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Patient controlled analgesia for children with life-limiting conditions in the community: Results of a prospective observational study

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TITLE: Patient controlled analgesia for children with life-limiting conditions in the community: Results of a prospective observational study

RUNNING HEAD: COMMUNITY PCA FOR CHILDREN WITH LIFE-LIMITING CONDITIONS

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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 paediatric palliative care as an alternative to continuous parental infusion with a separate breakthrough analgesia (1, 2). In paediatric 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 utilisation 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
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 (NRS) (4) or the 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, paediatric 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 sixteen month period, forty 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), died prior to needing PCA (n=3). Notably, in eight cases PCA was not offered due to lack of nursing support in the community. In seven cases reasons were unknown.

Of the eleven patients deemed suitable candidates for PCA and offered PCA, four patients declined and seven received PCA. Of the seven patients who received PCA, six malignant disease and one had a non-malignant diagnosis. Patients were aged between 6-17 years. Place of care for patients on PCA 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 fifteen 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 3 hours-5 weeks. Two patients requested to have their PCA removed after six and three days respectively. Reasons for removing PCA were difficulty mobilising, 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 0.4mls/hr for both patients (table 1).

Overall there were one hundred and thirty-eight assessments of patients on PCA. These contained one hundred 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 was missing for thirty-eight 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 NRS or the FLACC.

Pain scores were not associated with PCA bolus use (current pain score x bolus given, $r(60)=-.059$ $p=0.655$; pain in the last 24 hours x bolus given, $r(57)=-.124$ $p=0.356$). However, on further exploration when time from death was taken into account, there was a significant correlation between current pain and bolus given ($r(61)=.272$ $p=.034$) at 1-2 weeks prior to 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, twenty-nine 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 paediatric 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 towards a more multi-factorial formulation of the pain experience with attention to the “psycho-social” components of the biopsychosocial model of pain (e.g. the ability to mobilise, or engage in normal activities). In particular this multi-factorial

measure of pain should be appropriate to the experience of this population, especially prior to death (10) and amenable to the need for proxy scoring.

Conclusions

We should in paediatric palliative care, aspire towards 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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Patient number	Patient weight	Drug	Total Dose	Background dose	Bolus dose	Time on PCA	Other medications given
1*	22kgs	Morphine sulphate	55mg (2.2mg/kg)	None	440mcg (0.4mls) with a 10 minute lockout	8 days	Paracetamol, carbamazepine, ondansetron
2*	54kgs	Morphine Sulphate	1500mg (28mg/kg)	12mg per hour (0.4ml/hr)	12mg (0.4mls) with a 15 minute lock out	3 days	Ketamine, paracetamol, domperidone, transdermal hyoscine hydrobromide, docusate sodium
3	21.6kgs	Morphine Sulphate	Range: 333.2mg (15mg/kg) - 700mg (32mh/kg)	Range: 80mg/24 hour - 336mg/24hour	Range: 5mg (0.38mls) with a 10 minute lockout - 21mg (1.5mls) with a 10 minute lock out	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	35kgs	Oxycodone	50mg (1.4mg/kg)	2mg/hr (2mls/hr)	1.5mg (?) with a 5 minute lockout	7 days	Ketamine, gabapentin, paracetamol, transdermal fentanyl, metoclopramide, lorazepam, pantoprazole given IV, sucralfate, movicol

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Patient number	Patient weight	Drug	Total Dose	Background dose	Bolus dose	Time on PCA	Other medications given
5	60kgs	Morphine Sulphate	Range: 420mg (7mg/kg) – 1500mg (25mg/kg)	Range: 100mg/24hrs (0.5mls/hr) – 360mg/24hrs (0.5mls/hr)	Range: 4.2mg (0.5mls) with a 10 minute lockout – 21mg (0.7mls) with a 10 minute lockout	32 days	Sevredol, amitriptyline hydrochloride, ketamine, haloperidol, buccal midazolam, cyclizine, levomepromazine, octreotide, glycopyrronium bromide, self-prescribed medicinal use of cannabis
6.	80kg	Morphine Sulphate	200mg (2.5mg/kg)	2.5mg/hr (0.5mls/hr)	2.5mg (0.5mls) with a 10 minute lockout	3 hours	Paracetamol, ketamine, ibuprofen, sevredol, amitriptyline hydrochloride
7.	67kgs	Oxycodone	Range: 1120mg (17mg/kg) – 1750mg (26mg/kg)	Range: 336mg/24hr (0.5mls/hr) - 600mg/24hrs (0.5mls/hr)	Range: 14mg (0.5mls) with a 10 minute lockout - 25mg (0.5mls) with a 10 minute lockout	17 days	Transdermal fentanyl, ketamine, Amitriptyline, pregablin, midazolam, sublingual lorazepam, docusate sodium, phosphate enema, lactulose, sodium picosulfate

Table 1: PCA dose per patient

**requested to have PCA removed*

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