tools.

Guiding Questions

Our work was guided by the following questions:

Guiding Question 1: What data exists regarding the application of these tools specifically in clinical care, as quality indicators, or for evaluation of interventions?

Guiding Question 2: What are the key gaps in tool development and evaluation and what are the opportunities for future research?

Results

Summary of Engagement with Key Informants

We engaged nine Key Informants: two caregivers and seven clinicians/researchers who are experts in palliative care and assessment tools in areas including oncology, geriatrics, pediatrics, critical care, hospice, tool development, palliative care quality indicators, and evaluation of palliative care interventions.

Caregivers

Both caregivers reported completing numerous written questionnaires with “tons of questions,” which overwhelmed them and became so granular that the caregivers felt they could not provide an accurate depiction of their experience and the issues that mattered most to them. Caregivers also felt that the way the assessments were administered “always felt rushed” in that they did not have time to reflect on the questions and often just indicated “their initial thoughts” or just “bubbled in an answer”. They felt that the information captured in the tools was meaningful to clinicians, but they were not convinced the tools impacted patients or families.

To enhance the efficacy of detailed assessment tools, the advocates suggested that any encounter or survey should start with a question to identify the patient or family member’s unique “biggest concern,” and surveys or questionnaires should ultimately empower the patient or family member to “say what is on his or her mind.” For example, one caregiver supported her mother while she took care of her stepfather. The mother’s biggest concern was learning how she could keep her husband at home until the end of his life; this concern was not otherwise a priority for the physician.

Providers

Discussions with providers were focused on their experiences with the assessment tools. Many felt that these tools were being used appropriately in research but they were not used often enough in clinical care delivery or as quality indicators. Providers agreed that the eight domains and the “cross domains” category (multidimensional area) added by this team were valid, but they noted that more specificity is required in each domain and that the domains still do not address some crucial aspects of palliative care (e.g., overall scale of experience, advance care planning, and informed decision making). They specifically noted that there are few tools that assess the spiritual domain. They noted significant confounding between the care delivered and the experience of that care, as well as difficulty in assessing communication (including disagreement about whether communication is a process or an outcome).

The providers noted several issues related to the successful use of assessment tools. First, owing to their illnesses, patients are often unable to complete complex or lengthy assessment tools. Second, assessment tools as quality indicators are an inherent contradiction, which may result in poor or easily misconstrued measurements: “successful” palliative interventions do not typically lead to an improvement in assessment tool-based scores but, rather, to a slowing in the decline of impairments. Third, many tools include “ceiling effects” with consequent limitations in responsiveness or ability to detect change, particularly in patient experience metrics. Fourth, if used as quality indicators, some assessment tools could unintentionally incentivize actions that are detrimental to patient care, such as treating pain aggressively to bring down pain scores included in the tools, rather than balancing pain management with risks and harms of treatments, such as sedation, that are not included in the tools.

Finally, the providers also raised concerns that long, detailed assessments are often not completed and, thus, cannot capture a global assessment of the patient’s actual clinical experience.
Systematic Review and Supplemental Searches

For the systematic review search, we identified 354 unique citations, of which 40 systematic reviews were eligible for inclusion. From these, we selected ten recent high-quality systematic reviews: seven addressing domains of palliative care and three addressing applications of palliative care assessment tools. (Note: the systematic review for interventions, published after our search date, was brought to our attention by one of our advisors).

For three (physical, care at the end of life, and multidimensional) of the nine domains we identified key subdomains (Figure 1). For the physical domain, these key subdomains are pain, dyspnea, and fatigue. For the care at the end of life domain, the key subdomain was bereavement. For the multidimensional domain, we determined the key subdomains to be quality of life and patient experience. Only one domain (social) and one subdomain (bereavement) had systematic reviews with search strategies that were less than three years old such that we did not complete a supplemental search. Two domains (psychological and psychiatric; spiritual, religious, and existential) and three subdomains (dyspnea; quality of life; patient experience) had systematic reviews with search strategies greater than three years old and thus required supplemental searches. Three domains (structure and process; cultural; ethical and legal) and two subdomains (pain; fatigue) lacked any recent systematic review. There was only one domain (cultural) for which we identified no tools through either systematic reviews or our supplemental search, including a targeted search of PubMed.

We identified a total of 152 tools; 97 tools were identified from systematic reviews, and supplemental searches identified an additional 55 tools.

State of Research on Assessment for Domains (3-9) and Key Subdomains

Domain 3: Psychological and Psychiatric

The Ziegler 2011 systematic review included eight tools that met our inclusion criteria. Tools were tested in the following settings: inpatient and outpatient care and a palliative care unit, and included cancer patients with advanced disease and cancer patients at the time of first cancer recurrence. The tools addressed depression, anxiety, distress, and psychological response to cancer. No tools had data on responsiveness or usability (time to complete); one tool had data on internal consistency reliability and seven tools had data on convergent validity in the palliative care population.

Because the search from the systematic review for this domain was greater than three years old and addressed only cancer, we completed a supplemental search that yielded 18 additional tools.

Domain 4: Social Aspects of Care

The Michels 2016 systematic review included eight tools that met our inclusion criteria: caregiver-reported assessment tools that addressed outcomes of informal caregivers (i.e., caregiver burden, strain and quality of life). The review reported information on internal consistency reliability for all tools, convergent validity for seven tools, and responsiveness for three tools. The assessment tools ranged from 13 to 35 items, with only one tool with information on usability (time to complete). As the systematic review was published in 2016, we did not conduct a supplemental search.

Domain 5: Spiritual, Religious, and Existential

The Selman 2011 systematic review identified two tools that met our inclusion criteria. Of note, the review collected and described assessment tools for spirituality as defined by “religious faith as well as existential/humanist positions” and “applicable to all human beings” and no specific target population was pre-identified for the search. The two tools, The Beck Hopelessness Scale and the Ironson-Woods Spirituality/Religiousness Index, specifically address spirituality and are evaluated in an ethnically diverse U.S. palliative care population (i.e., the Beck Hopelessness Scale was validated in populations including AIDS patients and hospice inpatients with cancer; the Ironson-Woods Spirituality/Religiousness Index was validated in an HIV/AIDS population). Both tools had information on internal consistency reliability, convergent validity, criterion or discriminant validity, and responsiveness but no information on usability (time to complete).

Because the search from the systematic review was more than three years old, we completed a supplemental search, but did not identify any additional tools.

Domain 6: Cultural

The cultural domain refers to whether care is sensitive to a patient’s culture, race, or ethnicity. We identified no existing systematic review or eligible tools that focused on the cultural domain. In addition to completing the supplemental search, we also evaluated whether any of the tools addressing the multidimensional domain had items that addressed the cultural domain, and none did.

Domain 7: Care at the End of Life

The care at the end of life domain includes multiple subdomains such as bereavement, quality of death, symptom scores immediately prior to death, or caregiver assessments of the quality of death. Based on subdomains addressed in previous reviews, we selected the key subdomain of bereavement.

Subdomain: Bereavement

The Sealey 2015 systematic review identified 17 tools that met our inclusion criteria. The review did not define settings where the tools are tested, and tools are only for bereaved adults and caregivers (not patients). Some tools addressed specific patient populations (e.g., patients with dementia, cancer, trauma, or in hospice) or specific caregiver populations (e.g., spouses or those with prolonged grief disorder). The tools are designed for pre-death bereavement risk, after-death bereavement assessment, or for the assessment of complicated or prolonged bereavement. All tools had information on internal consistency reliability. Three tools had data on convergent validity. None of the tools had data on responsiveness, and only two had data on usability (time to complete). The number of items ranged widely from five to 91 items.

We did not conduct a supplemental search because the systematic review search strategy was conducted through 2014.

Domain 8: Ethical and Legal

We did not identify any systematic reviews focusing on tools addressing the ethical and legal domain.

We completed a supplemental search which identified two eligible tools, the Relatives’ Patient Management questionnaire and the Willingness to Accept Life-sustaining Treatment instrument.

Domain 9: Multidimensional

Multidimensional tools can include subdomains such as quality of life, patient experience, or satisfaction with care. Based on subdomains addressed in previous reviews, we selected the two key subdomains quality of life (which may include areas such as physical health and functional status, mental health, social and role function, and physical and psychological symptoms) and patient experience.
Life Care.

The Albers 2010 systematic review identified 28 tools that met our inclusion criteria. The tools were developed for and evaluated in hospice, home care, outpatient and inpatient settings (including palliative care units), and long term care. Populations included palliative care patients, seriously ill patients, cancer patients, and patients near the end of life. Many tools contained items that addressed most domains, including structure and process (four tools), physical (21 tools), psychological and psychiatric (20 tools), spiritual, religious and existential (11 tools), social (11 tools), ethical and legal (six tools) and care at the end of life (two tools). No tools contained items that addressed the cultural domain. All tools had data on internal consistency reliability, while 27 had data about convergent validity, seven had data on responsiveness, and 14 had data on usability (time to complete).

As the search from the systematic review was greater than three years old, we completed a supplemental search but identified no additional tools.

Subdomain Patient Experience

The Lendon 2015 systematic review identified eight tools that met our inclusion criteria. Six tools only addressed the caregiver’s perception of the patient’s quality of end-of-life care, and two addressed the patient’s or the caregiver’s perception. The tools had a range of 25-74 items and contained items that addressed most domains, including structure and process (six tools), physical (seven tools), psychological and psychiatric (seven tools), spiritual, religious and existential (seven tools), social (five tools), and are at the end of life (five tools); we could not determine from the review whether ethical and legal and cultural domains were addressed. Six tools had information on internal consistency reliability. Four had information on convergent validity. None had data on responsiveness or usability (time to complete).

Because the search from the systematic review was more than three years old, we completed a supplemental search which identified one additional tool, the Caregiver Evaluation of Quality of End-of-Life Care.

Applications of Assessment Tools

(Guiding Question 1)

Clinical Care

The Antunes 2014 systematic review evaluated the use of patient-reported outcome measures in clinical care in adults in palliative care settings and found 31 studies evaluating implementation issues. Six studies are conducted in the U.S. and reported on the use of specific assessment tools. The six tools used in these studies included multidimensional tools (quality of life tools, three studies), physical (numerical rating or visual analog scales for pain, two studies), and psychological or psychiatric (one study). We identified four of these tools in systematic reviews (The Edmonton Symptom Assessment Scale, Missoula-VITAS Quality of Life Index, Memorial Symptom Assessment Scale, and Functional Assessment of Chronic Illness Therapy-Lung) and two in our supplemental searches (Numeric Rating Scale for Pain, and Visual Analogue Scale for Pain). Settings included hospices, cancer centers, nursing homes, emergency care, and home. Most clinical care was of cancer patients.

Quality Indicators

The De Roo 2013 systematic review evaluated quality indicators developed specifically for palliative care. This review identified ten U.S. indicator sets. However, only one indicator specified a palliative care assessment tool (most are indicators abstracted from the medical record, rather than reported by or with patients or caregivers).

The one palliative care assessment tool, Family Evaluation of Hospice Care, was a multidimensional tool assessing patient experience, which we identified from the patient experience systematic review (Lendon, 2015).

Evaluation of Interventions

The Kavalieratos 2016 systematic review evaluated assessment tools used in randomized controlled trials of palliative care interventions in adults with terminal or life-limiting illness. In the 43 included studies evaluating palliative care interventions, the authors found 23 palliative care assessment tools that are used to evaluate the interventions related to the physical domain (seven tools), psychological and psychiatric domain (six tools), patient experience (two tools), or quality of life (six tools). The most commonly used physical domain palliative care assessment tool was the Numeric Rating Scale for Pain, but this was used in only four of the studies. The most commonly used palliative care assessment tool for the psychological and psychiatric domain was the Hospital Anxiety and Depression Scale, which was used in only six of 27 studies evaluating this domain. For multidimensional tools, the most commonly used palliative care assessment tool for quality of life was the Edmonton Symptom Assessment Scale, which was used in only five studies. Two studies used two different multidimensional patient experience palliative care assessment tools (Table 1).

Discussion

(Guiding Question 2)

We identified 152 different palliative care assessment tools with varying psychometric properties reported across eight of the nine domains of palliative care. While some domains and subdomains (dyspnea; psychological and psychiatric; social; bereavement) had many assessment tools, other domains had few (spiritual, religious, and existential; ethical and legal) or no (cultural) tools. Few tools addressed usability (time to complete). Moreover, the burden associated with tools, as evaluated by the number of items in each tool, varied significantly by domain; for example, the mean number of items per tool identified in the systematic review was 24, but domain means varied between: seven items (Dyspnea), 13 items (psychological and psychiatric), 21 items (social), 22 items (spiritual, religious, and existential), 33 items (bereavement), 30 items (quality of life), and 47 items (patient experience).

The key gaps by domain are:

- For the structure and process domain, we identified only two tools through our supplemental search, one on continuity and one on communication. Since our Key Informants identified communication as a key aspect of palliative care, this lack of tools suggests that this is an important area for future tool development

- For the physical domain, we focused on the subdomains of dyspnea, pain, and fatigue. For dyspnea, only eight of the 26 tools had testing of responsiveness (sensitivity to change), which is needed to evaluate the impact of clinical or other interventions. We identified no systematic review that specifically compiled and compared pain assessment tools in palliative care populations. We identified a number of pain assessment tools in our supplemental search, but given the critical importance of this subdomain for palliative care, a detailed systematic review of the evaluation of the use of these tools in palliative care populations and their psychometric testing is needed.
We identified seven tools assessing fatigue but no high quality recent systematic review.

- For the psychological and psychiatric domain, we identified eight tools in palliative care populations, but the scope of the review we found for this domain was limited to patients with cancer. We identified additional tools in our supplemental search that may be relevant. A systematic review to synthesize the properties and relevance of these tools would be useful.

- In the social domain, few of the eight tools were specifically developed for patients receiving palliative care and many potentially relevant tools described in the systematic review had not been tested in palliative care populations. Insufficient or incomplete information was available about the psychometric properties of these tools. Future research comparing these tools and exploring their responsiveness in palliative care populations is needed.

- The lack of tools assessing the spiritual, religious and existential domain is also a key gap, as noted by the Key Informants and confirmed by our search: we identified only two tools that focused on spirituality evaluated in palliative care populations. Further development of spirituality tools for palliative care and testing of existing tools in this population would be valuable.

- We found no assessment tools focusing on the cultural domain, and multidimensional tools also did not address this domain. This domain should be considered for future tool development. Future research is also needed to determine how this domain could be included in multidimensional tools.

- In the care at end of life bereavement subdomain, many of the tools were developed in palliative care populations but the information on validity and responsiveness was sparse. Most tools were also long, with one tool having 91 component items. As emphasized by our Key Informants, short, easy-to-complete tools are important, especially for the bereaved informal caregivers who complete these tools; few simple, low-burden, yet meaningful assessment tools exist.

- For the ethical and legal domain, we identified only three tools in our supplemental search and there were only six multidimensional assessment tools that had items addressing this domain. Future research is needed to both conceptualize and develop specific tools; this could also involve the evaluation of pre-existing items in multidimensional tools.

- The Key Informants emphasized the importance of patient-reported experience (multidimensional domain); however, we found only two tools assessing patient-reported experience (the rest were for caregiver-reported experience).

- Across domains, we identified no high-quality systematic review that addressed palliative care assessment tools for use in pediatric populations.

In assessing the applications for which palliative care assessment tools are used, the systematic review evaluating use of assessment tools in clinical care found only six studies.\(^2\) We did identify one assessment tool being used as a quality indicator\(^3\) in the United States, although this assessment tool from the National Hospice and Palliative Care Organization is no longer in use and has been replaced by the Hospice Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey.\(^4\) (Of note, this technical brief predates the new CMS Hospice Item Set (HIS) of quality indicators, which is being revised at the time of this report.\(^5\))

We identified 23 palliative care assessment tools that were used to evaluate interventions; however, none of these tools was used in more than six of the 43 palliative care intervention studies summarized in the systematic review.

### Table 1. Summary of palliative care assessment tools that are used in 23 studies evaluating palliative care interventions and how often they were used

<table>
<thead>
<tr>
<th>Domain, N Tools</th>
<th>Tool (Number of studies in which tool was used)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical, 7 tools</td>
<td>Numerical Rating Scale for Pain (4)(^1) Chronic Respiratory Disease Questionnaire (1) University of California, San Diego Shortness of Breath Questionnaire (1) Brief Pain Inventory (2)(^1) Pain as Assessed in the Medical Outcomes Study (1)(^1) Visual Analog Scale for Pain (1)(^1) Memorial Pain Assessment Card (1)(^1)</td>
</tr>
<tr>
<td>Psychological and Psychiatric, 6 tools</td>
<td>Center for Epidemiologic Studies Depression Scale (5)(^1) Cornell Scale for Depression in Dementia (1)(^1) General Health Questionnaire-12 Item (1) Hospital Anxiety and Depression Scale (6) Impact of Event Scale (1)(^1) Patient Health Questionnaire-9 (4)(^1) Profile of Mood States (4)(^1)</td>
</tr>
<tr>
<td>Multidimensional Patient Experience, 2 tools</td>
<td>Family Satisfaction with Advanced Cancer Care (16 item version) (1) McCusker Scale (1)(^1)</td>
</tr>
<tr>
<td>Multidimensional Quality of Life, 5 tools</td>
<td>European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-30 Item (2) Edmonton Symptom Assessment Scale (5) Functional Assessment of Chronic Illness Therapy-Palliative Sub Scale (3) Memorial Symptom Assessment Scale (2) McGill Quality of Life Scale (1) Quality of Life at the End of Life (3)</td>
</tr>
</tbody>
</table>

\(^1\) Indicates tool that was found during supplemental search
This lack of standardization may limit the ability to compare and synthesize evidence across studies of palliative care interventions.

**Next Steps**

**Tool Development**

- Research is needed to conceptualize, develop, validate, and test assessment tools that specifically address the following domains and subdomains in palliative care populations: structure and process; fatigue; cultural; spiritual, religious and existential; ethical and legal; and patient experience as reported by patients rather than caregivers.

**Tool Evaluation**

- Some domains and subdomains had multiple tools that were neither tested in palliative care populations nor evaluated for responsiveness. For the spiritual, religious and existential, and social domains, few tools had been developed for or evaluated in palliative care populations. For bereavement subdomain, patient experience, and quality of life, many tools were not only long and thus likely burdensome, but also had not been evaluated for responsiveness.

- Across all domains and subdomains, the following would be helpful: additional evaluation of existing tools in other populations, including pediatric populations (with modifications as needed for palliative care and for non-cancer populations); updates and modifications, as needed (many tools may be out of date and have not been updated or recently tested); and additional testing for validity and responsiveness.

- Further research should also address use of assessment tools longitudinally and across settings and populations.

**Systematic Reviews**

- For the physical domain, a systematic review of assessment tools addressing pain and fatigue in palliative care populations is needed, and an updated review is needed for dyspnea tools.

- For the psychological and psychiatric domain, a systematic review is needed to evaluate tools for conditions other than cancer and to evaluate psychometric properties of tools more broadly.

- For multidimensional – patient experience, a systematic review is needed to evaluate psychometric properties of the tools.

- For all domains, systematic reviews of psychometric properties following guidance of CONsensus-based Standards for the selection of health Measurement INstruments (COSMIN) would be useful. 178

- A high-quality systematic review focusing on the use of tools in pediatrics would also be useful.

**Applications of Assessment Tools**

- More research is needed on the use of assessment tools in clinical care across all domains. This research should include evaluation of the effectiveness of the tools in measuring changes in outcomes, feasibility, and usability in clinical care. It should also include broad input from patient and caregiver perspectives.

- Research is needed on the use of patient-reported assessment tools as quality indicators, including indicators of patient and caregiver experience outside the hospice setting.

- Additional analysis of the appropriateness of tools, particularly across diseases and populations, would help determine which patient and caregiver assessment tools are most useful in the evaluation of different types of palliative care interventions. This analysis could be a large study evaluating many different tools, or could be included as part of the pilot testing for future evaluations of palliative care interventions. This sort of analysis could help to standardize which tools are used and how they are implemented.

- Other organizations may use the survey of tools in this report to provide more specific recommendations for tools; consensus work to recommend tools would be helpful for researchers in palliative care. Such consensus recommendations should include broader input from patient and caregiver perspectives. Further research should also facilitate or clarify consensus about the use of specific assessment tools across settings and populations.

**Limitations**

By using the National Consensus Project Guidelines as a framework for the domains and limiting our Technical Brief to tools evaluated in palliative care populations, we possibly excluded tools that may be relevant in some applications in palliative care populations. We also recognize that other definitions of palliative care exist, and the tools covered in this report do not cover the full scope of potentially relevant populations. The systematic reviews we selected may not have summarized some potentially eligible tools or studies evaluating some properties of these tools.

As we excluded tools that were not specifically studied in palliative care populations, multiple tools assessing the spiritual, religious and existential domain including the Spiritual Well-Being (FACIT-Sp) tool, the Spiritual Well-Being Scale, and the Koenig Religious Coping Index were not included in this report, but may be useful in palliative care research. Similarly, many tools assessing social-caregiver domain have not been evaluated in palliative care populations. This report also focused on caregiver areas of burden, strain and quality of life, and did not include other subdomains relevant to caregivers that might be useful for palliative care.

Another limitation is our reliance on existing systematic reviews. While these systematic reviews were the best ones available, many had incomplete information regarding tool psychometric properties with some information on usability, reliability, and validity but minimal information on responsiveness. Although we did not find much information on responsiveness, a more detailed literature search for each tool would be needed to determine evidence for responsiveness.

Finally, some tools included in this review also have multiple versions that were not always noted in our sources. Future users of these tools should search for and consider different versions that might be more appropriate.

**Conclusions**

While we identified more than 150 assessment tools for palliative care, few tools focused on the spiritual, structure and process, or the ethical and legal domains, or the patient-reported experience subdomain of palliative care, and we found no tool addressing the cultural domain. Moreover, we found few studies assessing the use of tools in clinical practice or as quality indicators. Few studies of palliative care interventions used the same palliative care assessment tools. Future research should focus on further development of tools; evaluating tools in palliative care populations; and evaluating the responsiveness of tools.
Section 2:

Palliative/end-of-life care needs to cover the multiple domains described in the previous article, and it should accomplish this using a compassionate and collaborative approach. It must include a focus on mutual respect and empowerment throughout the team that not only includes providers, but may also include patients, family members, and surrogate decision makers. This model greatly differs from the traditional hierarchy in which decision-making and other powers were concentrated in the physician role. The following section by Pfaff et al describes the compassionate, collaborative care approach in the end-of-life setting.

Compassionate Collaborative Care: An Integrative Review of Quality Indicators in End-of-Life Care

Background

Since the early 2000s, there has been generalized concern over the decreasing state of compassion in health systems across developed countries. Defined as “the recognition, empathic understanding of, and emotional resonance with the concerns, pain, distress, or suffering of others coupled with motivation and relational action to ameliorate these conditions.” Not only is it viewed as a guiding foundation for ethical practice among healthcare professionals and organizations, but also as a cornerstone of quality healthcare by patients, families, clinicians, and policy makers. Emerging evidence shows a relationship among compassionate care, improved patient outcomes and enhanced provider well-being. Despite efforts, compassion remains elusive in many organizations and care settings, and is poorly conceptualized and empirically understood. According to a recent scoping review of the compassion healthcare literature, there is a lack of patient and family data to inform the body of literature. Looking beyond patient and family perspectives and into the team and organization is further required to understand their influence on values and practices.

Collaborative practice has numerous definitions, but the majority agree that it involves multiple disciplines of healthcare team members who work with patients and families to achieve common goals through processes, such as shared communication and decision-making. It is a practice model whose core domain involves a patient and family-centered approach.

Collaborative practice has been shown to improve health outcomes in and across care sectors and settings, and is linked with higher accessibility to care, better chronic disease management, patient safety, and healthy workplaces. Despite a growing body of literature, the integration of collaborative practice continues to lag behind in many healthcare settings.

As an exception, palliative and end-of-life care settings are places where compassionate patient and family centered care is the priority of the interprofessional (IP) team. This led us to theorize that compassion is the lever or ‘missing antecedent’ for fully operationalizing and sustaining collaborative practice in end-of-life care settings.

Compassion is a foundational value underlying the modern hospice movement and a core concept of palliative care. It involves a holistic approach in which IP care providers support patients and families throughout diagnosis, disease stages, death and bereavement.

Compassion is also considered a marker of spiritual care, a facilitator for ameliorating existential suffering towards end-of-life, and an enabler of an integrated patient-centered approach. Nevertheless, there is no robust evidence that describes how to systematically promote and improve the quality of compassionate collaborative care (CCC) in palliative or hospice care settings.

In 2014, the Schwartz Center for Compassionate Healthcare and the Arnold P. Gold Foundation convened an expert panel to recommend timely steps for integrating compassion and collaboration. Panel members included patients, family members, advocates, clinicians, health profession educators, licensure and accreditation agency representatives, funders, and administrators. The Compassionate Collaborative Care Model and Framework was identified as a vehicle for improving health and experiences of care while controlling health-related costs. Making CCC the standard of care in every healthcare organization and patient encounter was agreed upon as the ultimate vision for excellence in healthcare. Although the report identifies the major attributes and provider skills associated with CCC, it provides few steps for its assimilation into healthcare teams, settings, and organizations. Therefore, greater understanding of organizational culture and system change processes is essential.

Without this knowledge, teams and organizations will remain continually challenged to integrate and measure the impact of compassionate collaborative care.

Measuring the quality of care and services through indicators, including patient and family satisfaction, has become increasingly important. According to Schuster and colleagues, key indicators can be measures of structure, process, and outcome, classified according to type of care, function, and modality. For certain conditions, treatments or patient populations, indicators without evidence, based solely on professional consensus, may be all that is feasible. Because growing evidence suggests that practicing with compassion leads to better outcomes, it is important to understand the nature of CCC and its quality indicators. As CCC is philosophically and fundamentally applied in palliative and end-of-life care, this body of literature is theoretically appropriate for examination.

 Aim

The aim of this study was to identify quality indicators of CCC by systematically reviewing and synthesizing the current state of the palliative and end-of-life care literature.

Methods

Whittemore and Knaff’s methodology was chosen given its ability to synthesize literature from a wide range of sources. It involves five phases: problem identification, literature search, data evaluation, data analysis and presentation. Donabedian’s healthcare quality framework, as adopted by Mainz, was used to guide the data analysis phase. A conceptual definition of CCC was created to focus the review.

It was based on the WHO Framework for Action on Interprofessional Education & Collaborative Practice and the Compassionate Collaborative Care Model and Framework as follows:

Compassionate collaborative care (CCC) is a process through which caregivers from different professional and non-professional backgrounds work together with patients and families to deliver care that recognizes, understands and responds to concerns, pain, distress, or suffering, with the aim to promote positive patient-family-team, and organizational outcomes across healthcare settings.

Literature search

The following online databases were searched for relevant key terms: Medline, CINAHL, ProQuest, and PubMed. Numerous search terms were used in various combinations. These terms were identified from a preliminary review of the literature and author expertise, and included the following algorithm: (interprofessional OR interdisciplinary OR multidisciplinary OR transdisciplinary) AND (collaboration OR cooperation OR practice OR teamwork OR care OR caring) AND (compassion or empathy or sympathy) AND (hospice OR palliative OR end-of-life OR end of life). Truncation and wildcard symbols were applied to maximize retrieval of related reports.
Inclusion criteria were as follows: peer-reviewed, published in English, original research, systematic review, literature review, case study, conference proceedings, or position statements. The settings of interest were acute care, hospice palliative care, and long-term care. Given the conceptual nature of the review, there was no limit on publication date. We excluded studies that did not meet the inclusion criteria reported above.

Studies conducted in home or community settings were also excluded given the heterogeneity in their structures and processes.

The literature search produced a total of 296 citations. The removal of 22 duplicates left 274 citations for title and abstract screening. Two hundred and eighteen articles were rejected during title and abstract screening.

This number included one article (dated 1987) that was not accessible from library and digital sources. The title and abstract screening process produced 56 articles that were eligible for full manuscript screening. During the full manuscript review phase, 31 articles were rejected, resulting in a final literature sample of 25 articles. Outcomes of the literature search and screening procedures are reported in Fig. 2.

**Data analysis**

The process by which data analysis and synthesis was conducted is displayed in Fig. 3. It involved an iterative process that applied a constant comparative method throughout data abstraction, reduction, display, conclusion drawing, and verification stages. We continually focused on the research question and the adopted conceptual definition of compassionate collaborative care throughout the analysis. The process involved two phases: (1) literature abstraction and (2) data reduction and display. To achieve consistent coding and categorization of the data, the researchers met weekly to compare and agree on the attribution of the data.

**Literature abstraction**

During the literature abstraction phase, data that described the structures, processes, and/or outcomes of CCC were abstracted verbatim to an Excel file to facilitate coding, categorization, and sharing. The following definitions, stemming from Mainz, were applied as codes for the quality indicators:

- ‘Structure’ denotes the attributes of settings where care occurs. It refers to health system characteristics that affect the ability to meet the

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<thead>
<tr>
<th>Figure 2. Literature Search and Conclusion</th>
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<tr>
<td>Records identified through database searching</td>
</tr>
<tr>
<td>CINAHL = 53; Medline = 75; ProQuest = 167; PubMed = 1</td>
</tr>
<tr>
<td>Total records identified (n = 296)</td>
</tr>
<tr>
<td>Duplicates removed (22) (n = 22)</td>
</tr>
<tr>
<td>Titles and abstracts screened (n = 274)</td>
</tr>
<tr>
<td>Records excluded (n = 218)</td>
</tr>
<tr>
<td>Full-text articles assessed for eligibility (n = 56)</td>
</tr>
<tr>
<td>Full-text articles excluded (n = 31)</td>
</tr>
<tr>
<td>Studies included in integrative review (n = 25)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Figure 3. Phase Two Data Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data abstracted verbatim from articles and organized as structures, processes, outcomes based on a priori definitions</td>
</tr>
<tr>
<td>Data re-categorized into nine cell literature abstraction matrix (structures, processes, outcomes x individual, team, and organizational levels) Data checked for appropriate categorization and revised based on consensus</td>
</tr>
<tr>
<td>Conceptually important and recurrent indicators within each cell noted by individual researchers and codes attached Overarching categories identified based on data saturation across all levels</td>
</tr>
<tr>
<td>Remaining data re-categorized within each of the nine cells Data constantly compared and reduced to produce key indicators DeData</td>
</tr>
<tr>
<td>Data checked against framework to ensure that there were no omissions Framework revised accordingly and final indicators agreed upon</td>
</tr>
<tr>
<td>Range Overarching structures, values, processes and key indicators described in the narrative with illustrative quotes</td>
</tr>
</tbody>
</table>
health care needs of individual patients, families, or a community. Structural indicators describe the type and amount of resources used (i.e. staff, clients, money, beds, supplies, buildings) in order to answer whether care is provided under favorable or unfavorable conditions to good care.

‘Process’ denotes what is actually done in giving and receiving care. Processes are a series of interrelated activities undertaken to achieve objectives. Process indicators measure the activities and tasks in patient episodes of care. For some researchers, seeking care and carrying it out are also viewed as process indicators.

‘Outcome’ describes the effects of care on patient and/or population health status. These may include knowledge improvement, changes in behavior and ultimately, satisfaction with care. Outcome indicators are states of health or events that follow care and should be evidence-based.

Data reduction and display

The data from phase one were further abstracted for reduction and display across the patient-family-provider, the team, and the organization levels. As the analysis proceeded, the cell descriptors were refined to best fit the data. The data were further reduced into sub-categories within each of the cells.

This also involved a rigorous and iterative process of comparing data points within each cell to all other data in each cell.

Data presentation

A narrative summary of the synthesized findings with exemplar data sources is also consistent with Whittmore and Knafli’s integrative review method. It is presented in the results section. The overarching categories and sub-categories that reflect key indicators (structure, process, outcomes) of CCC at the individual, team, and organizational levels are displayed in Table 2.

<table>
<thead>
<tr>
<th>Table 2. Data reduction and CCC operational framework</th>
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</thead>
<tbody>
<tr>
<td>CCC Indicators</td>
</tr>
<tr>
<td>Structures</td>
</tr>
<tr>
<td>Patient-Family Values &amp; Expectations</td>
</tr>
<tr>
<td>• Commitment</td>
</tr>
<tr>
<td>• Dignity</td>
</tr>
<tr>
<td>• Supportive care</td>
</tr>
<tr>
<td>-Continuous</td>
</tr>
<tr>
<td>-Non-judgmental</td>
</tr>
<tr>
<td>Provider Needs &amp; Expectations</td>
</tr>
<tr>
<td>• Commitment</td>
</tr>
<tr>
<td>• Support</td>
</tr>
<tr>
<td>• Education</td>
</tr>
<tr>
<td>Processes (tools / mechanisms)</td>
</tr>
<tr>
<td>• Symptom management</td>
</tr>
<tr>
<td>• Spiritual care</td>
</tr>
<tr>
<td>• Transitional care</td>
</tr>
<tr>
<td>• Advance care planning</td>
</tr>
<tr>
<td>• Bereavement care</td>
</tr>
<tr>
<td>• Bereavement rounds</td>
</tr>
<tr>
<td>• Schwartz Rounds</td>
</tr>
<tr>
<td>Informal Impromptu communication</td>
</tr>
<tr>
<td>(hallway, telephone)</td>
</tr>
<tr>
<td>Outcomes</td>
</tr>
<tr>
<td>Patient-Family Development and Satisfaction</td>
</tr>
<tr>
<td>• Self-care</td>
</tr>
<tr>
<td>• Coping</td>
</tr>
<tr>
<td>• Holistic care</td>
</tr>
<tr>
<td>• Dignity and “being known”</td>
</tr>
<tr>
<td>• Patient-provider relationships</td>
</tr>
<tr>
<td>Provider Development and Satisfaction</td>
</tr>
<tr>
<td>• Patient-family goal achievement</td>
</tr>
<tr>
<td>• Self-compass</td>
</tr>
<tr>
<td>• Self-care</td>
</tr>
</tbody>
</table>
Results

Overarching findings

Based on data from 19 of 25 articles, our analysis revealed ‘patient and family centeredness’ as the primary structure for CCC across the individual, team, and organizational levels. Overarching structural values were: a) empathy, b) sharing, c) respect, and d) partnership. Further to these findings, empathy, sharing, respect, and partnership are values that must be structurally present for CCC to evolve.

In the literature sample, the act of co-suffering, or suffering alongside a patient and family, is demonstrated through compassion presencing, as well as recognizing and acting on the presence of patient-family suffering. You need to know that the people caring for you, whether they can or can’t help you with your disease, honor you for who you are and care about you.

Sharing is manifested when patients, families, and caregivers relate care concerns and preferences, learning needs, decisions, and care experiences. Respect involves careful attention to the patient’s physical and bodily needs, and sharing and verbal emotional support among patient and family members, as well as team members.

Finally, partnership involves forging formal and informal connections between patient, family, the team, organization, and external agencies or resources. Partnerships among patients, families, and providers involve a shared journey, that is not agenda driven and transcends sectors and settings.

Structures

Individual structures

Patients and individuals value, need, and expect holistic and continuous care across the continuum of care. This includes supportive, non-judgemental care in the patient’s home or residential care, as well as team. Time and shared spaces for planning, shared decision-making, and education, with patients and families, are essential as teachers:

"Sometimes it’s learning from the family. Sometimes we’re not the expert. You know your mother. You understand your culture...Help us...so that it’s meaningful for all of us."  

Team structures

Attributes of CCC at the team level include shared values, skills, and resources. Teams must value authentic relationships, a shared team commitment, and a holistic approach that supports bio-psychosocial-spiritual care.

When a resident dies and they leave the home...the staff will line the corridors to say cheerio to them and that includes domestic staff, kitchen staff, everyone...I always go with the undertakers because I want to make sure that the person I’m looking after is still being looked after."

Skills at the team level are relational, and involve active listening, leadership, advocacy, reflection and self-awareness. According to our analysis, human resources and time are key structural indicators at the team level. In particular, the literature sample supports an IP team approach in delivering CCC.

Time and shared spaces for planning, sharing, and debriefing are essential to support CCC among teams.

...time needs to be allocated for this initiative to work, and it needs to be integrated into staff professional development as opposed to being a forum that can be attended only if staff have spare time.”

Organizational structures

Nine articles revealed structural indicators within organizations that support CCC. Among those emphasized how a shared mission and vision for CCC can be influential in driving organizational programs and activities. Leadership is essential for championing and supporting the planning and policies that promote IP and patient-centered care. Support CCC integration.

"Organizational policies should promote and support spiritual compassionate care at the bedside, in the boardroom, and in staff relations." Finally, adequate organizational resources are required for patient and family programs, IP staffing and support across the institution, and compassionate spaces for patients and families.

"We try to create a home-like rather than an institutional environment.... When everything is right, we’re sending a message that we do care..."

Processes

Three overarching processes emerged at the individual, team, and organizational levels. These are: 1) communication, shared decision-making and 3) goal setting. Not only do these processes bridge all levels, our analysis suggests that they may enable several CCC sub-processes among patients, families, teams, and organizations.

Individual and team processes

The sub-processes associated with CCC were similar across the individual and team levels: pain and symptom management, care rounds, case conferences, consultations and referrals, spiritual care, advance care planning, transitional care, and bereavement care. These processes can be developed and sustained:

“The more formal venues, such as the rounds or the chemo meetings, are not just meetings where we talk about what therapy someone’s on, they become, “Oh my God. She is 38. She has two kids, and she has cancer.”

SCR provides a venue for sharing the emotional work of caring with other carers, and this sharing can support CCC.

"For the responsible and empathic practice of medicine, health-care providers have to engage in the routine process of reflecting, self-monitoring,
processing emotion, and coping with its effects; tasks that are quite challenging without support. We have found the Rounds help to provide that support in 

Organizational processes

Our analysis revealed three sub-processes in organizations that support CCC: 1) strategic planning, 2) policy development, and 3) program development and evaluation. For example, palliative and end-of-life expertise was integrated in a U.S. pediatric hospital through strategic planning and development of a Compassionate Care Network in 19. In several instances, development of programs began with institutional pilot projects, such as the 3 Wishes Project, an integrated psychosocial treatment team, and memorial services. These organizational processes may support the achievement of outcomes that are reported in the next section.

Outcomes

Satisfaction and development emerged as the two overarching outcomes across all three levels. Knowledge and behavioral development occurred across the individual and team levels, whereas satisfaction emerged as a prominent outcome among patients, families, teams, and organizations. Our analysis suggests that indicators of development and satisfaction may be evidenced by integrating the structures and formal processes that are described in the preceding results, however, empirical study is required.

Individual outcomes

Indicators of patient-family knowledge and behaviour development include engagement in self-care, enhanced patient-family coping, reduced fear and depression, and improved quality of life. Patient satisfaction is reflected through "being known" and holistic care by others on the care team. Finally, when compassion and collaboration are integrated in end-of-life care, patients and families report satisfaction with overall care delivery and provider relationships.

"This service is very important because of the intensity by which fear, love, anger, grief, stress, and loss overtake you. By giving compassion and tools to cope, patients and families are helped to love one another and stay connected. This is vital to making the process a healing one.

Provider satisfaction is associated with the achievement of patient end-of-life care goals, including spiritual peace, pain and symptom management, and the provision of patient-family support across the continuum of care through bereavement.

Both cure and healing fall within the responsibility of the health care profession. I think doctors and nurses offer the most powerful kind of healing possible when they really care about someone. You weren't just a pro doing what you had to do. You went beyond being technically competent.

Finally, the ability to engage in self-care and self-compassion are additional prominent indicators of provider satisfaction.

One must acknowledge the losses, accept the pain, strive to move beyond the grief, and then be willing to embrace new relationships guaranteed to include more loss.

Team outcomes

Knowledge development, behavioral development, and team satisfaction are the main team outcomes. Quality indicators of team knowledge development include expertise in managing complex end-of-life care, including pain management and ethical decision-making. Team behavioral development outcome indicators are: effective IP communication, a collective purpose, strengthened team relationships, and enhanced team coping.

The synergy between all those interacting with the patient enhances the overall care and wellbeing of the patient. But it also makes the work of each individual healthcare professional richer in that the contribution of each healthcare member to the treatment plan potentiates each individual contribution. The wholeness is more than the sum of its parts.

According to our analysis, team satisfaction is evidenced through role fulfillment and positive teamwork experiences associated with collectively achieving the patient-family goals of care.

It's really important to bring someone out of the world. I think it's a real privilege to do it. After they have passed away—changing them, laying them out and everything, putting the flowers on and seeing their family's reactions when they see them like that—it makes you feel really proud of what you do.

Organizational outcomes

The findings suggest two main organizational outcomes, the first of which is organizational development. It can take the form of innovative programs, partnerships, and patient-centered care programming. Examples of quality indicators include: evidence-based pain management protocols, institutional advance care planning procedures, spiritual care programming, integrated acute care and community palliative teams, staff education and development, Schwartz Rounds, bereavement rounds, and family bereavement care.

"Findings indicate high levels of engagement and intentionality about building community...it's really important was the benefit of interdisciplinary exchange and understanding. Participants reported that the sessions increased their capacity to provide palliative care and integrate it into care on the units where they practiced. Participants in each bereavement care-session identified specific new learning that would influence their clinical practice."

Secondly, indicators of organizational satisfaction that include reduced healthcare provider burnout and compassion fatigue emerged from several articles.

The thing that keeps you going, even in the middle of a busy, frustrating day is when you can't help all of the patients, is being able to connect with people. That is the only thing that keeps me coming back every day...I've been here...for about four years and have seen incredible changes. I've been thinking about how you survive in a place like this that keeps growing and getting busier every year...The goal for the day can be that you'll connect someone...I hear the positive perceptions that patients have of their care providers...The regular newsletter "Hotline" occasionally publishes encouraging letters from patients. Reading these makes you feel really good because they identify the people that the patient had come into contact with.

Discussion

This integrative review was motivated by our shared practice experiences, and the voices of researchers, clinicians, and educators who advocate CCC as an essential component of healthcare quality. To that direction, our work builds on the CCC Model and Framework to promote operationalization of CCC in a way that is meaningful and measurable for patients and families who receive end-of-life care, as well as teams and organizations who provide end-of-life care.
To achieve this purpose, our integrative review process entailed an analysis and synthesis of the published literature related to CCC and end-of-life care over the last twenty years (1996 to 2016). Among the sample of 25 articles, less than one-third were published in the last five years. This finding indicates that CCC is an emerging field that has yet to receive the necessary attention by the scientific community, despite international calls for more compassionate care. The country of origin for the overwhelming majority of articles was the US (n = 17), followed by four Canadian articles, three from the UK, and one from Iran.

This is not surprising as similar literature sample characteristics were reported in a recent scoping review of compassion and a palliative care meta-analysis.

Patient and family-centered care was a dominant finding across the literature sample, and as such, we emphasize it as an overarching structure and key quality indicator of CCC. Patient and family-centered care is defined as “working with patients and families, rather than just doing ‘to’ or ‘for’ them”, and it should take place in all settings and across all care levels.

At end-of-life, patients must be at the core of all end-of-life care processes, and families recognized as care team members, and not merely “visitors”. Achieving a patient and family-centered care delivery model requires an extreme culture shift from a historic provider-driven model to one that involves patients and families in quality of care initiatives. This culture shift from passive, trusting and compliant patients, to engaged and empowered team members requires acquisition of a specific set of patient-centered care competencies. However, according to critical social theory, integration of patient-centered care into health care organizations is frequently hindered by the inherent knowledge and power of healthcare providers. According to our analysis, it also requires a sharing of values among patients, providers, teams, and organizations.

The structural values identified in this review are also reflected in the IPFCC’s four core concepts of patient and family-centered care, namely: respect, information sharing, participation and collaboration. Empathy, although lacking in IPFCC’s concepts, is commonly accepted as a value in hospice and palliative care. It is also often used as a synonym for compassion, although conceptually different. Compassion extends empathy beyond merely understanding and acknowledging another’s experience, to include actions that are motivated by love and acts of kindness.

Communication, shared decision-making, and goal setting are three overarching processes that can support CCC. Acknowledging the abilities of other team members, as well as their contributions, is of great importance to engaging these processes. In end-of-life care, the IP team includes the patient and his or her family, physicians, nurses, social workers, and the many professionals and non-professional volunteers who “cocoon” the dying patient.

The inclusion of patients and families expands previously accepted definitions of IP collaboration that only included professional caregivers. Collaborating with, valuing, seeking, and offering support to this extended IP team are all important attributes of CCC. The team seeks communication at all levels, and understanding of how the environment influences care to integrate meaningful processes, such as honoring dying patient wishes, humanizing the environment, offering tributes, facilitating family reconnections, rituals and observances, and “paying it forward”. More formal IP team processes include care conferences, rounds, advance care planning, and are listed as quality indicators of CCC. A significant finding from this review is the value of formalized team rounds, and their impact on provider self-care and emotional regulation.

Eight articles reported narrative summaries of SCR with great richness and depth in dialogue, and poignant descriptions of each healthcare provider’s unique perspectives and contributions to the IP care plan. SCR are multidisciplinary forums where HCPs come together to discuss and process emotionally and ethically complex care issues. In these rounds, reflection on the emotional aspect of care strengthens a provider’s ability to deal with similar situations in the future, providing support towards empathic practice.

For palliative and end-of-life care, SCR provide an ideal milieu for promoting compassion and IP teamwork among attendees. According to Manning and colleagues, SCR are very well received by healthcare professionals. Moore and Phillips report improved attendee insights into psychosocial aspects of patient care, teamwork, and less clinical isolation. Issues raised by staff during SCR center around three concerns: (1) staff uneasiness with a patient’s decision for continuing or discontinuing a therapeutic regime, (2) verbalizing the need to say goodbye to a patient at end-of-life, and (3) going through the emotions elicited by the death of a patient with whom a provider identified and bonded.

Unexpected positive outcomes include patient-centered changes in institutional policy or practice, greater use of palliative care teams/enhanced palliative care services, and discussion among staff about advanced illness and palliative care issues. Implementing SCR requires human resources, advanced planning, and commitment by institutional administration.

Development and satisfaction emerged as overarching outcomes at the individual, team and organizational levels.

Outcomes such as self-care, dignity, self-compassion, holistic care provision, therapeutic patient-provider relationships, and goal achievement are important indicators for evaluating quality care among patients, families, as well as professional and non-professional caregivers. Examples include “giving voice to the family”, and promoting family involvement in the caring process. Several of these outcomes can be measured to evaluate quality. For example, the Patient Dignity Inventory is a reliable and valid measure for measuring dignity-related distress at end-of-life. Walker and colleagues recently developed and tested a scale to measure patient perspectives of holistic and integrated care. The McGill Quality of Life Questionnaire is widely used among individuals with advanced disease and at end-of-life.

Key indicators of team development include interdependency and synergy, and are attributes of IP collaboration. According to the American Academy of Pediatrics guidelines, children’s hospitals should have dedicated interdisciplinary pediatric palliative care and hospice care teams. These teams provide integrated multimodal care (cure seeking, life-prolonging, comfort-enhancing, quality-enriching), facilitate clear and compassionate discussions, and support families and staff beyond the end-of-life period. A recent systematic review by Mulvale and colleagues reveals that interrelated ‘gears’ at the macro, meso, micro and individual levels are critical considerations for IP collaboration. Although focused on primary care, Mulvale’s findings are similar to those of this review in that dedicating human resources, setting a common vision, attending to formal and
social processes, and valuing the contributions of team members are highly recommended actions. Continuous improvement activities, such as quality audits and regularly scheduled team meetings, are equally important to understanding how policy and organizational contexts affect the ability of teams to collaborate effectively. According to the gears model, collaboration should extend beyond the team itself to include policy-makers, organizational leaders, team leaders and individual professionals.

**Strategies to enable CCC**

Our findings draw attention to environmental factors at all three levels that can enable or hinder CCC, and are congruent with the recently published compassionate care flow model by Tierney et al.

This study examines how compassionate care is delivered to patients with type 2 diabetes within a range of healthcare settings. This model demonstrates that mere intention to providing compassionate care is not enough. Rather, working within an environment that supports compassionate practice is perhaps more important. The flow of compassionate care can be enhanced by defenders (i.e. empathizing with patient, supportive colleagues, professional autonomy, faith, controlling own emotions) and/or depleted by drainers (i.e. competing agendas, time and resource limitations, negative emotions). Compassionate care is learned within the work environment, and shaped by the influence of colleagues, patients and organizational demands and expectations.

Nevertheless, the extent to which an organization can modify provider behavior, and enhance CCC performance is under debate. Regardless, our findings complement previous research which suggests that organizations and systems can enable rather than impede compassionate, high quality healthcare. Main enablers include: 1) resource allocation and policy setting focusing on the needs of patients/families and caregivers (professionals and non-professionals), 2) valuing and recognizing compassionate caregivers and organizations, 3) supporting providers to manage the emotional stress of caring, and to diminish personal or moral distress, and burnout, 4) forming partnerships with patients and families, 5) educating providers, patients, and families about the attributes and benefits of CCC, and 6) developing flexible QI processes to implement and continuously improve compassionate care.

When conducting the analysis, commitment and support were coded with high frequency at the individual and team levels. The importance of ongoing support from relatives, friends, and the team as resources, described as “circles of strength” and having “a safety net” emerged as exemplars. Nevertheless, there were wide variations in how these indicators were reported. Given the subjectivity, these indicators need to be interpreted from a clinical perspective. That is, when discussing goals of care, a meaningful ongoing assessment should occur. The following practical and powerful question for patients and families should be routinely asked: “How can I and/or the team demonstrate commitment to you and how can I / we support you in your journey?” Our analysis also suggests that individual practitioners and teams require ongoing organizational support; the attributes and processes of support should be systematically assessed and implemented by institutional leaders.

Several strategies to promote and engage individuals, teams, and organizations in CCC were discussed in the sample articles. Among them, the Comprehensive Pediatric Bereavement Program is characterized by a team approach, recognition of cultural differences, integration of family into care of the dying, support groups, resource lists and information, remembrance ceremonies, continued contact with family, staff education and development, program evaluation and feedback. The most documented strategy, SCR, is developed and sponsored by the Schwartz Center for Compassionate Healthcare. The Schwartz Center supports individual organizations to implement SCR through providing educating and training programs in compassionate care. The Schwartz Center’s “Compassion in Action Webinar Series” teaches participants how to sustain compassion and collaboration in healthcare while sustaining one’s well-being. Presenters teach some of the concepts and skills that are essential components of the CCC model in ways that are meaningful to patients, families and providers. For example, the 2017 webinar series includes CCC training at the organization and systems level.

Because the required skills to deploy empathy and compassion are not routinely taught nor systematically assessed and evaluated across the continuum of learning and practice, targeted measures and policies that reinforce humanistic values, such as kindness and compassion, are important in healthcare institutions and in healthcare education. Recently, a UK educational institution introduced SCR in undergraduate medical education. Medical students perceived SCR to support their self-reflection, insight and emotional processing. Challenges include training, cost, optimal timing, and participation.

At the organizational level, the use of indicators allows for ongoing monitoring of health care quality, setting the basis for quality improvement (QI) and prioritization in the healthcare system. Rushton and team evaluated four QI initiatives at a U.S. Children’s Hospital that included: 1) the establishment of a Compassionate Care Network that spanned all units of the institution, 2) institutional palliative care rounds, 3) patient care conferences, and 4) bereavement debriefing. The above QI initiatives can enable CCC, however both top-down and bottom-up organizational commitment and support must be enacted.

As highlighted in the IMPACT study, the use of quality indicators to drive improvements in palliative care settings is determined by the organization’s orientation towards continuous improvement. Furthermore, sustainability is determined by the perceived value of the QI package which can differ across settings (i.e. specialist palliative care vs. generalist care). Finally, ‘top-down’ engagement approaches were reported to be less effective.

**Implications**

We assert palliative and end-of-life care as the ‘gold standard’ for operationalizing CCC. Given that palliative care should begin once a life-limiting condition is diagnosed, the majority of patients and families who access healthcare can benefit from CCC. The findings of this review can be applied by institutions and systems implementing and maintaining a culture of CCC as part of QI, accreditation and/or magnet status projects.

Our study validates the work of the Schwartz Center for Compassionate Healthcare and the Arnold P. Gold Foundation whose visual representation (Fig. 4) shows how person-family-centered care can be achieved when compassion and collaboration intersect and are supported within the family, community, education and healthcare systems. In addition, our work contributes to the understanding of the quality indicators within each system, with exception of the community and educational systems. It indicates how the CCC approach can optimize patient-family and provider outcomes, such as satisfaction with care and satisfaction with providing care, respectively. Although our analysis did not reveal key indicators related to staff turnover, it is reasonable to hypothesize that reductions in burnout/compassion fatigue will positively affect provider and staff retention.

As previously highlighted, the usefulness and applicability of the review’s findings outside of facility-based end-of-life care cannot be assured. The community requires in-depth exploration, with Compassionate Communities representing an opportunity for comprehensive understanding. ‘Compassionate Communities’ or ‘Compassionate Cities’ are examples of CCC that are applied using a public health approach to comprehensively address end-of-life care at the community level. Now expanding across the globe, ‘Compassionate Communities’ engage citizens to partner with HCPs and others to meet the holistic healthcare needs.
identified by patients and families. As more of these communities evolve, evaluation of the fit of the quality indicators in the community setting will be interesting and may increase its utility.

Reliable and valid indicator measures will be required to measure quality outcomes of CCC. ‘The Schwartz Center Compassionate Care Scale’ is a new instrument that measures patients’ perceptions of compassionate care provided by hospital physicians. It is unknown if the scale has been tested in end-of-life care settings, and the instrument does not provide a level of team engagement in CCC. With the growing debate on the ability to measure CCC, experts urge the inclusion of compassionate care elements in national surveys of patient experience using standardized protocol items. Sinclair’s team is actively developing a patient-reported instrument to measure compassionate care, and this work will support the advancement of CCC within teams and organizations. Although patient and family satisfaction with healthcare is a quality indicator valued by most organizations, policy and institutional decision-makers are primarily driven by economic and high quality clinical data. Future work is needed to evaluate the benefits of CCC on costs, efficiencies, staff turnover and retention. Evaluation will be challenged by the complexity of the concept. Randomized controlled studies remain the bedrock of evidence-based practice, and their application in evaluating complex interventions can be fraught with challenges. Pragmatic trials and mixed methods studies may be more feasible to generate the strength of evidence needed to change practice and policy.

Strengths & limitations

Our review adds to the existing body of knowledge and builds on the recent work and recommendations of several professional organizations and experts. It overcomes the limitations identified by Gaertner et al. by providing an in-depth analysis of a complex phenomenon. With regard to the review process, rigor was supported through a comprehensive search strategy, using explicit inclusion and exclusion criteria. Two authors independently reviewed each citation and abstract, and a database was developed ‘a priori’ to support the organization and sharing of data. The authors met and reviewed their assessments and decisions, and came to consensus for all discrepancies.

This review is limited by a largely US literature sample, and the focus was end-of-life care. Therefore, the findings cannot be generalized beyond this population. There were no studies that explicitly examined the quality indicators of CCC as a primary outcome. The overall quality of the literature sample was weak since over two thirds reflected position/consensus statements, case studies, literature reviews and SCR reports which could not be appraised. Inter-rater reliability for the abstract reviews was not calculated.

The usefulness of the quality indicators outside of end-of-life care settings will be contingent on the organization’s structures and processes. Future studies and pilot implementation are required to further refine the key indicators.

Conclusion

Compassionate collaborative care (CCC) is an emerging, complex concept. Although limited by a lack of strong empirical evidence, it is of growing importance for healthcare quality. This integrative review suggests that CCC is inextricably linked to the inherent values, needs and expectations of patients, families and healthcare providers. Communication, shared decision-making and goal setting comprise the overarching processes, while development and satisfaction are overarching outcomes. These findings may be applied to facilitate the assessment and evaluation of existing structures, processes, and outcomes at the patient-family, provider, team, and organizational levels, and guide the planning of team and organizational changes to achieve the essential quality indicators for CCC. Given the growing numbers of individuals who require quality end-of-life care, this review provides a synthesis of the evidence for clinicians, administrators, and policy makers wishing to maximize the delivery of CCC in palliative and end-of-life care settings.
Section 3:
Rooted throughout the complex, multiple domains of end-of-life care is respect for the wishes of patients and their family members. Advance care planning (ACP) is designed to ensure that patients with serious and chronic illnesses receive medical care in agreement with their preferences and values. The next section by Howard et al shows how patient care preferences and values may be in contradiction and how decision aids for ACP may be designed to prevent inconsistency between patient preferences and values.

Recognizing Difficult Trade-offs: Values and Treatment Preferences for End-of-Life Care in a Multi-Site Survey of Adult Patients in Family Practices

Background
When people are faced with the need to make decisions about health care during serious illness or near the end-of-life, they may not be adequately prepared. Most people who are approaching the end of life have a point after which they shift their preferences from a treatment and cure orientation and express a preference for non-invasive treatment aimed at improving quality of life and symptoms. However this may not be clear to health care providers. Treatments given or ordered are often discordant with this preference and may be more intensive than desired. Advanced care planning (ACP) has been proposed as one solution to improve patient centered care and ensure that the values and preferences of patients are used to direct health care decisions. ACP is defined as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care”. In prospective and randomized trials, ACP significantly improves outcomes including increased likelihood that clinicians and families understand and comply with a patient’s wishes, reduces hospitalization at the end of life, results in less intensive treatments at the end of life (according to patients’ wishes) and increases use of hospice services.

In some western countries approximately half of adults surveyed in the community have engaged in some aspects of ACP such as thinking about their wishes and who would make treatment decisions on their behalf if they were to become mentally incapable, however these activities alone may be inadequate. Advance care planning has been equated with the completion of advance directive documents. However, the consideration and communication of values and preferences in preparation for future decisions made by patients or their substitute decision-makers in consultation with health care providers, are also key aspects of ACP. Furthermore, advance directives have limited utility because they contain instructions that may not apply to the specific situation of the patient when the decision is needed and they do not have legal standing in some jurisdictions.

The success of ACP rests on the assumptions that patients have adequately communicated their values to others who will make specific treatment decisions on their behalf in the future and that those values truly reflect what is most important to the patient at the time of decision-making. However research has shown that substitute decision-makers are often unclear about the patient’s treatment preferences, preferences sometimes change over time and patients’ expression of their values can be inconsistent, making them unhelpful as preparation for discussion of treatment decisions with health care providers. A sub-optimal process of clarifying values may contribute to difficulties with ACP. Structured interventions and decision aids have been recommended as tools to improve the process and outcomes of ACP. However, a systematic review that examined decision aids for end-of-life decisions found that patient values and treatment goals were not well addressed in the tools, limiting the usefulness of some decision aids for ACP.

Methods
Setting and design
We conducted a cross-sectional study in primary care practices between October 2014 and March 2015 as part of a larger project to improve the quantity and quality of ACP discussions in primary care practices. The methods of the main study that provided these data have been described previously. The study was conducted in a convenience sample of 20 family physicians’ practices in Canada: 13 practices in the province of Ontario, five in Alberta, and two in British Columbia. The family practices were located in the same communities as members of the research team and were invited by physician members of the research team. Included practices had a defined patient population (versus episodic walk-in clinics) and provided comprehensive family medicine services (as opposed to a focused practices such as psychotherapy or sports medicine). A variety of practice types were intentionally invited. All were located in urban centers, three were teaching clinics and 17 were community-based private practices, 17 employed allied health professionals, and 17 were practices with more than one physician in the same office.

Participants
Staff or clinicians in the family practices invited consecutive eligible patients to speak to the research assistant. Eligible patients were 50 years of age and older, could read and speak/understand English, and did not have cognitive impairment that would limit participation. The referring staff member or clinician knew the age of the patient and determined whether the patient was cognitively suitable but a formal assessment of cognitive impairment was not done. The research assistant met with the patients in a private space in the clinic and explained the study and obtained informed consent.

Questionnaire
We adapted a questionnaire that was previously developed and validated for use in hospitalized patients. The hospital version has face and content validity and good ratings of clarity and low emotional burden. We modified this questionnaire for use in primary care and piloted it with 25 patients in primary care to assess its clarity, sensitivity, and acceptability. Revisions were made to improve clarity. These questions addressed the patient’s engagement in ACP. Our definitions of values and
preferences are taken from a consensus-based framework on end-of-life communication and decision-making.

‘Values’ refer to an expression of a person’s overarching philosophies or most important priorities in life (such as maximizing quality of life or time spent with family). Preferences refer to specific preferred options for treatments (such as use of resuscitative treatments or not) or preferred health states (conditions that would be acceptable or unacceptable). To assess the values of respondents, we used the End of Life (EOL) Values Scale, a multi-item questionnaire that asks the respondent to rate the level of importance (1 = not important; 10 = extremely important) of each item in a list of common values that are relevant to EOL care (Table 5). The values questionnaire was based on a previous studies on EOL values in community dwelling elderly individuals, and adapted through expert input and pilot testing with seriously ill patients in hospital and in primary care. To elicit preferences for use of life-sustaining treatments, we used a taxonomy of different levels of the use or non-use of life-sustaining treatments (shown in Table 4). This taxonomy was developed with inputs from medical experts and has been used extensively in our previous research. The questionnaire also included socio-demographic items and the brief clinical frailty scale with text description and pictographs on which patients were asked to rate themselves. Patients self-completed the questionnaire.

**Results**

The survey was completed by 810 patients (92% completion rate among patients approached by family practice staff). The number of patients recruited per family practice ranged from 23 to 140 (in one multi-physician practice approximately 20 patients per physician were recruited).

The mean age of patients was 66 years (range 50-95 years) and 56% were female (449/809).

Most patients were Caucasian (88%; 713/810). The median score on the clinical frailty scale was 2 (corresponding to ‘well’).

There was a ceiling effect, that is the median rating was 10 out of 10 for three values statements: being comfortable and suffering as little as possible, having more time with family, and that death is not prolonged. The lowest rated statements were for the belief that life should be preserved and avoiding hospitalization (median rating = 6) (Table 3).

Across all items 11% to 13% of the statements were answered as ‘unsure’.

Of the 24 a priori predicted correlations between importance ratings for value statements, 14 were statistically significant in the expected direction but 11 of those were negligible correlations (defined as r < 0.3) (Table 4). For example, we hypothesized that there would be a strongly positive correlation between the importance of being comfortable and suffering as little as possible and the importance of avoiding machines, and between the importance of the belief that death should not be prolonged and the importance of the belief that nature be allowed to take its course. However, the correlations were negligible (0.24, 0.19 respectively). Of the 12 correlations we expected to be negative, four were in fact significantly positive; for example there was a positive correlation between the importance of living as long as possible and being comfortable and suffering as little as possible (r = 0.08, p = 0.036).

We hypothesized that the correlation between the importance of avoiding tubes and machines and the belief that life should be preserved would be strongly negative, and found that it was negligible (-0.03, p = 0.494).

Similarly, we expected the correlation between the importance of living as long as possible and avoiding machines to be strongly negative and observed no significant results (r = 0.02, p = 0.518). The largest of any correlation was (moderate): the correlation between living as long as possible and having more time with family (r = 0.64, p < 0.001).

Most patients preferred the treatment option that excluded CPR (92%). Nearly one-third of patients preferred ‘comfort measures only’ (30%), 7% preferred full medical care without resuscitation or breathing machines, and 36% preferred short term use of machines but not CPR, switching to comfort measures or all possible measures but without CPR (4%). Only 8% preferred all possible measures including CPR, and 15% were unsure or did not answer the question (Table 5).

The Kendall’s τ-b for the correlation between the importance rating for values and the five-option preference question (1 = all measures including CPR, 5 = comfort care only, no CPR; increasing number means less use of life sustaining treatments) were negligible, ranging from 0.03 to 0.13. The highest correlations between values and preferences were found for ‘nature allowed to take its course’, ‘death not prolonged’, and ‘life should be preserved’ (Kendall’s τ-b = 0.12, 0.13 and -0.12 respectively, all statistically significant). These correlations were in the expected direction where a higher importance rating of values related to not prolonging life correlated positively with the choice on the preference scale and values associated with prolonging life correlated negatively with the preference item.

<table>
<thead>
<tr>
<th>Item: How important ...</th>
<th>Median (q1,q3) (n)</th>
<th>Unsure</th>
<th>Missing or declined % (n/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I be comfortable and suffer as little as possible?</td>
<td>10(9,10) (793)</td>
<td>13% (100/793)</td>
<td>2% (15/793)</td>
</tr>
<tr>
<td>I have more time with my family?</td>
<td>10(8,10) (785)</td>
<td>13% (102/785)</td>
<td>2% (15/785)</td>
</tr>
<tr>
<td>I live as long as possible?</td>
<td>8(5,10) (777)</td>
<td>12% (97/777)</td>
<td>2% (15/777)</td>
</tr>
<tr>
<td>I avoid being attached to machines and tubes?</td>
<td>9(7,10) (753)</td>
<td>11% (83/753)</td>
<td>2% (14/753)</td>
</tr>
<tr>
<td>My death is not prolonged?</td>
<td>10(8,10) (750)</td>
<td>11% (81/750)</td>
<td>2% (14/750)</td>
</tr>
<tr>
<td>Belief that nature should be allowed to take its course?</td>
<td>8(5,10) (760)</td>
<td>12% (89/760)</td>
<td>2% (14/760)</td>
</tr>
<tr>
<td>Belief that life should be preserved?</td>
<td>6(3,8) (736)</td>
<td>11% (83/736)</td>
<td>2% (13/736)</td>
</tr>
<tr>
<td>I respect the wishes of other family members?</td>
<td>7(4,10) (778)</td>
<td>12% (97/778)</td>
<td>2% (14/778)</td>
</tr>
<tr>
<td>I avoid hospitalization?</td>
<td>6(3,9) (762)</td>
<td>12% (90/762)</td>
<td>2% (13/762)</td>
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</tbody>
</table>
Table 4. Correlations between different values pertaining to decisions about life-sustaining treatments

<table>
<thead>
<tr>
<th></th>
<th>a</th>
<th>b</th>
<th>c</th>
<th>d</th>
<th>e</th>
<th>f</th>
<th>g</th>
<th>h</th>
<th>i</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a)</td>
<td>1.00</td>
<td>0.11</td>
<td>0.0022</td>
<td>0.08</td>
<td>0.28</td>
<td>0.09</td>
<td>-0.04</td>
<td>0.05</td>
<td>0.12</td>
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<tr>
<td>(shorten)</td>
<td>&amp; 0.0364 &amp; &lt;.0001 &amp; &lt;.0001 &amp; 0.0130 &amp; 0.2882W &amp; &lt;.0001 &amp; 0.1453 &amp; 0.1453 &amp;</td>
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<td>b)</td>
<td>1.00</td>
<td>0.64</td>
<td>0.0011</td>
<td>-0.03</td>
<td>0.08</td>
<td>0.07</td>
<td>0.37</td>
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<td>(prolong)</td>
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<tr>
<td>c)</td>
<td>1.00</td>
<td>0.02</td>
<td>0.5183</td>
<td>0.10</td>
<td>0.16</td>
<td>0.03</td>
<td>0.52</td>
<td>0.03</td>
<td>0.13</td>
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<td>(prolong)</td>
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<tr>
<td>d)</td>
<td>1.00</td>
<td>0.46</td>
<td>0.0011</td>
<td>0.16</td>
<td>0.52</td>
<td>0.02</td>
<td>0.29</td>
<td>0.09</td>
<td>0.001</td>
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<td>e)</td>
<td>1.00</td>
<td>0.19</td>
<td>0.0011</td>
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<td>(shorten)</td>
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<td>f)</td>
<td>1.00</td>
<td>0.18</td>
<td>0.0011</td>
<td>0.15</td>
<td>0.04</td>
<td>0.017</td>
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<td>(shorten)</td>
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<td>g)</td>
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<td>0.38</td>
<td>0.0011</td>
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<td>h)</td>
<td>1.00</td>
<td>0.17</td>
<td>0.0011</td>
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<td>i)</td>
<td>1.00</td>
<td>0.01</td>
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Association between value statements and likely influence on length of life indicated in brackets (prolong, shorten, neutral)
A priori, correlations indicated ↑ were expected to be strongly positive and correlations indicated ↓ were expected to be strongly negative
P values are written under correlation coefficient

Table 5. Preferences for care if life supports were needed to stay alive

<table>
<thead>
<tr>
<th>Response item</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All possible measures including resuscitation (CPR)</td>
<td>8 (65)</td>
</tr>
<tr>
<td>All possible measures, no resuscitation</td>
<td>4 (35)</td>
</tr>
<tr>
<td>Machines only in the short term, change focus to comfort measures, no resuscitation (CPR) or breathing machines</td>
<td>36 (294)</td>
</tr>
<tr>
<td>Use full medical care, no resuscitation (CPR) or breathing machines</td>
<td>7 (55)</td>
</tr>
<tr>
<td>Comfort measures only</td>
<td>30 (239)</td>
</tr>
<tr>
<td>Unsure</td>
<td>13 (106)</td>
</tr>
<tr>
<td>Missing or declined</td>
<td>2 (16)</td>
</tr>
</tbody>
</table>

CPR cardiopulmonary resuscitation
On visual inspection of the figures, the mean importance ratings of values statements discriminated better between the preference for ‘all possible measures including CPR’ and ‘comfort care only’ (the extreme points) but there was less variation across the other three options for care. After collapsing to three categories for the preference question: all measures including CPR, collapsing the options for life-prolonging treatments without CPR, and comfort care only, the correlations increased but remained negligible, ranging from 0.11 to 0.29 (Fig. 5).

**Discussion**

In this multi-site cross-sectional survey of approximately 800 adult patients in the family practice setting, patients’ ratings of a set of values statements and response to a question about treatment preference demonstrated that there is a ceiling effect for some values statements, the ratings of some values statements are inconsistent or illogical when compared to each other, and the ratings given to the importance of some values statements are minimally associated with the expected treatment preference. Taken together, these findings suggest that patients are not able to discriminate values that compete with or trade-off with each other and have trouble linking their values statements to preferences for medical treatments.

Patient decision aids have been proposed as a way to improve decision-making relating to serious illness or end of life\(^{20, 35–37}\) and values clarification is a central component of these decision aids\(^{24}\). Our results suggest that patients do not recognize that trade-offs may be required with respect to receiving health care that would be consistent with values. For example if trade-offs are recognized we would expect a negative correlation between the importance ratings of living as long as possible and being as comfortable and suffering as little as possible. However both items had a median importance rating of 10 out of 10, and the correlation between them was weak.

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**Figure 5. Box-plots**

Box-plots of relationship between importance ratings for values and preference option for life-sustaining treatment, CPR – cardiopulmonary resuscitation. 1 = Use comfort measures only with a focus on improving my quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation. 2, 3, 4 = combined categories of: Use full medical care to prolong my life but if my heart or my breathing stops, no resuscitation (CPR) or breathing machine; Use machines only in the short term to see if I will get better but if my illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR); Use machines and all possible measures with a focus on keeping me alive but if my heart stops, no resuscitation. 5 = Use machines and all possible measures including resuscitation (CPR) with a focus on keeping me alive at all costs.
There is growing literature supporting the need for approaches to designing questions such as ranking, constant sum, and discrete choice experiments that ask patients to specifically compare the relative importance of each issue. It is possible that asking patients to consider the importance of each issue on its own, without considering any trade-offs, did not necessarily elicit informed values from individuals. The decision theory literature suggests values only become informed and stable when individuals have the opportunity to trade off one aspect with another and reflect on those trade-offs. Values can then be determined by considering the amount one is willing to sacrifice from something else.

There appears a role for these questions to not just elicit, but also help clarify patients’ values, and help them recognize the trade-offs in end of life care. Understanding how a patient prioritizes his/her values, may then allow the clinician to guide the patient to further prioritize decision options if they are faced with decisions whose outcomes will not align with all of their values. Further research should explore whether these explicit questions can overcome the problems of ceiling effects and inconsistency among values ratings that arose with our results.

We used a taxonomy for preferences regarding life-sustaining treatments that provided five options, three of which were for various degrees of medical care without CPR that would attempt to prolong life to some extent. The patterns of values statement ratings across these three medical care options suggested that patients may not have understood the differences between the nuanced treatment approaches because the correlations with values statements were very low and improved when the taxonomy was collapsed to combine these three categories. For patients to express a preference for a treatment approach and appreciate the connection to their values, attention to language and level of detail regarding the goals of the treatment approaches are needed.

The findings of this study could be helpful in designing decision aids that elicit the values that are most strongly associated with treatment preferences and therefore support the process of ACP because they are informative to patients, their substitute decision-makers and clinicians. For example, our results have demonstrated that some values in our values questionnaire such as being comfortable and suffering as little as possible, and having more time with family would not be helpful to elicit in a clinical setting because of a ceiling effect in importance ratings. The values statements that might have utility were the importance of living as long as possible, the belief that death not be prolonged and the belief that nature be allowed to take its course or that life should be preserved, because these were the items with the greatest association with preferences for life sustaining treatments. In this study, values and preferences were assessed at one point in time and the question of the usefulness of considering them in advance arises. Studies have reported that some patients change their preferences once they experience a health condition and some have difficulty predicting how they will feel about future health states. Thus, it is important that the patient’s values and preferences be revisited with their clinicians on an ongoing basis, and in particular if health deteriorates. Prior values clarification exercises still have utility because the process may help patients to be informed and more able to confront trade-offs so they can arrive at better decisions than if they are thinking about these issues for the first time, or the patient may lose capacity making it necessary to rely on past expressions of values. Preferences for health care options can remain stable even with changing experience of health care, and the majority of patients have stable preferences relating to end of life decisions, especially those who have completed an advance directive.

Our finding that 13% of patients are uncertain about their preferences regarding use of life-sustaining treatments may not be surprising given that the sample of generally healthy patients with an average age of 66 may not have given much prior consideration to these issues. However, similar findings have been reported in seriously ill older adults in hospital who might be expected to have considered decisions about life-sustaining treatments. Similar to other findings in older adults who live in the community, only 8% of patients in the current study expressed a preference to receive CPR. It may be that patients do not understand the implications of their preference regarding CPR and therefore there is an imperative to ensure high quality and timely communication and decision-making. Guideline-recommended elements of goals of care discussions that are desired by patients in hospital, such as discussions about values happen infrequently.

A strength of this study is that we surveyed patients in multiple family practices across regions. It is a limitation that the values statements instrument we used was not designed for the purpose of this study to assess consistency of values and compare values to treatment preferences. A more constrained technique with ranking of values may increase the recognition of trade-offs. It is possible that in this population of patients from primary care settings aged 66 years on average and who were not acutely ill, the responses to questions that are relevant to decisions during serious or critical illness may differ from responses in the future when faced with the situation. In addition, family practices and patients were not randomly sampled and we cannot be certain of the generalizability of the study results. Finally, our participants were predominantly Caucasian and had a higher level of education; results may not apply to people who are not Caucasian or who have lower educational attainment.

Conclusion

The reported values and preferences related to use of life-sustaining treatments among primary care patients reflect considerable inconsistency and discordance. To engage in high quality ACP, patients will need assistance to recognize possible trade-offs among their values and to understand the relationship between their values and their treatment preferences. The results demonstrate a need to improve the processes and tools to support advance care planning. These efforts should specifically include approaches that recognize trade-offs among values and link values explicitly to treatment preferences.
Family Communication about End-of-Life Decisions and the Enactment of the Decision-Maker Role

Introduction
In the United States, when an individual is incapacitated at the end of life and cannot make a decision for him or herself, family members often are called upon to make decisions for the individual. End-of-life (EOL) care decisions encompass decisions to initiate, withhold, continue, or end life-sustaining treatment. Making a decision for a family member at the end of life is one of the most emotionally difficult decisions families will ever face. How this decision is managed has important implications for the patient’s quality of life at the end and affects family members’ emotional well-being long after the decision has been made.

During decision-making, families encounter various dilemmas and challenges, including uncertainty about what to do and how to behave.

As they navigate this emotionally-charged experience and coordinate action together, family members take on roles in the decision-making process that may be supported or challenged by others in the interaction. One particularly important role in this context is the decision-maker role itself. The U.S. legal and medical systems encourage the use of an advance care directive (ACD) to designate a formal decision maker, although many individuals do not engage in EOL planning. In contrast to other legal systems (e.g., the United Kingdom where clinicians serve as default decision makers based on best interests), in the U.S., a family member typically takes on the decision-maker role in cases where a patient can not make decisions for him or herself, using substituted judgment or best interests to guide the decision-making. The decision-maker role, however, is rarely enacted in isolation. Multiple family members, for example, often participate in the decision-making interaction.

Given the interdependence of the family and the value of family engagement in the decision-making process, expectations and behaviors for the decision-maker role likely emerge in and are shaped by interaction with others in the family. Understanding the enactment of the decision-making role in family interactions about EOL decisions provides insight into how family members coordinate EOL interaction together and either support or undermine the performance of the decision-maker role.

Family Communication and End-of-Life Decision-Making
In the U.S., the legal and medical systems emphasize individual autonomy in health-care decision-making, expecting decision makers to follow the wishes of the individual. Individuals are encouraged to engage in EOL planning and complete formal documentation that specifies preferences regarding life-sustaining treatment and names a surrogate decision maker. Despite this emphasis on advance care planning, the percentage of U.S. adults completing an advance care directive (ACD) is relatively low. Several different surveys have demonstrated that many individuals feel that talking to family members about EOL wishes and having written documentation of wishes are both important, but a low percentage of respondents have actually had conversations with family and even fewer have legal documentation in place.

Most often, in situations where a surrogate decision maker has been established, the individual identified as a surrogate is a family member (e.g., spouse, child or grandchild). This reflects a dominant preference across cultural groups in the United States for family to be involved in surrogate decision-making. Additionally, regardless of whether or not a formal decision maker has been identified in an ACD, multiple family members usually participate in decision-making conversations when a decision must be made, and some families may expect consensus in the decision-making process.

The complexity of EOL decision situations creates a number of dilemmas for family members required to make a decision for a loved one at the end of life. Family members may face challenges in obtaining the information needed to make a good decision or knowing when a decision point is nearing. Without adequate information from health care providers to inform the decision, families can experience resentment and emotional burden after a decision is made. Family members also may be uncertain about the right decision to make, even when there is an ACD in place. Living wills, for example, do not always provide insight into the specific decision that must be made. Additionally, when family members are aware of the patient’s wishes, they still may encounter a contradiction between their own desires and the patients’ desires, often experienced as a tension between holding on and letting go. Family members also may struggle to make sense of the decision and of a loved one’s likely death. In interaction during clinician-family conferences in an intensive care unit, for example, family members grappled with understanding withdrawing or withholding life support as killing a loved one versus seeing it as letting him or her die. They also experienced a contradiction between perceiving death as a burden or as a benefit.

As family members make decisions, they can experience challenges in effectively coordinating family decision-making and working with medical professionals. Families, for example, sometimes experience conflict and disagreement as multiple family members participate in the decision-making process. Family members may disagree over who should be included in the decision-making or, ultimately, what decision to make. A history of family conflict prior to the EOL decision, communication in which family members try to assert control over the decision, and families having difficulty talking with each other about the situation all predict greater family conflict when making an EOL decision. Conflict in EOL decision-making can lead to more aggressive treatment and reduce the degree to which decisions match the preferences of the patient. Conflict in the family during decision-making also may undermine the quality of family relationships after a decision has been made.

Family Roles and End-of-Life Decision-Making
Clearly family interaction around EOL decisions is fraught with complications that affect the well-being of both the patient and the family. As families negotiate this unfamiliar communicative terrain, members take on a variety of informal roles in the decision-making process. Roles refer to communicatively negotiated understandings of behavior to be enacted by family members in particular positions. Roles are communicatively created and recreated in interaction with others. Roles both develop in and then guide interaction as family members form expectations about how someone holding a particular role will act. As a family faces an EOL decision, family members in both formal (e.g., designated surrogate decision maker) and informal decision-making roles must work out what their roles mean for family communication and decision-making behaviors.

Within family interaction, the behaviors of others shape how a role is enacted. Role appropriation is shaped by role expectations and others in the family can facilitate or undermine the enactment of a particular role, which may need to be negotiated...
among family members\textsuperscript{32}. Additionally, Salazar\textsuperscript{11} recognizes that roles that develop in groups are shaped by both past and present interaction and have environmental constraints. In EOL decision-making, roles likely build on past family interactional histories, formal familial roles (e.g., spouse, child), and gender role expectations\textsuperscript{10,13} but also adapt to the unique decision-making situation facing the family.

The larger medical and legal systems in the U.S. also add an extra layer of expectations for formal role assignments that shape interaction within the family and between the family and medical professionals\textsuperscript{21}. Although there might be a variety of different informal roles that develop in the family system when making an EOL decision for a loved one\textsuperscript{3}, of particular interest for this project is the decision-making role itself. More specifically, we pose the following research question:

RQ: How do family members enact the decision-making role in EOL decision-making interactions?

Materials and Methods

Participants

Individuals who participated in family decision-making for a loved one at the end of life, either as a surrogate decision maker or as a family member involved in the communication about the decision, were interviewed about their family communication during the decision-making process.

Many of the decisions faced by families in this study involved decisions about initiating or withdrawing life support. Others included decisions about pursuing specific interventions (e.g., surgery, chemotherapy), stopping treatment and going on hospice, and whether or not a patient could return home or must remain in the hospital. In many cases, decision makers and families faced a number of different decisions as they navigated the end of life with their loved one. All of the decisions except one were made within the context of the health-care and legal system in the United States. However, decision narratives involved families of mixed citizenships and cultures. In one case, the family member at the end of life had moved from her lifelong residence in Singapore to the United States to be with her end of life had moved from her lifelong residence and cultures. In one case, the family member at the end of life had moved from her lifelong residence and cultures. In one case, the family member at the end of life had moved from her lifelong residence.

Results

The Structure of Decision-Making Roles within the Family System

When making EOL decisions for a loved one, one or more family members took on the decision-making role. Three different patterns of role enactment were identified in the interview data. The first two patterns of consulting and informing emerged in families with a single designated decision maker who received collective family input. Within these patterns of role enactment, family and gender roles shaped decisions regarding who took on decision-making roles. The third pattern of collaborating emerged in families in which the collective family unit took on the decision-maker role.

Single Designated Decision Maker with Collective Family Input: Consulting or Informing

In many cases, one individual was designated, formally or informally, as the official decision maker for a loved one’s end-of-life care, but there was also collective family involvement. In these cases, there was a clear expectation that a specific individual would make the decision for the loved one. For a number of families, this role was established by formal legal documentation. Phyllis, for example, had health care power of attorney for her mother and noted, “Throughout the whole decision-making process, obviously, my dad and my sister, we kind of always conferred as a family, but I was the one making the ultimate decisions on her end-of-life care.”

In other families, a decision-maker was not specified through legal documents, but family members understood who should make the decision based on legal and cultural understandings of family roles (e.g., spouse rather than children) as well as gender role expectations. For example, Laura indicated that in her Dominican family “it is usually the elder daughter who always makes the decision, but she does not make the decision on her own.” Jackie, for example, specifically noted that her role in the decision-making was unexpected to her because she was the youngest child and female. In situations where the decision-maker role was held by someone unanticipated (e.g., the youngest sibling), participants typically rationalized the role. For example, some participants pointed to the expertise of the chosen individual (e.g., “I’m the nurse so everyone turned and looked to me,” Sheila), closeness and trust in the relationship with the patient, or their willingness to make difficult decisions. Jackie, for example, said that her mom chose her to be the decision maker even though she was the youngest “because the rest of my siblings were all sissies. She chose the tough one.”

Less commonly, the decision-maker role emerged through decisive behaviors on the part of a family member in the absence of formal, legal documentation. Beatrice, for example, observed that her mother “wasn’t prepared for the situation because it had occurred so quickly.” Her mother and her brother were in denial about her father’s end of life, and when Beatrice arrived, she took over, asking questions and making arrangements.

According to her, “I protected him; I mean I literally felt like his guard dog . . . . if I hadn’t had been there they would have just kept treating him. Even though there was no treatment.”

Family roles (e.g., spouse, child), gender roles, and age all emerged as existing roles in the family that shaped expectations regarding who would take on the decision-making role.

Specifically, if a spouse was living, he or she was expected to take on the decision-making role, and participants provided explanations for why that did not happen in situations where a child or sibling took on the role instead.

The need to protect the husband or wife given his or her emotional distress often emerged as an explanation for role enactment by a child instead. Beatrice, for example, indicated, “My mother, God bless her soul, she was just a bystander . . . . She could not communicate well with the doctors or the nurses, you know, she just . . . it was almost as if she was in shock.” Although the gendered nature of the role varied from family to family, descriptions of who should take on decision-making roles intersected with gendered expectations regarding children’s influence and support. Expectations regarding age and family roles were apparent in the data as well. Beatrice, for example, specifically noted that her role in the decision-making was unexpected to her because she was the youngest child and female. In situations where the decision-maker role was held by someone unanticipated (e.g., the youngest sibling), participants typically rationalized the role. For example, some participants pointed to the expertise of the chosen individual (e.g., “I’m the nurse so everyone turned and looked to me,” Sheila), closeness and trust in the relationship with the patient, or their willingness to make difficult decisions. Jackie, for example, said that her mom chose her to be the decision maker even though she was the youngest “because the rest of my siblings were all sissies. She chose the tough one.”

Regardless of the formality of the decision-maker role, collective family input was an important part of the decision-making process. How individuals enacted the decision-maker role in relationship to this collective input, however, varied across situations. In some cases, like Phyllis’s described above, family conferences and other types of group interaction offered an opportunity for a number of different family members to have input into and, at times, get on board with the decisions that were going to be made. The behaviors of the decision maker involved consulting other family members as a way to enact the decision-maker role. Caroline, for example, talked about her sisters offering different suggestions to her dad about what to do, which
he took into consideration as he made decisions for her mom. John’s brother-in-law included his wife’s family in conversations about his wife’s EOL decisions prior to making decisions. In these types of role enactments, the individual in the formal decision-making role integrated the input of family members into the decisions made.

In other cases, the decision-maker role in family interaction involved informing more than consulting. Both listening and explaining were a part of the behaviors enacted in this type of decision-maker role. For example, individuals in the decision-maker role used family interactions to create a space for family members to express themselves before the decision maker made the decision he or she already knew would honor the loved one’s wishes. This offered an opportunity to recognize and hear other family members’ thoughts and opinions. Jackie, for example, said “I would tell them, ‘Hey guys, this is where we are, this is the outlook, this is what things are.’ And it was always . . . the discussion was always . . . we’ll do everything possible to keep her alive. And which . . . I had to always . . . had to hear them out and allow them to express themselves and allow them to say what their desires were.” Even though Jackie was officially recognized in her mother’s medical record as the surrogate decision maker and knew that her mother should be taken off of life support, she included her family in a collective discussion to give them an opportunity to share before telling them what needed to happen.

At times, the decision maker used collective interaction as an opportunity to inform the family members of what the loved one would want and explain what the decision should be. Amy, for example, described her mom telling her adult children “this is what’s going on, this is what the best decision was for him, and him and I talked about it before” at their family conference around the kitchen table. When her father had a stroke, Maria said that “my mother looked to me and my son . . . she said ‘no that is not what we had discussed . . . you know, your father and I already discussed it.’” These conversations offered an opportunity for the decision maker to demonstrate knowledge of what was best and provide an argument for it grounded in the desires of the patient.

The Collective Family Unit as Joint Decision Makers: Collaborating

Although most families indicated that one person specifically took on the decision-maker role, a few families did not display this type of role enactment. Instead, family members jointly took on the decision-maker role together as a unit and collaborated together. In the families where this happened, there was a designated surrogate decision maker or a spouse who might have been expected to take on the decision-making role given the formal expectations of the legal and medical systems. That person, however, preferred to structure the interaction around collaborative group decision-making rather than take on the decision-making role individually. Catherine’s mom, for example, had given her sister medical power of attorney.

Family Members and Role Enactment

Given the importance of family interaction for the decision-making process, it is not surprising that family members’ responses shaped the decision-maker role. This primarily occurred through two means. First, family members sometimes offered supportive behavior that bolstered the decision-maker’s influence and helped him or her cope with the decision to be made. Alternately, conflictual behavior that challenged the decision-maker’s right to make the decision or the wisdom of his or her decision-making behavior was also evident.

One way in which families facilitated decision-making roles was by supporting one another’s suggestions. Agreeing with the decision reinforced the decision-maker’s rights and responsibilities in that role. Family support was particularly important for decision makers who took on the role through decisive behavior. Sheila’s sister did not have a surrogate decision maker, and Sheila reported that, “when I told them that enough is enough, don’t put her through surgery, my other sister, she was supportive of that. And then my mom was kind of supportive of that. So, it was really us trying to tell the rest of the family that this is probably the best.” Others’ acceptance of that decision contributed to Sheila’s enactment of the decision-maker role in the absence of legal documentation and/or a family role that would position her as next-of-kin. Support also became important in the context of family conflict. Charlotte’s sister-in-law, for example, did not approve of the choices that her brother-in-law was making for her sister and was calling people in the family about it. Charlotte said everybody else in the family “told her basically we trust Adam’s choices.” Showing support could be seen as a sign of collective solidarity reinforcing the decision-maker role.

Additionally, family communication also provided an opportunity for other family members to reinforce the decision-maker’s formal role by reminding the designated surrogate decision maker about the EOL care that had already been discussed or the wishes of the patient. Phyllis, for example, noted that “I just had to be the one to sign the paper. And I was always a little hesitant. Umm . . . And my dad would just kind of chime in and say, ‘You know, remember what you and your mom had discussed last week. Remember what the three of us talked about the week before.’” Edna talked about sitting with her best friend Patty, whose son had been in a car accident. At one point, Patty was talking about how she could not let her son go, and she said, “I get to make the decisions.” Edna said, “And I said ‘yes you do.’” At the same time, Edna pointed out that this is not what he would want. In this moment, Edna supported Patty’s right to make the decision while also encouraging her to consider what her
son would want when that was a very difficult thing to face. Family members who were not considered primary decision makers acted as a support system to reinforce the decision that was made and to show support for the surrogate decision maker.

The decision-maker’s role enactment was undermined when family members engaged in conflict around who should take on the role or what the right decision should be. In Jackie’s situation, for example, family conflict emerged around whether or not the baby of the family should get to make decisions, even though she had legal standing as the surrogate decision maker. In contrast, Lynn, who was caring for a mother with dementia, indicated that her siblings were divided over the decision to keep her mother in her home, with four supporting the decision and three not supporting it. At one point, she said “we were one man down for a while, could you help us and all three of them said ‘if you need help, put her in a nursing home.’” Family members were not always consistently unsupportive in their response to the decision-maker’s behavior. Phyllis, for example, reported that her dad “was very argumentative with me and using a lot of foul language and kind of yelling at me” when she made the decision to decline a pacemaker for her mom. At other times, however, he had been supportive and encouraging given the difficult decisions she faced.

Physicians and Medical Professionals and Role Enactment
Other family members were not the only ones to influence the enactment of the decision-maker role. Physicians and medical professionals played an important part in supporting the decision maker in his or her role or in supporting the family as a collective. In addition, physicians were an essential source of information for the decision-making process, and how they responded to questions also shaped the enactment of the decision-maker role. For the most part, physicians respected multiple voices in the family decision and encouraged family meetings about the decision, regardless of whether or not a designated surrogate decision maker had been named. In other cases, physicians played a role in ensuring that the family as a decision-making unit was honored. For example, Molly reported that her mother was the formally designated decision maker when her father had a stroke. However, she indicated that the physicians engaged all of the family members in discussion about her father’s care at the end of life, helping the family to make a decision collectively. She said, “When the doctors talked to us, they looked at everybody . . . “ In the end, all of the family members came together to play a part in the decision, which, according to Molly, was supported by the hospital staff. “Everybody got equal amount of respect from the doctors and the nurses,” she said. This support provided space for the kind of collective interaction that was important for families, regardless of the type of decision-making role being enacted.

If, however, families engaged in conflict or hesitated in making a decision, the physician often encouraged the formal surrogate to step in to make the decision and reinforced the centrality of his/her legal position for taking on that kind of decision-making responsibility. Similarly, if families were not following the formalized wishes of the person at the end of life, physicians seemed to encourage those family members who were committed to following the formal wishes of the person at the end of life to take a lead. Jackie, for example, was faced with making a decision to withdraw treatment that was consistent with her mother’s wishes but conflicted with her siblings’ preferences. This conflict motivated the physician to encourage her as the designated decision maker, to take the lead: “It came to uh . . . . the point of the physician talking to me one on one. And telling me it was my duty and it was my responsibility . . . . He said, ‘This is not about them; this is about your mom.’ And he said, ‘You need to regain your focus.’”

In very few situations, participants also indicated that physicians engaged in behavior that undermined their ability to effectively perform the decision-making role. Most often, this revolved around failing to provide important information. Across interviews, it was clear that physicians provided key information that helped decision makers and family members understand the nature of the decision that they faced and orient to the possible consequences of different decisions. Questioning medical professionals was an important part of the decision-maker role. Molly, whose family reflected the collaborating pattern of role enactment, described everyone in the family asking questions “like a round table”. When physicians were ambiguous or avoided sharing difficult information, this made decision-making more difficult. Beatrice, for example, was frustrated with her father’s physician who did not provide important information for deciding whether or not to shift to hospice. Due to his reluctance to share difficult information, her persistent questioning of the doctor became a part of her enactment of the decision-maker role.

Discussion
The primary decision-maker role is a key role in EOL decision-making. This study offers insight into the expectations and behaviors that constitute that role in families when decisions must be made. The findings of this study highlight the importance of collective family interaction as a part of the decision-makers’ role enactment and the significance of family interaction for facilitating or inhibiting the enactment of the role. Additionally, this study provides insight into the ways in which the larger cultural, legal, and medical contexts intersect with specific family interaction to shape the structure and performance of the decision-maker role.

Family Interaction and the Enactment of the Decision-Maker Role
Across decision situations, interaction with other family members was an important part of the role enactment. This is consistent with research indicating that families in the United States often prefer family conversations about decisions over individual decision-making. The findings demonstrate, however, that there can be important variation in the nature of that family interaction in relation to the decision-making role. In some families, the collective input was a key component of the decision-making, and in other family contexts, collective conversations were an opportunity for the decision maker to help other family members understand what decision should be made.

Although the U.S. legal system emphasizes the role of an individual surrogate decision maker, some families chose to construct the role as either a collaborative or consultative process rather than individual action. This occurred even in decision situations in which the patient had designated a specific person to be the legally recognized decision maker. For families who enacted a collective group decision-maker role or who had an individual decision maker who actively consulted other family members and adapted to their perspectives, collaborating and consulting created a more distinctive shared responsibility for the decision. Making an EOL decision for a family member carries a significant emotional burden and diffusing the responsibility for the decision across family members may be one way to mitigate or share the emotional weight of the decision.

Additionally, a desire to develop a shared understanding might help explain the informing approach to decision-maker role enactment. In those families, individual decision makers used the family’s collective interaction to explain the decision to other family members. In these cases, the surrogate decision maker’s responsibilities extended beyond making a decision for the patient to also ensuring that the family understood the rationale for the decision. Family interaction was oriented around educating other family members about what the patient would want, rather than jointly reaching a decision together.

Regardless of the type of role enactment, the construction of the decision-maker role as one that engages collective family input reflects the complexity of making a decision in the context of an on-going, interdependent relational system. As
long as it is not conflict laden, family interaction in EOL decision-making may help to create a shared perspective on whether or not we are “doing the right thing”, something that family members struggle with as they face EOL decisions. In addition, incorporating collective family interaction in the decision-making role, regardless of the form that it takes, may be one way in which families coordinate interaction so that they are able to go on together after a loved one has died. It is likely that what occurs in family interaction at the end of life, including the way in which the decision-maker role is enacted, has important consequences for how family members relate to each other after the death of their loved one.

**Enactment of the Decision-Maker Role within the Cultural, Legal, and Medical Context of the United States**

Understanding the Patients’ Wishes and the Enactment of the Decision-Maker Role

Debate exists about whether or not family members are the best people to make decisions at the end of life. Whereas some scholars argue that their lack of medical expertise and/or emotional distress might undermine their decision-making capacity (e.g., 37), others contend that they are uniquely positioned to know the values and preferences of the patient (e.g., 17). Family members in this study, however, did not question whether or not a family member was the appropriate person to be making a decision for a loved one. The few conflicts that were reported oriented around the specific decision being made or who in the family was making the decision, but did not challenge the legitimacy of a family member as the appropriate decision maker. At the same time, however, the patients’ wishes were clearly essential to knowing how to be a family member as the appropriate decision maker. The decision-making role was clearly enacted within a familial context that carries with it a hierarchy of influence and responsibility in relationship to the decision-making process. Given the importance of that role to the family, the relational processes that the family brings to EOL decision-making may help to create a shared understanding of family members’ responses for why unexpected role performances occurred.

**Medical Professionals and the Enactment of the Decision-Maker Role**

Based upon the pattern of findings in this study, medical professionals helped to bolster and support decision makers and reinforce the legitimacy and importance of that role to the family. Past research in the U.S. indicates that medical professionals can find family involvement in decision-making to be problematic, particularly when multiple different family members expect to participate in decision-making interaction. Group interaction contradicts a medical model that emphasizes the relationship between the physician and the patient and/or a single surrogate decision maker. Family members in this study, however, described ways in which physicians’ behaviors helped to support the inclusion of collective family input in the performance of the decision-maker role. Research has demonstrated that physicians and other medical professionals serve as an important source of information for families facing a difficult decision. In serving as a source of information for families, physicians are in a position to support collective family discussions about EOL decisions through their communication with the family as a whole during this time. When family members experience conflict around who should be making EOL decisions, physicians also offer support for surrogate decision makers, reinforcing the legitimacy of their role as a decision maker.

**Family Roles, Age, Gender and the Decision-Maker Role**

The decision-making role was clearly enacted within a familial context that carries with it a hierarchy of influence and responsibility in relationship to decision-making. Family, age and gender roles all appeared in family members’ explanation for who took on the decision-making role in the family. This hierarchy of influence is culturally grounded. Research, for example, indicates variation across ethnic and racial groups in the U.S. in what individuals identify as the preferred formal family role (e.g., spouse, child, sibling) to draw on for a surrogate decision maker. In situations where the person taking on the decision-making role in this study did not fit cultural or legal expectations for who should be making a decision (e.g., an adult child instead of a spouse), participants offered explanations for why unexpected role performances occurred.

**Conclusions**

The findings of this work offer valuable insight regarding how family members enact the decision-making role in family interactions surrounding the end-of-life decisions. However, the study is limited in several ways. First, the sample of this study was partially drawn from snowball methods, which limits the perspectives included. In contrast to other research interviewing surrogate decision makers (e.g., 40), our participants had generally positive experiences with medical professionals and reported very little conflict with physicians. The influence of the physician in role enactment would be very different in contexts of disagreement around treatment decisions. Additionally, no participants who volunteered for the study reported on EOL decision-making for a spouse. Given the importance of the spousal role for EOL decision-making, the absence of the spousal perspective limits the transferability of findings.

Future research should attend to both cultural and familial factors that shape family interaction during EOL decision-making. The intersection of autonomy and interdependence that emerges in work attending to family processes in EOL decision-making reflects a particular cultural understanding of families and their relationship to EOL decisions. Cross-cultural comparisons regarding family structure and expectations as well as beliefs about decision-making responsibility would offer additional insight into family processes related to EOL decision-making. The relational processes and expectations that family members bring to the decision-making situation also likely shape the patterns that emerge in the family. Molly, for example, suggested that the cohesiveness that characterized relationships within her immediate family network helped to explain why everyone was involved actively in making the decision together. Future research should explore the ways in which the relational dynamics that the family brings to the decision-making situation shape the roles that emerge.

The end of life of a family member is an emotionally challenging and complex site of family decision-making. How family members socially construct the decision-maker role is critical for the decisions that are made and the coordination of family members in the decision-making process. Given the importance of collective interaction for role enactment and the significance of family members’ responses for supporting or undermining that role enactment in EOL decisions, researchers and practitioners need to attend carefully to the interdependent family context when considering the process of EOL decision-making.
Section 5

Conversations between physicians and patients about end-of-life care are crucial for patients’ experiences so that patients’ preferences and values are conveyed to their providers. Physicians do not always undergo adequate training to engage in these conversations. The last section, by Periyakoil et al, describes reasons for physicians’ reluctance to hold these discussions and provides suggestions for improving physician-patient communication in these settings.

No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients

Introduction

By 2030, there will be 71 million older Americans accounting for roughly 20% of the U.S. population. While biomedical advances have resulted in an unprecedented growth in the number and proportion of older adults, most (an estimated 80%) bear the burden of chronic illness(es) for several years before eventually succumbing to it. Costs of caring for patients with chronic illnesses have escalated the U.S. health care costs which were 17.7% of the Gross Domestic Product in 2011 (250% more than the average health care spending of most developed nations). These costs are projected to further increase by an alarming 25% in the next two decades due to the demographic shifts in a greying nation. A disproportionate amount of the total Medicare budget is expended on patients in the last two years of their life on repeated hospitalizations. An estimated 78% of costs in the final year of life is spent in the very last month of life on ineffective and burdensome high-intensity treatments which are associated with poor quality of death. Better health outcomes do not necessarily accompany these higher spending patterns leading to the inference that judicious cost curbing is possible without compromising the quality of care at the EOL.

In analyzing the growing population patterns, it is clear that the minority populations are growing rapidly, and the U.S. is projected to become a minority-majority nation by 2043. The ethnogeriatric population is exploding into a ‘silver-brown tsunami’ of older Americans who are living longer while enduring the burdens of chronic illnesses for many years. Data show that ethnic patients are more likely to consume ineffective and burdensome high-intensity treatments at the EOL, incur higher end-of-life costs and are less likely to utilize hospice care.

EOL decision making for ethnic patients is impaired by poor communication and lack of understanding about the treatment options. Compared to Whites, African-American decedents report more problems with physician communication.

Doctors do not necessarily believe that high-intensity treatments are desirable at the EOL. In our previous work we have demonstrated that most doctors personally prefer to forego high-intensity treatments and wish to die gently. One key reason for why terminally ill patients are subjected to ineffective and burdensome treatments is the lack of effective EOL conversations that elicit the patient’s values and preferences early in the chronic illness trajectory and what matters most to them. Research shows that patients who have EOL conversations with their physicians are less likely to experience physical distress at life’s end, less likely to undergo high-intensity interventions, less likely to die in the Intensive Care Unit, more likely to receive outpatient hospice care and be referred to hospice earlier.

EOL conversations per se are very sensitive communication encounters and conducting these may be very challenging. To our knowledge, doctor-reported barriers (if any) to conducting effective EOL conversations have not been well studied. This large mixed-methods study was conducted to determine if doctors struggle with conducting EOL conversations with their patients and to better characterize barriers doctors may face in conducting such conversations with diverse patients.

Methods

Study sample

Multi-specialty doctors who care for seriously ill patients in two large training hospitals in California (Stanford Hospital and Clinics and the VA Palo Alto) participated at the end of the clinical training year just before graduation in the academic years of 2010 and 2011 (data were collected from calendar years 2010 through 2012). We specifically did purposive sampling of trainees from various subspecialties just before graduation as these doctors have very high practice volumes and care for numerous seriously ill persons from various ethnic backgrounds. Of the 1234 eligible participants, 1040 participated (84.3% response rate).

Data collection

The questionnaire was administered one time online and no personal health identifiers were collected in an effort to promote participant confidentiality and honest responses without concerns about individual scrutiny. There was no repeated contact of participants.

The Stanford Institutional Review Board approval was obtained to analyze the data presented in this paper.

Questions and prompts used in data collection.

a. Have you encountered any barriers to conducting effective EOL conversations with seriously ill patients and families?

b. If yes, to what extent conducting effective EOL conversations with patients and families who belong to a different cultural/ethnic background was challenging (Likert response choices: not at all, somewhat, quite a bit and a great deal).

c. Please list the top three barriers (if any) that you have faced in conducting effective EOL conversations including those with patients and families who belong to an ethnic/racial group different from your own.

The participants’ age, gender, ethnicity and medical sub-specialty information and its influence on their perceptions were analyzed, all with a view of improving the training and resources of doctors to deal with EOL problems.

Results

Of the total 1040 participants, only 8 doctors (<0.1%) did not report any barriers to conducting effective EOL conversations. 1032 (99.9%) doctors reported barriers to conducting effective EOL conversations and most doctors (85.7%) stated that conducting effective EOL conversations with ethnic patients to be “a great deal” or “quite a bit” challenging. Subgroup analyses showed no significant differences by gender or age but revealed significant differences by ethnicity (Chi-Square = 12.8, DF = 4, p = 0.01) and by medical sub-specialty (Chi-Square = 19.3, DF = 10, p = 0.04). Asian doctors reported the most struggles (91.3%), followed by African American doctors (85.3%), Caucasian doctors (83.5%) and finally Hispanic Latino doctors (79.3%).

Next, the Friedman’s test was used to examine the differences in rankings for the 6 primary barriers across sub-groups of participants. There were no significant differences by gender or ethnicity. There were significant differences in barrier ranking by age group (F statistic = 303.5, DF = 5, p < 0.0001). Younger doctors felt that patient/family’s limited health literacy was a bigger barrier compared to the older doctors in our sample. There were also significant differences based on medical sub-specialty (F statistic = 163.7, DF = 5, p < 0.0001). (See Fig 6). The largest sub-specialty groups in the validation cohort were Internal Medicine (n = 289) and Surgery (n = 188). Of the six primary barriers, all sub-specialties identified “language and medical interpretation issues” to be the most problematic and “patient/family’s mistrust of doctors and the health care system” to be the least problematic.
of the barriers to effective EOL conversations with diverse patients. The biggest differences across sub-specialties were seen in Emergency Medicine, Neurology, Psychiatry and Anesthesia. Emergency Medicine doctors rated the patient/family’s limited health literacy barrier as being more problematic compared to doctors in general.

Neurologists rated doctors’ ignorance of patients’ cultural beliefs, values and practices as a more problematic and cultural differences in truth handling and decision making as less problematic as compared to doctors in general. Psychiatrists stated that cultural differences in truth handling and decision-making were more problematic compared to doctors in general.

Anesthesiologists felt that patient/family’s limited health literacy was less of a barrier compared to doctors in general. To note, 26 of the 29 (89%) of the Emergency Medicine doctors in our cohort were 20–29 years old and it is possible that the differences noted were a function of age in addition to sub-specialties.

**Barrier 1: Language and medical interpretation issues**
Medical jargon is difficult to translate into other languages (as equivalent words may not exist) and approximate translations do not convey the true meaning and may lead to misunderstandings and miscommunication. Doctors felt that the technical medical terms used in EOL discussions (cardiopulmonary resuscitation, ventilators) or vague phrases like “heroic measures” made it very challenging to have these discussions with persons of Limited English Proficiency (LEP). The doctors in our study identified medical interpreters (MI) services as a barrier to effective EOL conversations for the following reasons: (i) logistical difficulties encountered with in-person/phone/video MI’s, (ii) conversations involving MI’s were time intensive, (iii) using MI’s as communication intermediaries psychologically distanced the doctors from their patients, (iv) the variability in quality and accuracy of the MI’s, (v) sometimes MI’s interfered with the diplomacy of the doctor-patient encounter by giving advice to the patient or by assuming the role of a patient advocate.

As the US population is becoming more diverse, it is imperative that we train doctors and medical interpreters to work together respectfully and effectively following standard guidelines. Furthermore, system triggers need to be built to automatically identify patients with LEP and schedule adequate clinical encounter time for doctors to work with MI’s and these patients. Additionally, system changes need to be made so that all doctors will be able to use special billing codes like the interactive complexity add-on Current Procedural Terminology (CPT) codes when working with MI’s and be adequately reimbursed for these time-intensive and complex encounters.

**Barrier 2: Patient/family religious and spiritual beliefs about death and dying**
Doctors reported that religious and spiritual beliefs greatly influenced how ethnic patients perceived EOL issues ranging from (i) an unwillingness to discuss EOL issues or plan ahead due to their beliefs that the timing and nature of a person’s death should be determined “by the will of God” and humans should not tamper with the process (ii) religious taboos about withholding/ withdrawing high intensity interventions at the EOL (iii) as families were praying for miracles and thus refused to engage in EOL discussions and planning even in the face of impending death; and (iv) patient/family beliefs that the specific circumstances around the death impacts the patient’s afterlife and they were reluctant to participate in actions that may in some way alter the timing and course of death.

Doctors need to be trained to work effectively with patients and families from diverse religious/spiritual backgrounds and to consult and partner with chaplains and community spiritual leaders in providing necessary support to seriously ill patients and families to facilitate quality EOL decisions.

**Barrier 3: Doctors’ ignorance of patients’ cultural beliefs, values and practices**
The doctors felt that their ignorance about the diverse cultural values around death and dying was the third biggest barrier to effective EOL conversations with seriously ill patients and their families from diverse cultures. This lack of knowledge led to the doctors’ (i) inability to empathize with the ethnic patients’ cultural values that influence EOL decisions, and (ii) committing cultural faux pas by discussing taboo topics which inadvertently offended the patient/family and undermined the therapeutic relationship. Doctors need to be trained on how to effectively conduct EOL communications with ethnic patients, (iv) the variability in quality and accuracy of the MI’s, (v) sometimes MI’s interfered with the diplomacy of the doctor-patient encounter by giving advice to the patient or by assuming the role of a patient advocate.

As the US population is becoming more diverse, it is imperative that we train doctors and medical interpreters to work together respectfully and effectively following standard guidelines. Furthermore, system triggers need to be built to automatically identify patients with LEP and schedule adequate clinical encounter time for doctors to work with MI’s and these patients. Additionally, system changes need to be made so that all doctors will be able to use special billing codes like the interactive complexity add-on Current Procedural Terminology (CPT) codes when working with MI’s and be adequately reimbursed for these time-intensive and complex encounters.

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![Fig 6. Graphic shows how doctors in various medical subspecialties rate the relative importance of the 6 primary barriers to effective EOL conversations with ethnic patients.](image)

The dotted line represents the individual sub-specialty. The solid line represents the average ranks for doctors from the two largest sub-specialties, namely Internal Medicine and Surgery. The biggest differences across sub-specialties were seen in Emergency Medicine, Neurology, Psychiatry and Anesthesia and these are shown in comparison with the two largest sub-specialties (Medicine and Surgery) as line graphs. B1 to B6 represent the top six barriers to effective EOL conversations with ethnic patients. B1 = Language and medical interpretation issues; B2 = Patient/family religious and spiritual beliefs about death and dying; B3 = Doctors’ ignorance of patients’ cultural beliefs, values and practices; B4 = Cultural differences in truth handling and decision making; B5 = Patient/family’s limited health literacy; and B6 = Patient/family’s distrust of doctors and the health care system.
discussions in a culturally sensitive and competent manner with seriously ill persons from various cultural and ethnic backgrounds. Such training could be incorporated as a longitudinal curricular thread across the continuum of medical education ranging from undergraduate to postgraduate training and as an essential component of continuing medical education.

**Barrier 4: Cultural differences in truth handling and decision making**

Doctors stated that in some cultures, the patient/family believed that even speaking about death and dying would invoke death sooner and therefore refused to engage in EOL discussions. In others, the family wanted the diagnostic and prognostic information withheld from the patient due to a belief that (the patient) knowing the truth about the illness would cause the patient to lose hope. Sometimes, the patients recused themselves from decision making, especially common in women in certain cultures. Instead, they relegated decision-making to their family who may or may not use the principles of substituted judgment or, worse still, may act to promote their own personal interests over those of the patient’s. This was particularly challenging where large extended families were involved, the hierarchy and process of decision-making was unclear or group decision-making was preferred. These situations typically triggered multiple time-intensive family meetings about EOL issues, a source of great stress for doctors. Faced with these complex situations, doctors who may not have the time and/or training to engage patients and families in a constructive manner may procrastinate or even avoid vital EOL conversations with their seriously ill patients.

**Barrier 5: Patient/family’s limited health literacy**

National data show that limited health literacy disproportionately affects ethnic minorities, especially the poor, the uninsured and older adults. Research also shows that patients forget 40–80% of medical information provided to them and half of what they do remember is incorrect. Patients with limited health literacy may lack the ability to comprehend complex medical concepts like resuscitation preferences. Alternatively, they may have unrealistic expectations that medical technology is capable of curing any type of terminal illness or at least is effective in keeping the patient alive indefinitely with technological support.

Furthermore, it is very important to remember that even commonly used words can mean very different things to different people. For example, oncologists often use the word “cure” to indicate five years of cancer-free survival. However, to many cancer patients and families, the word “cure” means eradication of cancer and restoration of normal health. Another example is the English word “hospice” which sounds like “hospiscio” in Spanish, meaning poorhouse. It is possible that when a doctor raises the option of referral to hospice care, an impoverished Spanish-speaking patient may misunderstand that the doctor is withholding expensive interventions and referring them to the poorhouse and thus be deeply offended.

Such perceptions, whether merited or not, can create a deep mistrust in patients who may not vocalize these concerns but may resist end-of-life conversations with their doctors. The health literacy level of each patient needs to be assessed and clearly documented in the electronic medical records. Doctors need to be trained to avoid medical jargon when communicating with patients and use techniques like “teach back” to assess for the patient’s understanding of information imparted.

**Barrier 6: Patient/family’s mistrust of doctors and the health care system**

Because of historical events that have occurred between the medical establishment and certain ethnic communities, patients may not believe that doctors have their best interests at heart and may fear abandonment or being subjected to poor quality care by self-interested medical professionals. Patient’s family may also believe that high-intensity interventions are being withheld or withdrawn from the seriously ill patient because of racism. Thus, any notions of withholding high-intensity medical interventions and instituting hospice care may be misinterpreted as deliberate provision of sub-standard care, leading the families to be deeply suspicious of EOL discussions. In situations where there is conflict about EOL decision-making, doctors (fearing litigation, family mistrust) automatically provide high-intensity interventions that may be ineffective and burdensome to terminally ill patients. Honest and open communication in simple language and shared decision making will help foster trusting therapeutic alliances and thereby better quality EOL decision making. Additionally, public engagement campaigns are needed to educate Americans that high-intensity treatments on terminally ill patients do not necessarily result in prolonging life with quality but may only prolong the dying process while increasing the patient’s suffering.

To our knowledge, ours is the first and largest study of its kind using an innovative mixed methods approach to characterizing doctor-reported barriers to effective EOL conversations with diverse Americans. We were able to qualitatively identify the 6 main themes using a development cohort, empirically validate these themes by analyses of 50 randomly identified transcripts from the validation cohort and then finally use the results of the qualitative analysis to quantitatively analyze the validation cohort data. We believe that through this novel approach, we have demonstrated a strategy to employ rigorous quantitative research methods to assess the magnitude and frequency of constructs and rigorous qualitative research to explore the meaning and understanding of the constructs. Furthermore we have merged quantitative and qualitative data to develop a more complete understanding of a complex and important problem—in this case the barriers doctors face in conducting effective EOL conversations.

Our study is limited by the fact that the study participants were doctors from two hospitals in one geographic area. However, our institutions recruit and employ doctors from throughout the US and the ethnic and gender background of our doctors is reflective of the recent national trends of increasing women and diverse doctors reported by the Accreditation Council for Graduate Medical Education in 2013 (White 65.1%, Asian 21.2%, Black 6.3% and Hispanic American 6.3%). In fact, our diversity in doctors and the patients we serve was the main reason that made this study possible. Also, our study, is in part, a qualitative study and thus methodologically challenging to conduct nationally. However, it is to be noted that we have followed the COREQ guidelines in conducting our study and in reporting our qualitative findings.

**Conclusion**

Most doctors report that conducting effective EOL conversations with seriously ill patients is very challenging, especially with ethnic minority patients and their families. We have empirically identified the six primary barriers doctors report in conducting effective EOL conversations and demonstrated that the doctors’ age, ethnicity and sub-speciality influences their perceptions of these barriers. As the US is becoming increasingly diverse and as ethnic patients are more likely to consume ineffective and burdensome high-intensity treatments at the EOL, there is an urgent need to train doctors in conducting culturally effective EOL conversations early in the trajectory of any chronic and serious illness in order to facilitate dignity at the EOL for diverse Americans.
The legal formalization of patients' preferences for end-of-life care has evolved over the last several years with the growing recognition of the importance of incorporating patients' preferences into clinical decision-making, particularly at the end of life. In the 1990s, the Physician Orders for Life-Sustaining Treatment (POLST) was developed in Oregon, and many other states have adopted it. The POLST form enables providers to elicit and record patients' preferences for palliative care in a standardized, actionable format so that providers uphold these preferences.

New Jersey Physician Orders for Life-Sustaining Treatment Program (POLST) Frequently Asked Questions for Providers

What does "POLST" stand for?
POLST stands for Practitioner Orders for Life-Sustaining Treatment.

What is the POLST form?
POLST is a set of medical orders that help give seriously ill or frail elderly patients more control over their end-of-life care. Produced on a distinctive green form and signed by both the doctor/APN and patient/surrogate, POLST specifies the types of medical treatment that a patient wishes to receive toward the end of life. As a result, POLST can prevent unwanted or medically ineffective treatment, reduce patient and family suffering and help ensure that patients' wishes are honored.

What information is included on the POLST form?
Documentation on the POLST form includes:
• Goals of care for the patient
• Preferences regarding cardiopulmonary resuscitation attempts
• Preferences regarding use of intubation and mechanical ventilation for respiratory failure
• Preferences for artificially administered nutrition and hydration
• Other specific preferences regarding medical interventions that are desired or declined.

Is POLST mandated by law?
Filling out a POLST form is entirely voluntary. However, New Jersey law requires that medical orders contained in a POLST be followed by healthcare professionals and provides immunity from civil or criminal liability to those who comply in good faith with a patient's POLST.

Who should have a POLST form?
POLST is designed for seriously ill patients or those who are medically frail with limited life expectancy, regardless of their age.

Does the POLST form replace a traditional Advance Directive?
The POLST form complements an Advance Directive and is not intended to replace that document. An Advance Directive may still be necessary to appoint a legal healthcare decision maker and is recommended for all adults, regardless of their health status.

If someone has a POLST form and an Advance Directive that conflict, which takes precedence?
Ideally, the values expressed on both documents should be the same. If there is conflict between the two documents, a conversation with the patient or surrogate should take place to determine the most current preferences as soon as possible. The POLST and the Advance Directive can then be updated based on these more current treatment choices. If this cannot be done and a crisis ensues, care should be provided in accordance with the most recent document, whether it be the Advance Directive or the POLST.

Who should discuss and complete the POLST form with patients?
Having a conversation with a patient about end-of-life issues is an important and necessary part of good medical care. The law allows a physician or an advance practice nurse to complete a POLST form. In many cases, these practitioners will initiate conversations with their patients to understand their wishes and goals of care. Depending on the situation and setting, other trained staff members—such as nurses, palliative care team members, social workers or chaplains—may also play a role in starting the POLST conversation. However, physicians/APNs are responsible for the final clarification of those preferences and documentation of the appropriate orders on the POLST form.

Can a POLST form be completed for patients who can no longer communicate their treatment wishes?
Yes. A physician or advanced practice nurse can complete the POLST form based on a legally recognized surrogate decision maker's understanding of the patient's preferences. The surrogate can then sign the POLST form on behalf of the patient.

What should be done with the form after it is completed and signed?
• The original POLST form, on green paper, stays with the patient at all times. If the patient is transferred to another setting, the original POLST form goes with the patient.
• In the acute care or long term care settings, the original form should be kept in the patient's medical record or file in the doctor's order section, and copies should be made or scanned into the medical record to maintain.
• At home, patients should be instructed to place the original form in a visible location so it can be found easily by emergency medical personnel—usually on a table near the patient's bed or on the refrigerator. Copies may be kept for record-keeping.

Can a patient's POLST form be changed?
Yes, the POLST can be modified or rescinded by a patient with decision-making capacity, verbally or in writing, at any time. Changes may also be made by the patient's legally recognized surrogate, if the patient previously authorized the surrogate, via the POLST form, to make such modifications. Any changes to the POLST form should be made in collaboration with the patient's physician or advance practice nurse.

When should a patient's POLST form be reviewed?
It is good clinical practice to review a patient's POLST form when any of the following occur:
• The patient is transferred from one medical or residential setting to another
• There is a significant change in the person's health status, or there is a new diagnosis
• The patient's treatment preferences change.

Are facsimile copies and photocopies valid? Must green paper be used?
Faxed copies and photocopies are valid. Green paper is preferred and should be used to distinguish the form from other forms in the patient's medical record; however, the form will be honored on any color paper as long as it contains the appropriate signatures.
Where is POLST being used now?
POLST was originally developed in Oregon. There are a number of states that have established POLST programs or are currently developing programs. For more information on the national POLST paradigm, including published research and a complete listing of states using POLST, visit www.POLST.org

Does a POLST form take the place of other DNR order forms?
The patient’s preferences for cardiopulmonary resuscitation attempts and airway management are contained in a POLST form and should be honored upon receipt. However, hospitals and nursing facilities may still use other forms of Do Not Resuscitate orders in addition to the POLST in keeping with institutional policies. The N.J. Out-of-Hospital DNR form that has been utilized by EMS since 1997 will remain valid and should be honored upon receipt. However, eventually, the POLST form will evolve to replace most other order forms for resuscitation in all settings. Until that time, it is appropriate to honor all forms that are current and have not been rescinded or replaced by a more current form.

Does the POLST form expire?
No. However, it is recommended that a POLST form be reviewed frequently and especially when there is a change in medical condition, transfer to a different level of care setting or a change in preferences of the patient.

What happens if a POLST form is willfully ignored?
Healthcare professionals who intentionally ignore a POLST form will be subject to discipline for professional misconduct pursuant to Section 8 of P.L. 1978, c. 73 (C.45:1-21). Hospitals and healthcare facilities that intentionally ignore a POLST are subject to fines. Others such as family members who willfully conceal, ignore, hide, forge, falsify or fail to disclose a valid POLST form are guilty of a crime in the fourth degree. If the act of willfully concealing or withholding the form leads to the involuntary earlier death of the patient, it shall constitute a crime of the first degree.

Why is the first section about “Goals of Care”?
The goals of care for a patient’s healthcare plan are an important part of the comprehensive understanding of the patient’s medical condition, expected prognosis and the patient’s specific goals, such as wanting to spend time at home with family, wanting to get treatments that allow the patient to live until a loved one’s wedding or wanting to be comfortable and pain free regardless of length of life. These specific goals should be part of every conversation with patients about their treatment plans and the translation of those goals into physician/APN orders to accomplish those goals.
HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

NEW JERSEY PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

Follow these orders, then contact physician/APN. This Medical Order Sheet is based on the current medical condition of the person referenced below and their wishes stated verbally or in a written advance directive. Any section not completed implies full treatment for that section. Everyone will be treated with dignity and respect.

<table>
<thead>
<tr>
<th>PERSON NAME (LAST, FIRST, MIDDLE)</th>
<th>DATE OF BIRTH</th>
</tr>
</thead>
</table>

**A GOALS OF CARE** (See reverse for instructions. This section does not constitute a medical order.)

**B MEDICAL INTERVENTIONS:** Person is breathing and/or has a pulse.

- [ ] Full Treatment. Use all appropriate medical and surgical interventions as indicated to support life. If in a nursing facility, transfer to hospital if indicated. See section D for resuscitation status.
- [ ] Limited Treatment. Use appropriate medical treatment such as antibiotics and IV fluids as indicated. May use non-invasive positive airway pressure. Generally avoid intensive care.
  - [ ] Transfer to hospital for medical interventions.
  - [ ] Transfer to hospital only if comfort needs cannot be met in current location.
- [ ] Symptom Treatment Only. Use aggressive comfort treatment to relieve pain and suffering by using any medication by any route, positioning, wound care and other measures. Use oxygen, suctioning and manual treatment of airway obstruction as needed for comfort. Use Antibiotics only to promote comfort. Transfer only if comfort needs cannot be met in current location.

Additional Orders: __________________________________________________________________________

**C ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION:** Always offer food/fluids by mouth if feasible and desired.

- [ ] No artificial nutrition.
- [ ] Defined trial period of artificial nutrition.
- [ ] Long-term artificial nutrition.

**D CARDIOPULMONARY RESUSCITATION (CPR):**

Person has no pulse and/or is not breathing

- [ ] Attempt resuscitation/CPR
- [ ] Do not attempt resuscitation/DNAR

Allow Natural Death

**AIRWAY MANAGEMENT:**

Person is in respiratory distress with a pulse

- [ ] Intubate/use artificial ventilation as needed
- [ ] Do not intubate - Use O2, manual treatment to relieve airway obstruction, medications for comfort.

**E If I lose my decision-making capacity, I authorize my surrogate decision maker noted below to modify or revoke these NJ POLST orders in consultation with my treating physician/APN:**

Health care representative identified in an advance directive

- [ ] Yes
- [ ] No

Other surrogate decision maker

- [ ] Yes
- [ ] No

PRINT NAME OF SURROGATE (ADDRESS ON REVERSE) ____________________________ PHONE NUMBER ____________________________

**F SIGNATURES:**

I have discussed this information with my physician/APN.

Signature ____________________________

- [ ] Person Named Above
- [ ] Health Care Representative/Legal Guardian
- [ ] Spouse/Civil Union Partner
- [ ] Parent of Minor
- [ ] Other Surrogate

Has the person named above made an anatomical gift:

- [ ] Yes
- [ ] No
- [ ] Unknown

These orders are consistent with the person’s medical condition, known preferences and best known information.

PRINT - PHYSICIAN/APN NAME ____________________________ PHONE NUMBER ____________________________

PHYSICIAN/APN SIGNATURE (MANDATORY) ____________________________ DATE/TIME ____________________________

PROFESSIONAL LICENSE NUMBER ____________________________

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED
HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

PERSON NAME (LAST, FIRST, MIDDLE)  DATE OF BIRTH

PRINT PERSON'S ADDRESS

CONTACT INFORMATION

PRINT SURROGATE HEALTH CARE DECISION MAKER  ADDRESS  PHONE NUMBER

DIRECTIONS FOR HEALTH CARE PROFESSIONAL

COMPLETING POLST
• Must be completed by a physician or advance practice nurse.
• Use of original form is strongly encouraged. Photocopies and faxes of signed POLST forms may be used.
• Any incomplete section of POLST implies full treatment for that section.

REVIEWING POLST
POLST orders are actual orders that transfer with the person and are valid in all settings in New Jersey. It is recommended that POLST be reviewed periodically, especially when:
• The person is transferred from one care setting or care level to another, or
• There is a substantial change in the person’s health status, or
• The person’s treatment preferences change.

MODIFYING AND VOIDING POLST - An individual with decision making capacity can always modify/void a POLST at any time.
• A surrogate, if designated in Section E on the front of this form, may, at any time, void the POLST form, change his/her mind about the treatment preferences or execute a new POLST document based upon the person’s known wishes or other documentation such as an advance directive.
• A surrogate decision maker may request to modify the orders based on the known desires of the person or, if unknown, the person’s best interest.
• To void POLST, draw a line through all sections and write “VOID” in large letters. Sign and date this line.

SECTION A
What are the specific goals that we are trying to achieve by this treatment plan of care? This can be determined by asking the simple question: “What are your hopes for the future?” Examples include but not restricted to:
• Longevity, cure, remission
• Better quality of life
• Live long enough to attend a family event (wedding, birthday, graduation)
• Live without pain, nausea, shortness of breath
• Eating, driving, gardening, enjoying grandchildren

Medical providers are encouraged to share information regarding prognosis in order for the person to set realistic goals.

SECTION B
• When “limited treatment” is selected, also indicate if the person prefers or does not prefer to be transferred to a hospital for additional care.
• IV medication to enhance comfort may be appropriate for a person who has chosen “symptom treatment only.”
• Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), or bi-level positive airway pressure (BiPAP).
• Comfort measures will always be provided.

SECTION C
Oral fluids and nutrition should always be offered if medically feasible and if they meet the goals of care determined by the person or surrogate. The administration of nutrition and hydration whether orally or by invasive means shall be within the context of the person’s wishes, religion and cultural beliefs.

SECTION D
Make a selection for the person’s preferences regarding CPR and a separate selection regarding airway management.

SECTION E
This section is applicable in situations where the person has decision making capacity when the POLST form is completed. A surrogate may ONLY void or modify an existing POLST form, or execute a new one, if named in this section by the person.

SECTION F
POLST must be signed by a practitioner, meaning a physician or APN, to be valid. Verbal orders are acceptable with follow-up signature by physician/APN in accordance with facility/community policy. POLST orders should be signed by the person/surrogate. Indicate on the signature line if the person/surrogate is unable to sign, declined to sign, or a verbal consent is given.

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED
References

Section 1: Assessment tools for palliative care


99. Assessing complicated grief using the TwoTrack Bereavement Questionnaire (TTBQ). The 10th international conference on Grief and Bereavement in Contemporary Society: East meets West expanding frontiers and diversity; 2014 Hong Kong. p. 54.


Section 2: Compassionate collaborative care: an integrative review of quality indicators in end-of-life care


Section 3: Recognizing difficult trade-offs: values and treatment preferences for end-of-life care in multi-site survey of adult patients in family practices.


Cox CE, White DB, Abernethy AP. A universal decision support system. Addressing the decision-making needs of patients, families, and clinicians in the setting of critical illness. Am J Respir Crit Care Med. 2014;190:366–73.


Section 5: No easy talk: a mixed methods study of doctor reported barriers to conducting end-of-life conversations with diverse patients.


END-OF-LIFE: DOMAINS AND COMMUNICATIONS

Self-Assessment

Choose the best possible answer for each question and mark your answers on the Self-Assessment answer sheet at the end of this book. There is a required score of 70% or better to receive a Certificate of completion.

11. Which domains and subdomains of palliative care have many assessment tools?
   A. Dyspnea, psychologic, and psychiatric, social, bereavement
   B. Structure and process
   C. Ethical and legal
   D. Key informants

12. Which domains of palliative care have few or no assessment tools?
   A. Structure and process
   B. Spiritual, religious, and existential, ethical and legal
   C. Dyspnea, psychologic, and psychiatric, social, bereavement
   D. Usability

13. Which finding is an overarching structure and key quality indicator of compassionate collaborative care (CCC)?
   A. Development and satisfaction
   B. Empathy
   C. Goal setting
   D. Patient- and family-centered care

14. The most well documented strategy for promoting and engaging individuals, teams, and organizations in CCC is?
   A. The Comprehensive Pediatric Bereavement Program
   B. Schwartz Center Rounds (SCR)
   C. The Compassionate Collaborative Care Model and Framework
   D. The WHO Framework for Action on Interprofessional Education & Collaborative Practice.

15. What value statements did patients rank the highest relative to medical care wanted or not wanted at end of life?
   A. Being comfortable and suffering as little as possible, having more time with family, death is not prolonged
   B. Life should be preserved
   C. Nature should be allowed to take its course and hospitalization should be avoided
   D. Respect wishes of family

16. Which is an example of a conflict in values as indicated by a lack of correlation between the ratings of two value statements by patients?
   A. Living as long as possible and having more time with family
   B. Avoid machines/tubes and death not be prolonged
   C. Being comfortable/suffering as little as possible and avoid machines/tubes
   D. Having more time with family and respecting family wishes

17. In families in which the end-of-life decision-making role is based on legal and cultural understandings, which is not a factor in determining who would fill this role?
   A. Family role (eg, spouse)
   B. Gender
   C. Age
   D. Level of education

18. Which is not a supportive behavior on the part of a physician interacting with family members during end-of-life care?
   A. Respecting multiple voices in the family decision
   B. Ensuring that the family as a decision-making unit was honored
   C. Avoiding sharing difficult information with family members
   D. Encouraging the formal surrogate decision-maker to step in when families engaged in conflict or hesitated to make a decision
19. Regarding “Language and medical interpretation issues,” which recommendations were made to help overcome this specific barrier?
A. Doctors should be trained to not use medical jargon
B. Build in system triggers to automatically identify patients with limited English proficiency and schedule adequate clinical encounter time for doctors to work with medical interpreters and these patients
C. Hold public engagement campaigns to educate Americans that high-intensity treatments on terminally ill patients do not necessarily result in prolonging life with quality but may only prolong the dying process while increasing the patient’s suffering
D. Train more doctors from diverse culturally backgrounds

20. As “Cultural differences in truth handling and decision making” was one of the top six physician-reported barriers to end-of-life conversations, which was not an aspect of this barrier specifically identified by physicians?
A. In some cultures, the patient/family believe that even speaking about death and dying would invoke death sooner and therefore refuse to engage in end-of-life discussions
B. The family wants the diagnostic and prognostic information withheld from the patients due to a belief that (the patient) knowing the truth about the illness would cause the patient to lose hope
C. Patients feel psychologically distanced from physicians when communicating through medical interpreters
D. Some patients recuse themselves from decision-making (female patients in particular) and relegated the task to their family who may not base decisions according to the patient’s preferences or who may act to promote their own personal interests
VERIFIED CERTIFICATES AND LEARNER RECORDS

1. **Important:** To ensure accurate record keeping and reporting, your personal information entered at the beginning of the assessment should match your license record.

2. **Why we collect this info:** We use this information to uniquely identify each individual who successfully completes our activities and verify learner records for professional credentialing.

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**FIRST NAME:** John  
**LAST NAME:** Doe  
**EMAIL ADDRESS:** johndoe@e-mail.com  
**PHONE NUMBER:** (123) 456-7890  
**LICENSE NUMBER:** 25MA06613500  
**LICENSE STATE:** NJ  
**LICENSE EXPIRATION DATE:** 06/30/2019  
**MAILING ADDRESS:** 1234 Cherry Street  
**CITY:** Trenton  
**STATE:** NJ  
**ZIP CODE:** 08625  
**SPECIALTY:** Internal Medicine

**LICENSE NUMBER FORMATS:**

- **Physicians (MD):** 
  “25MA” followed by 8 numbers  
  (25MA06613500)

- **Doctors of Osteopathy (DO):** 
  “25MB” followed by 8 numbers  
  (25MB06613500)

- **Podiatrists:** 
  “25MD” followed by 8 numbers  
  (25MD00317200)

- **Physician Assistants (PA):** 
  “25MP” followed by 8 numbers  
  (25MP00317200)

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**MANDATORY CME ON END-OF-LIFE & OPIOIDS**

All licensed physicians (MD/DO), podiatrists, and physician assistants (PA) are required to complete one (1) credit of continuing medical education on prescription opioid drugs, including responsible prescribing practices, alternatives to opioids for managing treatment of pain, and the risks and signs of opioid abuse, addiction, and diversion as a condition of biennial renewal. Licensed physicians (MD/DO) and podiatrists must also complete two (2) credits of CME related to end-of-life care, unless exempt.

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**Turn in information online or by following these easy steps:**

1. Complete the customer information, self-assessment & activity evaluations on the next page.
2. Tear out the page.
3. Mail the form in the self-addressed envelope.

Phone: 1-800-237-6999  ● Fax: 1-800-647-1356

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SELF-ASSESSMENT ANSWER SHEET

2019 NEW JERSEY MEDICAL LICENSURE PROGRAM

To Receive Credit: Please ensure information entered matches your license record and all required fields are accurately completed. For help see the previous page.

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MARK ONE ANSWER PER QUESTION

NONPHARMACOLOGIC, NONOPIOID, AND OPIOID TREATMENT OPTIONS IN CHRONIC PAIN THERAPY (P. 22)

1. A B C D
2. A B C D
3. A B C D
4. A B C D
5. A B C D
6. A B C D
7. A B C D
8. A B C D
9. A B C D
10. A B C D

END-OF-LIFE: DOMAINS AND COMMUNICATIONS (P. 69-70)

11. A B C D
12. A B C D
13. A B C D
14. A B C D
15. A B C D
16. A B C D
17. A B C D
18. A B C D
19. A B C D
20. A B C D

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Please complete the activity survey on the following page.
# ACTIVITY EVALUATION(S)

For each of the objectives determine if the activity increased your: **A** Competence  **B** Performance  **C** Outcome  **D** No Change

<table>
<thead>
<tr>
<th>Nonpharmacologic, Nonopioid, and Opioid Treatment Options in Chronic Pain Therapy:</th>
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</thead>
<tbody>
<tr>
<td>1. Construct chronic pain management treatment plans that include non-pharmacologic and non-opioid pharmacologic therapies.</td>
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<td>3. Please identify a specific change, if any, you will make in your practice related to nonpharmacologic, nonopioid, and opioid treatment options in chronic pain therapy?</td>
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<td>4. What do you see as a barrier to making these changes?</td>
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<tr>
<th>End-of-Life: Domains and Communications:</th>
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<td>5. Choose strategies to apply in assessing palliative care domains.</td>
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<td>6. Design strategies to utilize with patients/family members/caregivers for improved communications.</td>
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<td>7. Please identify a specific change, if any, you will make in your practice related to caring for patients at the end-of-life?</td>
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<td>8. What do you see as a barrier to making these changes?</td>
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<tr>
<th>Program Evaluation:</th>
<th>Yes</th>
<th>No</th>
<th>If no, please explain:</th>
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<td>9. The program was balanced, objective &amp; scientifically valid.</td>
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<td>10. Do you feel the program was scientifically sound &amp; free of commercial bias or influence?</td>
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<td>11. How can this program be improved?</td>
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<td>12. Based on your educational needs, please provide us with suggestions for future program topics &amp; formats.</td>
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