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Development of a therapeutic algorithm to guide clinicians considering palliative sedation therapy in pediatric patients at the end of life

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Background: Despite advances in palliative care a subset of patients experience suffering at the end-of-life refractory to traditional therapy. Palliative sedation therapy (PST) with medications achieving continuous deep sedation (CDS) is well documented in the adult literature as an ethically permissible treatment for intractable suffering. Guidelines for CDS in children are less clear.

Objective: Clarify the ethical permissibility of CDS in children at the end of life and develop an algorithm for use in clinical practice.

Design/Methods: Identification of patients who received propofol PST within 20 days of inpatient death (2003-2010) and review of the medical record for indicators of pain, suffering, and sedation from 48 hours before PST to the time of death. Based upon this case series we conducted a literature review and developed a clinical algorithm for initiation of PST in children.

Results: Three of 192 (1.6%) of children received propofol PST. Use of opioids and supportive medications decreased in 2 cases and in the third case, CDS was effective in relieving other distressing symptoms. Clinical notes suggested improved comfort and rest in all patients. CDS is justified to relieve end-of-life suffering only if the distressing symptoms are refractory to standard palliative management. The indications for PST at the end of life include two core components: the presence of severe suffering refractory to standard palliative management and the primary aim of relief of distress. No ethical contraindication to the use of PST exists in children and numerous case series, including our own, demonstrate its' efficacy. We provide an algorithm for clinicians considering PST in a pediatric patient at the end of life.

Conclusions: Children with intolerable suffering at the end-of-life should not be allowed to continue with refractory symptoms due to clinician inexperience with this infrequent intervention "of last resort." Our algorithm provides a guideline for clinicians and institutions to use in clinical practice.

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Educational intervention increases primary care providers' comfort in discussing advance care planning

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Background: Advances in medicine have made end-of-life difficult for older adults without prior advance care planning (ACP). Benefits of ACP include decreasing family stress, allowing death with dignity and cost saving at end of life. Despite the benefits, less than a third of the population has ACP. Older adults want their primary care provider to initiate conversations on ACP. Primary care providers rate their own comfort level with ACP discussions as low. The purpose of this project was to increase primary health care providers' including physicians, nurse practitioners and physician assistants (PCP) comfort in discussing ACP with their older adult patients.

Method: An 8 step educational intervention on best practice for discussing ACP using the Medical Orders for Life Sustaining Treatment (MOLST) Model was conducted in PCP's offices. A convenience sample of 64 primary care providers (PCP) from NYC, who care for patients over 65 years of age, were surveyed using a descriptive, repeated measures design. The pre and posttest instrument is a Communication Strategy Questionnaire for ACP that uses 14-item Likert scale, with scores ranging from 14-56, measuring comfort in discussing ACP.

Results: The MOLST intervention significantly improved comfort in discussing ACP for PCP with their patients ($p < 0.001$).

Conclusion: A simple 8-step educational intervention demonstrates significant improved comfort level amongst PCPs when discussing end-of-life preferences with patients. Primary care providers can make an impact on older adults' end-of-life by discussing advance care.

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