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Assessing screening tools to identify patients with palliative care needs in the emergency department: a systematic review
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Introduction: With an increasing proportion of patients in need of end-of-life (EOL) care presenting to the emergency department (ED), many of these patients may benefit from early palliative care (PC) referral. In fact, early PC referral is one of the Choosing Wisely ED recommendations in the USA. As such, there is a potential benefit to identifying patients with advanced or end-stage illness with PC needs. The objective of this systematic review is to identify and synthesize the available evidence regarding the existence and psychometric properties of screening tools to identify patients with advanced or end-stage illness and PC needs presenting to EDs. Methods: A comprehensive search of eight electronic databases and the grey literature was conducted. Studies assessing the ability of a screening instrument to identify ED patients with advanced or end-stage illness in need of PC were eligible for inclusion. Two independent reviewers completed study selection, quality assessment, and data extraction. Disagreements were resolved through third-party adjudication. Due to the significant heterogeneity, as well as inconsistent outcome reporting, a descriptive summary of the results was completed. Results: Once duplicates were removed, the title and abstracts of 3516 studies were screened, of which, 15 studies were included. Overall, 10 unique screening instruments were assessed across the studies. The most commonly assessed screening tool was the use of the modified surprise question (SQ), in which physicians were asked if they would be surprised if the patient died within a specified period of time. Only four of the included studies assessed the diagnostic or psychometric properties of the screening tools. One study reported that the modified SQ had a sensitivity of 97%, specificity of 89%, and a negative predictive value of 97%. The proportion of patients identified with PC needs ranged from 12% to 73%, with studies utilizing the SQ reporting a range of 12% to 33%. Conclusion: A variety of screening tools are available to identify ED patients with advanced or end-stage illness who would benefit from a referral for PC. While the modified SQ was the most common instrument assessed and appears to be simple to implement, it is unclear if the diagnostic and psychometric properties of this tool are sufficiently robust to warrant widespread implementation. Keywords: pain experience, pediatric patients, vaso-occlusive crisis

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Patients’ and caregivers’ experiences with pain management in children and teenagers with sickle cell disease requiring admission for vaso-occlusive crisis
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Introduction: The quality of life of children with sickle cell disease (SCD) depends on the severity, timing and number of painful episodes (vaso-occlusive crises, VOC) and their need for medical treatment and hospitalizations. The objective of this study was to explore the experiences of pediatric patients and their families during VOC. Methods: This qualitative study used semi-structured one-on-one and focus group interviews, designed in partnership with two patients and one parent, in a single center, tertiary care pediatric university-affiliated hospital. Two groups of participants were interviewed independently: (1) adolescent patients aged 12 to 18 years old hospitalised within the last 2 years for VOC, (2) parents of pediatric patients with SCD hospitalised within the last 2 years for VOC. Data was transcribed in full and analysed using NVivo12. Descriptive thematic content analysis was performed by coding themes emerging from data. After validating codes through interjudge assessment by consensus, themes from teenagers’ and parent’s discourses were systematically compared for the final analysis. Results: Between June and August 2018, 8 interviews were conducted. 10 parents and 5 adolescents participated. Teenagers’ and parents’ answers mirrored each other’s. Prompt pain relief was crucial, although the side effects of pain relief medications used were an added source of suffering. Recent quality improvement initiatives such as standardised order sheets were noteworthy improvements, though personalizing care to each patient’s with pharmacological and non-pharmacological methods was also important to participants. Given the unpredictability and severity of VOC, their impact on both parents’ and families’ lives was substantial, as was the long term emotional burden. Parents felt guilty given the hereditary nature of the disease, they encouraged neonatal and prenatal testing, and they sought definitive treatments for both VOC and SCD. Tensions within parent-teenager relationships were described centered on developing autonomy and protecting the child to improve adherence to treatments. Conclusion: Participants emphasized the need to provide timely adequate analgesia, through both standardised quality improvement initiatives and a personalised approach to analgesia. Understanding the impact of VOC on patients’ lives and their socio-familial context is important to tailor clinical interventions. Keywords: emergency department, palliative care, screening tools

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A two-centre survey of caregiver perspectives on opioid use for children’s acute pain management
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Introduction: Given the current opioid crisis, caregivers have mounting fears regarding use of opioid medication in their children. Since caregivers are often the gatekeepers to their children’s pain management, understanding their perspectives on analgesia is essential. For caregivers of children with acute injury presenting to the pediatric emergency department (PED), we aimed to determine caregivers’: a) willingness to accept opioids from emergency care providers, b) reasons for refusing opioids, and c) past experiences with opioids. Methods: A novel 31-item electronic survey was offered, via tablet device, to caregivers of children aged 4-16 years who had a musculoskeletal injury <7 days old and presented to one of two Canadian PEDs between March and November 2017. Primary outcome was caregiver willingness to accept opioids for moderate pain for their children. Results: 517 caregivers completed the survey; mean age was 40.9 +/- 7 years with 70.0% (362/517) being mothers. Children included 62.2% (321/516) males with an overall mean age of 10 +/- 3.6 years. 49.6% of caregivers (254/512) reported willingness to accept opioids for moderate pain that persisted after non-opioid analgesia, while 37.1% (190/512) were unsure what they would do. Only 33.2% (170/512) of caregivers stated they would accept opioid analgesia upon discharge while 45.5% (233/512) were unsure about at-home use. Caregivers were primarily concerned about side effects, overdose, addiction, and masking of diagnosis. Caregiver fear of