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A MORE BALANCED APPROACH TO OPIOID USE AND MANAGEMENT IS ALSO NEEDED IN END-OF-LIFE CARE

Significant pain and suffering are frequent at the end-of-life, and opioids are often essential for relief. Although opioids must be readily available when appropriate, particularly for unbearable physical pain, some of the same issues causing current reconsideration of aggressive opioid guidelines for chronic pain[1] also apply at the end of life. These patients may be given opioids when other potentially beneficial treatments should be tried first or for reasons other than physical pain, prescribed excessive doses, and insufficiently counseled or supported. Opioids are easy to start but challenging to discontinue and can cause dependence and psychosocial consequences, and vulnerability at end-of-life may increase risk of and burden from harms and side effects. These patients and their families usually also have multifactorial suffering requiring multidisciplinary teams and approaches other than or in addition to opioids.

Since 2000, rates of use of common opioids have increased fourfold, with much of the increase in advanced illness such as cancer. Contributing factors include pharmaceutical company promotion, changes in attitudes and regulations regarding opioids, and health professional and other organizations' initiatives for more pain screening and treatment. Despite this trend, two recent rigorous, nationally-representative studies found that families' perspectives of quality of end-of-life care and pain management actually worsened in this time period, with one study finding that 25.2 percent of families reported unmet need for pain management at end-of-life in 2011 to 2013, compared to 15.5 percent in 2000 (adjusted odds ratio 1.9, 95% confidence interval 1.1-3.3).[2]

Although many potential reasons underlie this lack of progress, and some patients who would benefit from opioids still do not receive them, clearly more use of alternatives to opioids and improved approaches to opioid use are needed. Suffering sometimes is not founded in physical pain and almost never in physical pain alone, and opioids can worsen suffering. In the words of Eric Cassell, "Providers' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself."[3]

Even when opioids are necessary, they can cause significant harm and burden. As a daughter recently wrote about her dying mother, "…because her symptoms were constantly shifting and magnifying, the dosages changed too, and it soon became impossible for my family to distinguish which of Mom's symptoms were due to the disease process and which were due to side effects of the meds…."[4] The drugs can cause delirium, including confusion and agitation, especially in older patients, which can be distressing at the end of life and prevent patients from remaining at home. Families often worry about oversedation; it's difficult to determine the "right" level at end-of-life, but achieving balance is often difficult. Providers often discount constipation as minor and treatable, but constipation can be challenging to manage and devastating to comfort and dignity, especially for someone who can't easily get out of bed. And psychosocial and practical issues about opioids can cause significant burden at the end of life, with patients developing symptoms of tolerance, trying to cut back or stop due to guilt, having trouble getting medications or running out, even experiencing withdrawal.

How can providers possibly balance relief of pain at end-of-life with the suffering they might cause? One necessary advance is acknowledging this tradeoff and addressing it in end-of-life pain ethical frameworks as applied to clinical care. Clinicians' primary obligation is to "first do no harm" and minimize burdens while promoting meaningful benefits. Accomplishing this goal requires greater attention to addressing ethical tradeoffs with various treatment regimens. Maximizing patient understanding of options, harms and burdens requires a professional culture that seriously considers and carefully examines these tradeoffs, reduces efficiency-oriented pressures and supports clinicians to spend needed time to understand, assess and support patients' needs.

Another important approach is acknowledging these issues in conceptualizing quality of care at the end of life. End-of-life quality measurement must include pain management. However, rather than assessing only the outcome of whether pain has

been treated and the pain score decreased—which may encourage inadequate assessment and over-prescribing—a better potential measure may be to ask, "how is your pain management? Too little, too much, just right?" The goal is just right—and if not, to understand why through careful assessment. Organizations must also develop measures of appropriate opioid use to include in pain management quality improvement and palliative care interventions. Opioids are often needed—but the solution is almost never simply to give more of them.

Although these types of issues are now starting to be incorporated into guidelines for chronic pain, they have not yet been addressed in key position statements on pain management on opioids at end-of-life, which focus on the requirement to relieve pain and address only the ethical risk of possibly shortening life while doing so.[5,6] Important other principles from new chronic pain opioid guidelines[7] may also apply at the end of life and should be considered (Table 1), including the need for detailed assessment, beginning with non-opioid therapy where possible, considering the decision to initiate opioids carefully, using short-term initial opioid prescriptions for acute pain when appropriate, monitoring carefully for benefits and harms, and considering discontinuing opioids with support when harms exceed benefits.

Finally, clinicians need to listen more to patients and families, to achieve more balance in providing opioids only when really needed and even then along with other options for pain, even at the end of life. It is essential to address pain in the context of—and with services available that can alleviate – other symptoms and psychosocial and spiritual suffering. In the patient- and family-centered care framework, physical comfort is important but only one of many issues that must be addressed. Professional organizations need new dialogue and reassessment of assumptions about opioids at the end of life as well, to incorporate emerging knowledge on more judicious approaches to opioid use into care and better incorporate the patient and family perspective.

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REFERENCES

1. Nelson LS, Juurlink DN, Perrone J: Addressing the Opioid Epidemic. *JAMA*. 2015;314(14):1453-1454. doi: 10.1001/jama.2015.12397 [doi].

2. Teno JM, Freedman VA, Kasper JD, et al: Is Care for the Dying Improving in the United States? *J Palliat Med*. 2015; 18(8): 662-666. doi: 10.1089/jpm.2015.0039 [doi].

3. Cassel EJ: The nature of suffering and the goals of medicine. *N Engl J Med*. 1982; 306(11): 639-645. doi: 10.1056/NEJM198203183061104 [doi].

4. Lanning R: "Death doesn't come like it does in the movies:" What my mother's last days taught me about our right to die. *Salon.com*. 2015. Available at: *http://www.salon.com/2015/10/09/death_doesnt_come_like_it_does_in_the_movies_what_my_mothers_last_days_taught_me_about_our_right_to_die/*. Accessed October 25, 2016.

5. Hospice & Palliative Nurses Association. HPNA Position Statement: The Ethics of Opioid Use at End of Life. Available at *http://hpna.advancingexpertcare.org/wp-content/uploads/2015/08/The-Ethics-of-Opioid-Use-at-End-of-Life.pdf*. Accessed June 18, 2016.

6. American Society for Pain Management Nursing. American Society for Pain Management Nursing Position Statement Pain Management at the End of Life. 2013. Available at: *http://www.aspmn.org/documents/PainManagementattheEndofLife_August2013.pdf*, Accessed June 20, 2016.

7. Dowell D, Haegerich TM, Chou R: CDC Guideline for Prescribing Opioids for Chronic Pain—United States, 2016. *MMWR Recomm Rep* 2016; 65: 1–49. DOI: http://dx.doi.org/10.15585/mmwr.rr6501e1

Table 1. Proposed principles for opioid use for pain at the end of life*
Ethical approach for providers
"First do no harm"—carefully consider potential for benefit and harm in the context of patient and family goals, expectations, and probable consequences
Be aware of "empathic overarousal" and the desire to do something quickly and definitively, compared to a more measured approach
Promote professional culture where opioid decisions include careful consideration of benefits and harms, which are communicated to patients and families and monitored
Support providers in adequate time, support and resources, including availability of supplemental and alternative approaches, and managing their own distress and helplessness in the face of suffering
Clinical recommendations
When necessary, use short-term (<3 days) opioid use when possible as first step while other approaches are initiated, without increasing suffering
Reassess and consider weaning off with support when opioids are not helpful (including escalating doses) or harms exceed benefits
Include measures of potential opioid overuse with quality measures and interventions for pain management and relief of suffering
Patient- and family-centered use
Listen and seek to understand patient and family preferences, needs and concerns about pain, suffering and opioids
Ensure opioid availability and access when starting opioids
Ensure holistic assessment and management of other symptoms and sources of suffering, including engaging interdisciplinary clinicians such as nurses, chaplains, and social workers
*Adapted from the Centers for Disease Control and Prevention Guideline for Prescribing Opioids for Chronic Pain[7]