Letters

Patient-Controlled Analgesia for Children With Life-Limiting Conditions in the Community: Results of a Prospective Observational Study

To the Editor

The use of patient-controlled analgesia (PCA) for children and young people with life-limiting conditions and life-threatening illnesses is an emerging intervention in pediatric palliative care as an alternative to continuous parental infusion with a separate breakthrough analgesia.[1,2] In pediatric palliative care, PCA is characteristically a continuous infusion of opioid administered via a programmable pump, which enables patients to control their pain by use of on-demand supplemental bolus analgesia.[2,3] This letter highlights barriers to use of PCA in this population as found in our study of PCA in the community and invites comment as a first step in addressing the issues we encountered.

We undertook a prospective observational study of efficacy, suitability, and utilization of an opioid PCA for children and young people with life-limiting conditions and life-threatening illnesses cared for in the community (home, hospice, and community hospital) (from November 2011-March 2013).

Patients were invited to participate in this study if they had

1. rapidly escalating pain and were opioid naïve/only using a small amount of opioid analgesia by another route of administration,
2. relatively stable background opioid analgesia requirements but with incident or spontaneous breakthrough pain, and
3. stable background opioid analgesia and some breakthrough pain and were at end of life.

Once PCA commenced, parents or community nurses provided daily assessments of bolus doses attempted and given (as read from the PCA pump) and other medications given within the previous 24 hours. Efficacy of PCA was determined on the basis of pain intensity scores while receiving PCA (both during the assessment and overall pain intensity in the preceding 24 hours) as measured by the numerical rating scale[4] or the Face, Legs, Activity, Cry and Consolability (FLACC).[5] Pain was also assessed in terms of site, provocation, severity, and radiation, as well as a description of other interventions undertaken in addition to PCA and its reported success in managing pain.

In the UK, as in other countries, pediatric palliative care patients move between places of care, requiring joint working with other hospitals, hospices, home care, or community care teams.[6] The patients in this study were given PCA under the supervision of a hospital tertiary palliative care service; however, day-to-day implementation of their symptom management plan including the PCA pump was the responsibility of a local community-based nursing team. PCA was delivered using CME McKinley pumps. The subcutaneous route was used for delivery of PCA in instances where the child did not have a central venous access line or where the community nursing teams or hospice teams could not support central venous access therapy.

Findings

Over a 16-month period, 40 patients were discussed in the multidisciplinary team meeting of the tertiary palliative care team as possibly able to benefit from PCA. Of those discussed, 29 patients were considered unsuitable for PCA. Reasons for exclusion were primarily clinical: pain not the primary symptom ($n = 11$), pain managed by other strategies ($n = 8$), existing morphine toxicity ($n = 1$), renal issues ($n = 1$), pain was neuropathic in nature and the team opted to trial a neuropathic agent instead of PCA ($n = 2$), and died before needing PCA ($n = 3$). Notably, in eight cases, PCA was not offered because of lack of nursing support in the community. In seven cases, reasons were unknown.

Of the 11 patients deemed suitable candidates for PCA and offered PCA, four patients declined and seven received PCA. Of the seven patients who received PCA, six had malignant disease and one had a nonmalignant diagnosis. Patients were aged between 6 and 17 years. Place of care for patients on PCA

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Table 1
Patient-Controlled Analgesia (PCA) Dose per Patient

Patient Number	Patient Weight	Drug	Total Dose	Background Dose	Bolus Dose	Time on PCA	Other Medications Given
1[a]	22 kg	Morphine sulfate	55 mg (2.2 mg/kg)	None	440 mcg (0.4 mL) with a 10-minute lockout	8 days	Paracetamol, carbamazepine, ondansetron
2[a]	54 kg	Morphine sulfate	1500 mg (28 mg/kg)	12 mg per hour (0.4 mL/hour)	12 mg (0.4 mL) with a 15-minute lockout	3 days	Ketamine, paracetamol, domperidone, transdermal hyoscine hydrobromide, docusate sodium
3	21.6 kg	Morphine sulfate	Range: 333.2 mg (15 mg/kg)–700 mg (32 mg/kg)	Range: 80 mg/ 24 hours–336 mg/ 24 hours	Range: 5 mg (0.38 mL) with a 10-minutes lockout to 21 mg (1.5 mL) with a 10-minute lockout	35 days	Midazolam, cyclizine, levomepromazine, transdermal fentanyl, haloperidol, paracetamol delivered rectally, ibuprofen, keppra, transdermal hyoscine hydrobromide, co-danthramer, ketamine given in a separate syringe driver
4	35 kg	Oxycodone	50 mg (1.4 mg/kg)	2 mg/hour (2 mL/hour)	1.5 mg (?) with a 5-minute lockout	7 days	Ketamine, gabapentin, paracetamol, transdermal fentanyl, metoclopramide, lorazepam, pantoprazole given IV, sucralfate, movicol
5	60 kg	Morphine sulfate	Range: 420 mg (7 mg/kg)–1500 mg (25 mg/kg)	Range: 100 mg/24 hours (0.5 mL/hour)– 360 mg/24 hours (0.5 mL/hour)	Range: 4.2 mg (0.5 mL) with a 10-minute lockout to 21 mg (0.7 mL) with a 10-minutes lockout	32 days	Sevredol, amitriptyline hydrochloride, ketamine, haloperidol, buccal midazolam, cyclizine, levomepromazine, octreotide, glycopyrronium bromide, self-prescribed medicinal use of cannabis
6	80 kg	Morphine sulfate	200 mg (2.5 mg/kg)	2.5 mg/hour (0.5 mL/hour)	2.5 mg (0.5 mL) with a 10-minute lockout	3 hours	Paracetamol, ketamine, ibuprofen, sevredol, amitriptyline hydrochloride
7	67 kg	Oxycodone	Range: 1120 mg (17 mg/kg)–1750 mg (26 mg/kg)	Range: 336 mg/24 hours (0.5 mL/hour)– 600 mg/24 hours (0.5 mL/hour)	Range: 14 mg (0.5 mL) with a 10-minute lockout to 25 mg (0.5 mL) with a 10-minute lockout	17 days	Transdermal fentanyl, ketamine, amitriptyline, pregabalin, midazolam, sublingual lorazepam, docusate sodium, phosphate enema, lactulose, sodium picosulfate

[a]Requested to have PCA removed.

was primarily home ($n = 5$); one patient was an inpatient in a local district general hospital who sought advice from the palliative care team, and one patient had their PCA started in hospice before going home on day 15 of their care, continuing to use PCA when at home. The PCA doses are listed in Table 1 along with all additional medications (including adjunct analgesia).

PCA use ranged from three hours to five weeks. Two patients requested to have their PCA removed after six and three days, respectively. Reasons for removing PCA were difficulty mobilizing, leaving their home, and/or doing the full range of their usual activities with the PCA in situ. Both patients also reported pain at the subcutaneous infusion site. The volume of the PCA dose was 0.4 mL/hour for both patients (Table 1).

Overall, there were 138 assessments of patients on PCA. These contained 100 complete pain assessments for patients receiving PCA. All pain reports were proxy reports of the patient's pain by either a parent or a nurse. Complete pain score data were missing for 38 assessments over all seven cases. Reasons given for missing pain score data were the deteriorating patient's inability to score their own pain and parent inability to score pain in their unconscious child. Three pain scores from one child were excluded from the analysis as the score was not taken from either the numerical rating scale or the FLACC.

Pain scores were not associated with PCA bolus use [current pain score x bolus given, $r(60) = -0.059$, $P = 0.655$; pain in the last 24 hours x bolus given, $r(57) = -0.124$, $P = 0.356$]. However, on further exploration when time from death was taken into account, there was a significant correlation between current pain and bolus given [$r(61) = 0.272$, $P = .034$] at 1-2 weeks before death when pain was highest. However, in the last week before death, bolus use continued to rise when pain scores were falling, probably, because the children were less awake and able to self-report their own pain. Previous literature, when it has examined PCA use by phases of the illness,[1,7] have found a similar lack of correlation between bolus use and pain scores in the last week of life.

Discussion

Forty patients were assessed for their suitability for PCA. Yet, of these, 29 were considered inappropriate for PCA. We found PCA bolus use was correlated with pain scores only in those patients awake and able to score their own pain. There are a number of implications of these findings.

First, patients in this study required community nursing support to start and maintain their PCA. For eight potential participants, this support was unavailable. One of the goals of pediatric palliative care is to provide choice in place of care and death to patients and their families.[6,8] Lack of service provision for patients at home may be disadvantaging patients from the choice of certain types of pain management such as PCA.[3]

Second, there is a need for more nuanced approaches to pain measurement. Current measures for PCA pain assessment are adapted from inpatient pain management (pain intensity, PCA side effects, bolus requirement).[3,9] We did not find that these measures correlated with PCA use at end of life. This finding is consistent with previous literature.[1,7] We would suggest this finding indicates pain measurement in children and young people with life-limiting conditions/life-threatening illnesses requires a move away from pain intensity toward a more multifactorial formulation of the pain experience with attention to the "psychosocial" components of the biopsychosocial model of pain (e.g., the ability to mobilize or engage in normal activities). In particular, this multifactorial measure of pain should be appropriate to the experience of this population, especially before death[10] and amenable to the need for proxy scoring.

Conclusions

We should, in pediatric palliative care, aspire toward efficacious pain management, which allows patients' choice in location of care and is fit for purpose regardless of this location. To achieve this, we need to develop robust strategies to deliver equitable care and to evaluate this care in a way which is tailored to children and young people with life-limiting conditions and life-threatening illnesses.

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Acute-on-Chronic Breathlessness: Recognition and Response

Lovell et al. are to be commended for their description of the widespread effects of breathlessness within the construct "total breathlessness".[1] Despite the large body of evidence on the experience of people living with chronic breathlessness, clinicians still struggle with its recognition and assessment. Even when recognized, the symptom is undertreated[2] and is experienced by people over many years[3–5] and is associated with repeated unplanned presentations to health services.[6]

In our prospective observational study of 1212 patients presenting to the emergency department by ambulance,[5] 20% presented due to acute-on-chronic breathlessness (acute worsening of chronic breathlessness). The concept of acute-on-chronic breathlessness builds on the definition of chronic breathlessness syndrome[7] and mirrors concepts of disease (acute-on-chronic renal failure) or symptoms (acute-on-chronic pain). Acute-on-chronic breathlessness is a construct beyond the "dyspnea crisis," which is limited in its definition to late-stage disease[8] and encompasses all forms of episodic breathlessness, triggered or untriggered.[9]

In our emergency department study, one-third of people with acute-on-chronic breathlessness were discharged home but without evidence of a plan to manage the ongoing chronic breathlessness. Unless clinicians (in any setting) recognize *both* the acute and chronic aspects of acute-on-chronic breathlessness, the life experience of chronic breathlessness remains invisible, which denies the patient access to evidence-based interventions[10,11] and misses opportunities to lessen the likelihood of representations.[6]

Community clinicians struggle with how to identify, assess, and manage chronic breathlessness. There are now useful frameworks to guide clinicians' assessment[12] and management.[13] As described in the Breathing Space concept,[14] the clinician plays a pivotal role in recognizing background chronic breathlessness—a step often overlooked.

Defining chronic breathlessness syndrome[7] has been an important first step. There is a new imperative: if a patient presents with acute breathlessness, there is now a responsibility for clinicians to determine whether this is an isolated episode of acute breathlessness or a presentation of acute-on-chronic breathlessness.