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**Title**

Understanding the toolbox: a mixed methods study of attitudes, barriers and facilitators in parental intervention of children's cancer pain at home

**Short running title**

Parents managing children's cancer pain at home

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## Abstract

Children with cancer experience pain throughout their cancer trajectory. Pain has short- and long-term negative consequences for children physically and psychologically. Children with cancer spend more time at home with their families and less time in hospital. Whilst this has benefits for quality of life, it shifts responsibility for pain management from healthcare professionals to parents. Little is known about parents' pain management abilities in this setting. This study aimed to understand how parents of children with cancer manage their child's pain at home. A convergent, parallel, mixed methods design including pain diaries, surveys, and interviews was used. Participants were parents of children with cancer on active treatment recruited from one tertiary cancer centre. Each data collection method was analysed separately and then integrated. Parents frequently under-medicate their child's pain at home. Practical barriers including the analgesic context and children finding medications unpalatable led parents to prefer non-pharmacological interventions. Attitudinal and practical barriers result in parents having an "empty toolbox" of pharmacological interventions. Consequently non-pharmacological interventions are essential to parents managing their child's cancer pain at home.

## Introduction

Worldwide it is estimated around 300,000 children are diagnosed with cancer annually (International Agency for Research on Cancer, 2016). In the United Kingdom (UK), recent figures suggest 1,821 children (Cancer Research UK, 2015a) and 2,630 teenagers and young adults (Cancer Research UK, 2015b) develop cancer annually. In recent years, survival rates in England and Wales have increased to 82% for children and 84% for teenagers and young adults; figures are similar in the United States (US) (National Cancer Institute, 2015). These growing survival rates are a result of increasingly aggressive treatments (Clarke, Fletcher, & Schneider, 2005; Fortier, Wahi, Bruce, Maurer, & Stevenson, 2014).

Advances in symptom management have not matched progress in survival rates (Fortier, Sender, & Kain, 2011) resulting in children experiencing severe side-effects (Jibb et al., 2018). Side-effects are wide ranging and include reductions in physical wellbeing, psychological wellbeing and autonomy (Collins et al., 2000).

Children with cancer experience pain originating from three sources: the disease itself; side-effects of treatment; and procedures (Fortier et al., 2014; Olson & Amari, 2015; Twycross, Parker, Williams, & Gibson, 2015). Experiences of childhood pain have lasting negative effects (Tutelman et al., 2018). Pain produces a biological stress response (Vaccarino & Couret, 1995) which can negatively impact an individual's ability to eat, sleep, think and interact with others (Berger, Shuster, & Von Roenn, 2013). In children with cancer, pain impairs quality of life (Jibb et al., 2018), delays recovery (Shepherd, Woodgate, & Sawatzky, 2010), and if unresolved can lead to chronic pain in survivorship (Tutelman et al., 2018)

Due to advances in treatments, there is a trend towards children with cancer being cared for as outpatients (Fortier, Sender, et al., 2011; Kazak & Noll, 2015). Many authors recognise a subsequent shift in responsibility for symptom management from nurses and doctors, who are trained in pain management, to parents most of whom are not (Fortier et al., 2014; Kars, Duijnste, Pool, van Delden, & Grypdonck, 2008; Kazak & Noll, 2015; Twycross, Parker, et al., 2015). This shift incurs a burden on parents who are coping with this in addition to multiple new tasks which come with caring for a child with cancer (Clarke et al., 2005; Flury, Caflich, Ullmann-Bremi, & Spichiger, 2011).

## Methods

This study was part of a mixed methods project which aimed to understand how parents of children with cancer manage their child's pain at home. This paper reports on findings which answer research questions:

1. How do parents intervene to manage their child's pain at home?
2. What influences parents' choice of interventions to manage their child's pain at home?

## Design

A convergent, parallel, mixed methods design was used (Creswell & Plano Clark, 2011) as neither qualitative nor quantitative methods could adequately answer the research questions (Dures, Rumsey, Morris, & Gleeson, 2011). The Theory of Planned Behaviour (TPB) guided study design and conduct (Ajzen, 1985). Methods were mixed primarily for the purpose of complementarity (Greene, Caracelli, &

Graham, 1989). Secondary purposes for mixing were completeness (Bryman, 2006), offset (Bryman, 2006; Petros, 2011), and explanation (Bryman, 2006).

To answer research question one, parents recorded interventions in response to their child's cancer pain over a one-month period. This data were combined with interview data in which parents described their interventions qualitatively. To answer research question two, firstly, parents' attitudes towards medications were measured in a quantitative survey. Secondly, in pain diaries, when parents did not provide an intervention, they were asked to provide further details. These responses along with general comments made by parents were used to understand influences on parents' pain management intervention choice. Thirdly, parents were interviewed regarding what influenced their choice of pain management interventions.

#### Participants

Participants were:

1. Mothers, fathers, guardians or anyone with primary caregiving responsibility for a child with cancer (hereon in referred to as "parents").
2. Over 18 years of age.
3. Proficient in spoken and written English.
4. Parents of children with cancer of any diagnosis, on active treatment, aged from birth to one day before their 17<sup>th</sup> birthday on day of recruitment.

#### Procedure

Participants were recruited from one tertiary cancer centre in the UK. A convenience sample of participants completed the survey. For pragmatic reasons, a sample of 100 participants was chosen to allow 95% confidence intervals to be calculated with

+/- 10% margin of error to be calculated with the exact method (Morris & Gardner, 1988). A subset of survey participants chose to continue their participation and complete pain diaries. Due to requiring a high level of involvement, it was anticipated fewer parents would want to participate so a target sample size of 40 was chosen. A subset of pain diary participants were recruited to interview through purposive sampling (Table 1) which ensured a range of participants in terms of age of child and time since diagnosis. Children experience, process, express and communicate pain differently at different stages of development so it was important to gather data from a range of ages (Gaffney & Dunne, 1986, 1987; Twycross, 1998). Participant selection according to stage of treatment was important because evidence suggests family's needs evolve throughout the treatment trajectory (Woodgate & Degner, 2003).

**Table 1: Purposive sampling for interview participants**

<b>Age</b>	<b>Birth – 4 years</b>	<b>4-7 years</b>	<b>8-16 years</b>	<b>Total</b>
First six months	3	3	3	9
After six months	3	3	3	9
Total	6	6	6	18

#### Ethical considerations

Ethical approval was granted from the Health Research Authority (16/NS/0121) following governance and approval from The Royal Marsden NHS Foundation Trust (AM1702/04).

Healthcare professionals acted as gatekeepers to ensure potential participants were not approached at a time which would be emotionally sensitive to them. A process consent model was adopted (Dewing, 2007) with consent obtained at point of recruitment as well as just prior to commencement of each data collection method. Parents and children have been given pseudonyms to protect their identity.

## Data collection

### Survey

The Medication Attitudes Questionnaire (MAQ) is a 16-item questionnaire with each item rated on a seven-point Likert scale from strongly agree to strongly disagree (Forward, Brown, & McGrath, 1996). This questionnaire was initially developed to examine attitudes of mothers of healthy children towards paracetamol. In mothers of healthy children this scale had Cronbach's alpha of 0.68 (Forward et al., 1996). This reached 0.73 when tested on parents of children undergoing surgery (Chambers, Reid, & McGrath, 1997). Demographic data including parental age, gender, ethnicity, household income, and educational background as well as child age, gender, diagnosis, time since diagnosis, and treatment were collected.

### Pain diaries

Parents were provided with paper or electronic pain diaries depending on preference to be kept for one month. For each pain episode, parents recorded pain score on an 11-point numerical rating scale. Free text allowed parents to describe individualised pain management techniques, their actions in response to pain, and perception of the result of their actions. If medication was administered, parents recorded the type of medication and dose. If a non-medication intervention was used, parents recorded this. If there was no intervention, parents were asked to state their reasons.



## Interviews

A semi-structured qualitative (Parahoo, 2006) interview schedule was derived from background literature, and guided by TPB (Ajzen, 1991). The interview schedule received face validity from three experienced researchers with expertise in cancer, pain, and paediatrics as well as eight experts by experience (Jones & Rattray, 2010; Parahoo, 2006; Teddlie & Tashakkori, 2009).

## Analysis

Figure 1 displays data analysis processes and meta-inference generation for this study. Initially each dataset was analysed separately and then integrated.

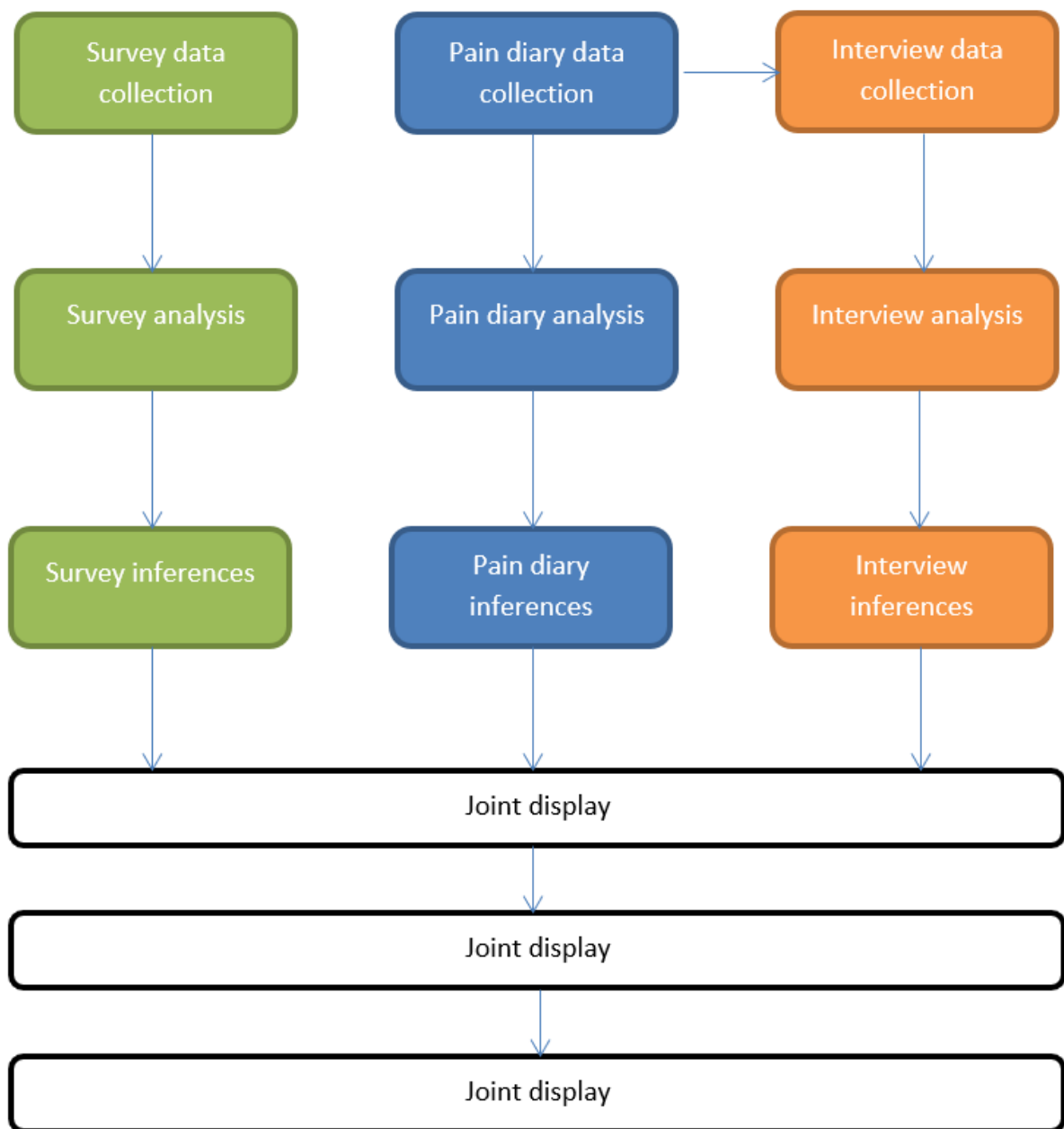


Figure 1: Analysis process and meta-inference generation

#### Survey

Survey data were analysed using SPSS (version 21, manufacturer IBM) and Microsoft Excel. Demographic characteristics of the sample were analysed using descriptive statistics. Inferential statistics were used to compare demographic variables to scores on scales and subscales. Choice of statistical test depended on whether data was categorical, ordinal, or interval, and distribution of data (Myles &

Gin, 2000). Where tests involved multiple comparisons, a Bonferroni post-hoc test was used to reduce the chance of getting spurious results. Results were considered statistically significant at a probability (p) value of  $\leq 0.05$ . Correlations were considered small if  $< .3$ , medium if  $> .3$  and  $< .5$ , and large if  $> .5$  (Cohen & Holiday, 1982; Penn et al., 2008).

#### Pain diary

Data entry, data checking, and choice of inferential statistics matched those used in analysis of survey data. Data were analysed on two levels: Episode data consisted of each individual diary entry; Aggregate data consisted of summary data for each participant. Qualitative responses were analysed using manifest (Graneheim & Lundman, 2004), phenomenological (Egberg Thyme, Wiberg, Lundman, & Graneheim, 2013), content analysis with low abstraction degree and low interpretation level (Graneheim, Lindgren, & Lundman, 2017).

#### Interviews

Interview data were analysed according to six stages of thematic analysis (Braun & Clarke, 2006) using NVivo TM (Version 10, QSR International).

#### Integration

Integration of survey, pain diary, and interview inferences was conducted via joint display (Creswell & Plano Clark, 2011; Fetters, Curry, & Creswell, 2013; Guetterman, Fetters, & Creswell, 2015) using a matrix (Dickson, Lee, & Riegel,

2011; Miles & Huberman, 1994) from which meta-inference generation stemmed (O’Cathain, Murphy, & Nicholl, 2010).

## Results

Of the 161 parents invited to participate, 101 (62.7%) returned the survey. Due to the anonymity of the survey, reasons for non-participation cannot be established. Pain diaries were received from 37/101 (36.6%) potential participants. In the interview sample, older children who had been diagnosed less than six months prior to recruitment were under-represented and older children who had been diagnosed more than six months prior to recruitment were over-represented. Demographic characteristics are displayed for children in Table 2 and for parents in Table 3. Chi-squared tests revealed no statistically significant differences between those who participated and those who did not in gender and age of child, or parental relationship.

**Table 2: Demographic characteristics of children represented in the sample**

Child demographic data n (%)		Survey	Pain diary	Interview
Age	1	4 (4)	2 (5.4)	6 (33.3)
	2	4 (4)	4 (10.8)	
	3	9 (8.9)	2 (5.4)	
	4	10 (9.9)	4 (10.8)	6 (33.3)
	5	15 (14.9)	6 (16.2)	
	6	4 (4)	2 (5.4)	
	7	7 (6.9)	2 (5.4)	
	8	5 (5)	1 (2.7)	6 (33.3)
	9	7 (6.9)	3 (8.1)	
	10	4 (4)	1 (2.7)	
	11	6 (5.9)	2 (5.4)	
	12	4 (4)	2 (5.4)	
	13	3 (3)	1 (2.7)	
	14	2 (2)	2 (5.4)	
	15	4 (4)	1 (2.7)	

	16	5 (5)	2 (5.4)	
Gender	F	36 (35.6)	14 (37.8)	9 (50)
Ethnicity	Asian	11 (10.9)	3 (8.1)	1 (5.6)
	Black	8 (7.9)	2 (5.4)	0 (0)
	Mixed	12 (11.9)	4 (10.8)	2 (11.1)
	Other	2 (2)	1 (2.7)	0 (0)
	White	65 (64.4)	27 (73.0)	15 (83.3)
Diagnosis	Leukaemia	56 (55.4)	22 (59.5)	10 (55.6)
	Lymphoma	10 (9.9)	5 (13.5)	4 (22.2)
	Brain	11 (10.9)	2 (5.4)	1 (5.6)
	Solid tumours	16 (15.8)	7 (18.9)	3 (16.7)
	Other	2 (2)	1 (2.7)	0 (0)
Time since diagnosis	0-6 months	44 (43.6)	23 (62.2)	8 (44.4)
	6-12 months	9 (8.9)	2 (5.4)	10 (55.6)
	1-3 years	35 (34.7)	8 (21.6)	
	3-5 years	8 (7.9)	3 (8.1)	
	5+ years	2 (2)	1 (2.7)	

## Survey

Percentage responses for each MAQ item are displayed in Figure 2. When “strongly agree”, “agree”, and “slightly agree” were combined, the highest level of agreement (73%) was for the statement “Side-effects are something to worry about when giving children pain medication”. Lowest agreement (28%) was for the statement “Using pain medication for children’s pain leads to later drug abuse”. The highest level of uncertainty (33%) was for the statements “It is unlikely a child will become addicted to pain medication if taken for pain” and “Giving children pain medication for pain teaches proper use of drugs”. The lowest level of uncertainty (9%) was for the statement “Pain medication works best if saved for when the pain is quite bad”. No statistically significant difference was found between MAQ scales or subscales and time since diagnosis.

**Table 3: Demographic characteristics of parents represented in the sample**

<sup>1</sup> Parent demographic data n (%)		Survey	Pain diary	Interview
Relationship	Both	1 (1)	1 (2.7)	0 (0)
	Father	20 (19.8)	6 (16.2)	1 (5.6)
	Mother	75 (74.3)	29 (78.4)	17 (94.4)
	Other	1 (1)	1 (2.7)	0 (0)
Age	25-34	22 (21.8)	5 (13.5)	2 (11.1)
	35-44	53 (52.5)	22 (59.5)	11 (61.1)
	45-54	22 (21.8)	9 (24.3)	4 (22.2)
	55-64	1 (1)	1 (2.7)	1 (5.6)
Ethnicity	White	71 (70.3)	29 (78.4)	16 (88.9)
	Asian	11 (10.9)	3 (8.1)	1 (5.6)
	Black	12 (11.9)	4 (10.8)	1 (5.6)
	Mixed	3 (3)	1 (2.7)	0 (0)
Income	Less than £14,000 per year	13 (12.9)	3 (8.1)	1 (5.6)
	£15,000 – £24,000 per year	25 (24.8)	2 (5.4)	0 (0)
	£25,000 – £39,000 per year	14 (13.9)	13 (35.1)	7 (38.9)
	£40,000 – £59,000 per year	11 (10.9)	7 (18.9)	4 (22.2)
	More than £60,000 per year	26 (25.7)	10 (27.0)	4 (22.2)
Education	Didn't finish school	22 (21.8)	0 (0)	0 (0)
	Finished school	12 (11.9)	2 (5.4)	0 (0)
	Certificate or partial studies at college/universities	43 (42.6)	15 (40.5)	7 (38.9)
	Completed a bachelor's degree	16 (15.8)	10 (27.0)	6 (33.3)
	Completed a postgraduate degree	2 (2)	9 (24.3)	4 (22.2)

<sup>1</sup> Note that where figures do not add up to sample total, this is due to participants choosing not to disclose demographic information

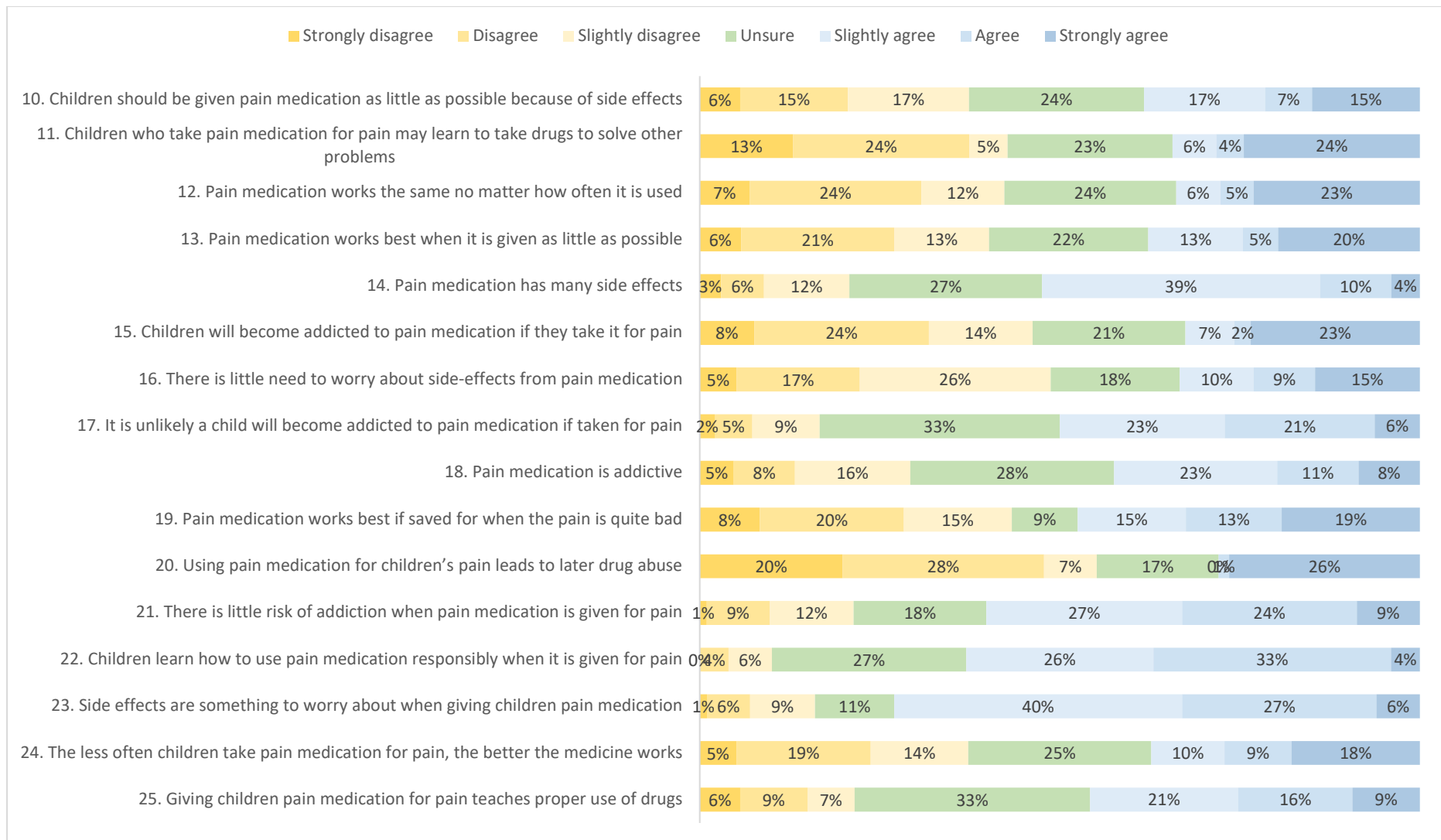


Figure 1: Percentage response for MAQ items

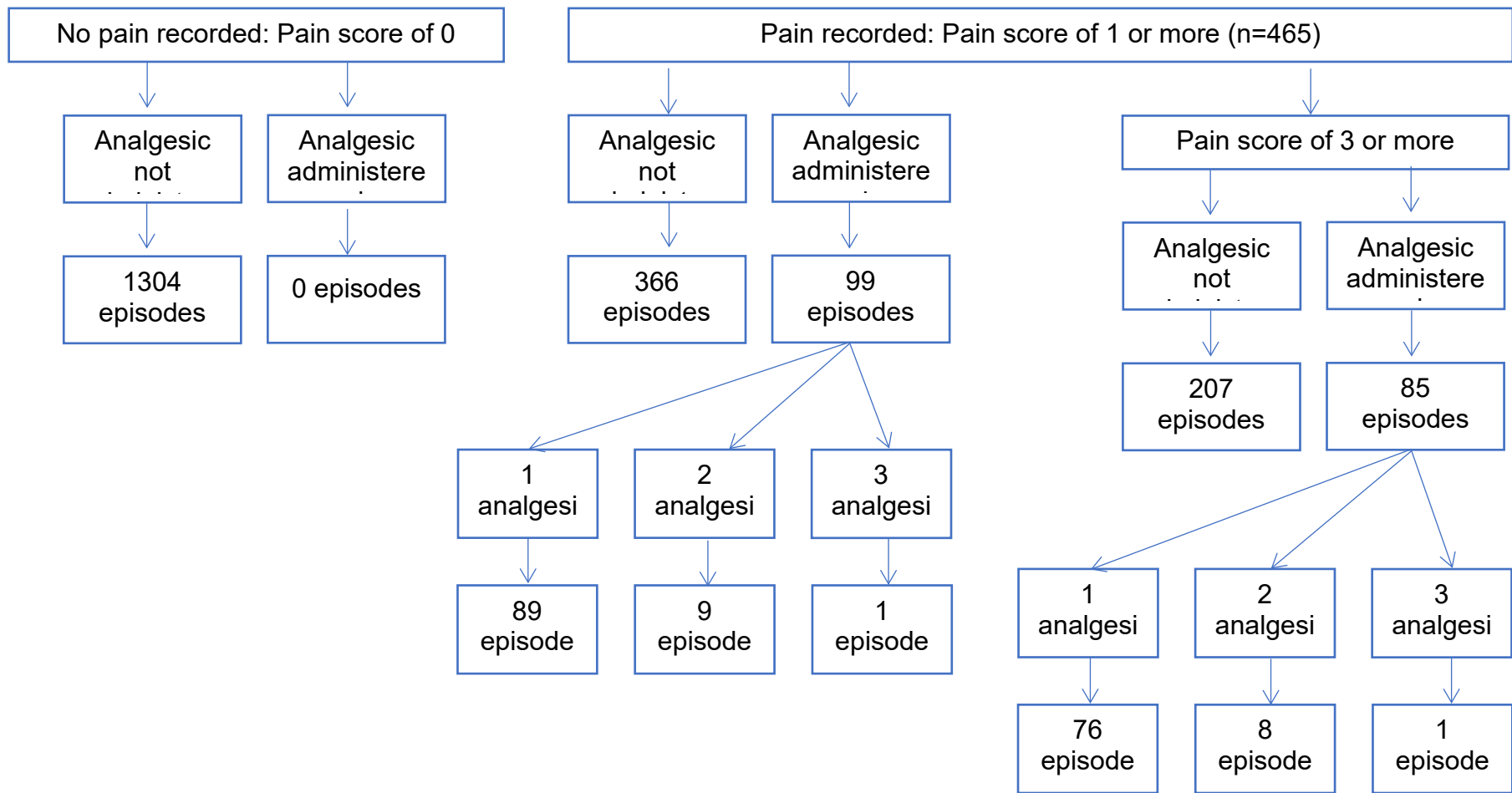


Figure 2: Medication administration in response to pain score



## Pain diary

A pain score was recorded for 1769/2137 (82.8%) episodes. Parental response to pain was recorded for 506 episodes. In 121 episodes, parents recorded both a medication and a non-medication response. No action was taken on 51 (8%) of episodes.

A univariate ANOVA revealed that as pain score increased, there was a statistically significant increase in parents' administration of a combination of medication and non-medication responses when compared to only administering medication (mean difference=1.48,  $p<.0001$ ), only using a non-medication response (mean difference=1.30,  $p<.0001$ ), and no action (mean difference=1.02,  $p=.009$ ).

Parents administered medications in response to 231 (37%) episodes. Figure 3 displays the number of analgesic drugs administered in response to varying levels of pain. Children received an analgesic drug in 21% of episodes where a pain score was recorded as one or more. In 207 (71%) episodes where children had clinically significant pain, of three or more no analgesic drug administration was recorded.

Table 4 displays the most frequent response for each type of medication and each type of analgesic drug for episode data (number of episodes) and aggregate data (number of children for which this was the most frequent response). A non-medication response was recorded for 345 (55%) episodes. Table 5 displays non-medication response for episode data and aggregate data per child.

**Table 4: Frequency and type of medication and type of analgesic drug administered**

	Number (%) of episodes	Number (%) of children for whom this is the most frequent intervention
<b>Type of medication administered</b>		
Analgesic	119 (50)	14 (50)
Topical	59 (25)	6 (21)
Anti-emetic	29 (12)	4 (14)
Laxative	26 (11)	3 (11)
Costive	3 (1)	1 (4)
<b>Type of analgesic drug administered</b>		
Paracetamol	78 (51)	12 (71)
Morphine	53 (35)	5 (29)
Pregabalin	18 (12)	0 (0)
Co-codamol	3 (2)	0 (0)
Codeine	1 (1)	0 (0)

**Table 5: Frequency of non-medication responses**

Non-medication response	Number (%) of episodes	Number (%) of children for whom this is the most frequent response to pain
Cuddles	86 (17)	6 (16)
Food and Drink	67 (13)	3 (8)
Distraction	65 (13)	3 (8)
Massage	62 (12)	7 (19)
Sleep / rest	45 (4)	4 (11)
Heat	29 (6)	3 (8)
Bath / shower	28 (5)	2 (5)
Oral care	26 (5)	1 (3)
Verbal reassurance / comfort	18 (4)	3 (8)
Toilet	18 (4)	0 (0)
Exercise	12 (2)	1 (3)
Hospital or contact HCP	8 (2)	1 (3)
Other	48 (9)	3 (8)

HCP: healthcare professionals

Participants provided a total of 40 comments under “If no action is taken or required, please say why”. Many of the 313 comments under “Any other comments” also related to why no action had been taken. Reasons for no action were coded into four categories and nine subcategories (Table 6).

Parents described analgesic mediations, and non-pharmacological interventions to manage their child’s pain at home.

**Table 6: Reasons for no action in response to pain**

Category	Subcategory	Number (%) participants who commented
Features of the pain	Pain not severe enough	8(21.6)
	Pain went away	4(10.8)
Inadequacy of analgesic drugs	Child refusing medication	6(16.2)
	Side-effects of analgesic drugs	2(5.4)
	Analgesic drug won't help	2(5.4)
HCP influence	HCP advises against analgesic drug	4(10.8)
	Waiting to seek advice from HCP	3(8.1)
	Not allowed to give analgesic drug	2(5.4)
Daily challenges	Circumstances prevent analgesic drug administration	3(8.1)

HCP: healthcare professionals

### *Analgesic medication*

Many parents held positive attitudes towards analgesic medications and wanted to encourage other parents to use analgesic medications:

*“So, I think probably I’ve got a very relaxed attitude, rightly or wrongly to taking medicines...I will dose her up as much as she can have it and I won’t be worried.” – Beth*

When asked what advice they would give to other parents in a similar situation, some parents advocated administering analgesic medications:

*“don’t be afraid...a lot people don’t like using medicines. But at the end of the day, why make your child suffer? Just use medication, because it’s hopefully not gonna be for long.” – Ruth*

Parents expressed a range of attitudes towards paracetamol due to its antipyretic properties having potential to mask a temperature in their child. Some parents expressed no hesitation in administering paracetamol while others were more cautious but would give it if their child had no sign of a temperature or were not neutropenic. Other parents never gave their child paracetamol due to fear it would mask a temperature:

*“Paracetamol definitely wasn’t allowed because of temperature spikes and stuff like that.” – Priya*

One parent received conflicting information regarding paracetamol administration:

*“Some doctor in the [principle treatment centre], she said when he’s in pain give him paracetamol...But in [shared care] they said that I can’t give him anything.” – Natalia*

Some parents talked about not being allowed to administer ibuprofen, although they were less clear on the reasons for this:

*“And he can’t have ibuprofen I don’t think. I can’t remember why but I don’t think he can.” – Angie*

Regarding morphine administration, one parent encountered anti-morphine attitudes from HCPs:

*“I remember them saying she was morphine naive and they were quite pleased about that...they said it was a good thing.” – David*

When administering morphine some parents were aware of its pharmacological limitation of causing constipation as a side-effect. This was especially pertinent when the child's pain was caused by constipation:

*"...the risk of constipation cos she is adamant she doesn't want to take any laxatives so I've yet to get enough...morphine" – Margret*

Some parents held misconceptions based on personal experiences of exposure to morphine which influenced their attitude. In this excerpt, Beth admits feeling negatively towards morphine, but believes she is open to change:

*"...my husband had issues with it, with morphine, and his mum as well...So I'm quite frightened of morphine...even though it shouldn't be subjective, it is...seeing people high on morphine when they shouldn't have been when they've abused it...If someone had said to me, well it would really help her...I think I would have changed my mind about it. So, it's not like I've got this really stuck attitude." – Beth*

Importantly, many parents changed their attitudes towards analgesic medications throughout the cancer journey:

*"And there was one evening when Eleanor was particularly bad, and she was screaming...And my mother said well have you used that morphine...And I did. And it worked...it's an amazing drug. Yes, let's have more of it." – Suzannah*

Often, if parents wanted to administer analgesic medications, they had to weigh up whether it was worth upsetting their child due to non-palatability of medications meaning children refused to take them:

*“...he wasn’t gonna have it just for the taste of it. And then it put him off all the other ones that are actually okay to take” – Elena*

This left parents questioning their parenting skills and feeling that interventions available to them prior to diagnosis were no longer available leaving them with nothing to offer.

*“... [being able to give paracetamol is] almost like a safety blanket you know it’s there. But the moment you don’t have it you just think oh my god...what am I going to do?” – Annabelle*

*“...they’ve taken it out of the bag of goodies” – Margret*

*“I went on a journey with the back pack only half packed. I needed a bit more. So that’s the way I felt about it.” – Suzannah*

Parents felt there was nothing they could do:

*"I: what do you do if you think it is genuine sore tummy?*

*P: Not a lot. Obviously, we can’t really give her pain relief...I don’t think there’s much else we do.” – David*

This left parents with an “empty toolbox”

*“...but that sense of fear of feeling like the toolbox that you’ve grown up as a parent...suddenly all that’s taken away from you.” – Georgia*

### *Non-pharmacological interventions*

Non-pharmacological interventions include physical strategies such as massage, psychological strategies such as distraction, non-analgesic medications such as ondansetron, and other analgesic interventions such as topical analgesics. Analgesic medications may have been the preferred choice prior to diagnosis but since diagnosis, parents preferred non-pharmacological interventions. Parents used non-pharmacological interventions to restock their “empty toolbox”.

Parents expressed a belief that non-pharmacological interventions could be a sufficient solution:

*“...if you don’t have to take a medicine, then why would you, if there’s another solution” – Laura*

Parents listed a wide variety of non-pharmacological interventions including: heat, distraction, being there, reassurance, food, drink, cuddles and physical affection, herbal remedies, aromatherapies, massage, acupuncture, bath, treats, sleep, rest, going to the toilet, mouth washes, topical creams, numbing creams, laxatives, giving the child space and/or time, siblings, role play, hydrotherapy, TENS machine, fresh air, walking, mindfulness, phone apps, relaxation techniques, positioning, talking, placebo, plasters, probiotic yoghurts, singing, and physiotherapy.

Parents felt comfortable using more than one non-pharmacological intervention and were willing to try anything:

*"...all of a sudden he said his front of his head was hurting, no first he said his head was hurting. So, I would sort of press it there for him and he says yeah that feels good and then I offered him some hot drink like tea...that made him feel better, but the pain wouldn't go away and then...I gave him hot water bottle...and he felt a little bit better with it. And then I said to him look, you need to have some fresh air...let me put a chair here and...I said okay let's go for a walk cos that fresh air and drinking water and then...why don't you lie down and have a nap...and then he woke up and the headache was gone." – Priya*

Parents re-stocking of the pain management toolbox often involved creative interventions, flexible interventions, and life adaptations:

*"Try to think outside the box...And trying alternatives." – Margret*

*"...having a range of strategies and being flexible...so looking at each situation." – Suzannah*

*"...at home, I think we've adapted quite well to even just little things... we've all adapted our behaviours...to minimise his pain" –  
Laura*



## Discussion

Survey results revealed parents showed negative attitudes towards medication which did not resolve over time. Pain diaries revealed parents frequently under mediated their child's pain at home but used a variety of non-pharmacological interventions to manage their child's pain. Interview results revealed a preference for non-pharmacological interventions and parents expressed reasons for this.

### How do parents intervene to manage their child's pain at home?

In 71% of episodes where children were in clinically significant pain, no analgesic drug was administered. This confirms Fortier and colleagues finding of frequent under-medication of children with cancer at home (2014). Paracetamol was the most frequent analgesic drug administered, a finding consistent with recent research in a sample of outpatient and inpatient parents of children with cancer both on and off treatment (Tutelman et al., 2018). When pain increased, parents were not more likely to administer analgesic medications but were more likely to intervene with a combination of analgesic medications and non-pharmacological interventions. Non-pharmacological interventions were the most frequent response to children's pain in pain diaries. In interviews, parents expressed a preference for non-pharmacological interventions. In pain diaries, the most frequent non-pharmacological interventions were cuddles, followed by food and drink, distraction, and massage.

Literature in support of non-pharmacological interventions to manage pain in children with cancer is growing but remains limited (Jibb et al., 2015). Children with cancer use more physical and psychological strategies than other populations (Post-White,

Fitzgerald, Hageness, & Sencer, 2009). Parents use more physical and psychological strategies to manage their child's cancer pain than pharmacological strategies (Tutelman et al., 2018). Distraction is frequently the most common strategy used by parents to manage cancer pain (Bettle, 2015; Fortier, Chung, Martinez, Gago-Masague, & Sender, 2016; Tutelman et al., 2018).

Pain diary and interview data converge on what parents do in response to their child's cancer pain at home. Parents may be under-medicating their child's pain but contrary to previous literature (Fortier et al., 2014), this research concludes that parents are responding to their child's pain using a variety of physical and psychological strategies. Parents frequent use of non-pharmacological interventions shows that previous research which did not consider these interventions may have underrepresented parents pain management abilities.

What influences parents' choice of interventions to manage their child's pain at home?

Quantitatively measured attitudinal barriers towards analgesic medications

MAQ results revealed parents of children with cancer hold negative attitudes towards medications which did not vary with time since diagnosis. Previous research found parents of children with cancer have a steep learning curve to become experts in their child's condition (Bettle, 2015). This finding suggests pain management does not improve with exposure to healthcare settings. Nurses are instrumental in educating parents on their new responsibilities (Flury et al., 2011). A possible explanation for this lack of improvement may be the stability of attitudes. Extensive

work on attitudes has found they rarely change over time and are relatively stable (Ajzen, 2006; Edwards et al., 2007). Providing education to improve parental pain management during the post-operative period has been found ineffective (Chambers et al., 1997; Chorney, Twycross, Mifflin, & Archibald, 2014). A recent integrative review examining interventions to improve parental pain management at home found few interventions were effective at altering pain management attitudes and practices (Parker, McKeever, Wiseman, & Twycross, 2018).

#### Qualitatively measured attitudinal barriers towards analgesic medications

Parents held a range of attitudes towards analgesic medications. Some parents in this research expressed negative attitudes towards analgesic medications but many reported improvements in attitudes towards analgesic medications throughout the duration of their child's cancer treatment. At point of interview, few expressed current stigma towards analgesic medications. This range of attitudes is reflected in literature. Swedish parents of children with cancer denied refusing opioids to children for fear of addiction (Ljungman, Kreuger, Gordh, & Sörensen, 2006). But parent-held stigma is acknowledged in literature (Andrzejowski & Carroll, 2016; Cheng & Tattermusch, 2014; Twycross, Dowden, & Bruce, 2009). Taiwanese parents of children with neuroblastoma were more free in giving medication as they progressed through treatment (Lu et al., 2011).

Parents occasionally described episodes in which they had sensed negative attitudes towards medications from HCPs. It has been reported that HCPs caring for children with cancer worry that children easily become addicted to pharmacological interventions, have no memory of pain, do not experience pain in the same way, and

metabolise opioids differently (Hanmod & Gera, 2016). This may in part explain why survey results revealed no changes in attitudes towards medication with time since diagnosis: If HCPs responsible for educating parents hold negative attitudes, continued exposure to the healthcare setting will not improve attitudes.

#### Practical barriers to medication administration

In addition to attitudinal barriers, practical barriers including the analgesic context and the non-palatability of analgesic medications hinder parents' management of their children's cancer pain at home.

In interviews parents expressed their fear of administering paracetamol due to its antipyretic effect meaning its administration may mask a temperature which, at home, could be parents' only sign of a potentially fatal infection (Patterson, 1992). Others reported that they were never allowed to administer paracetamol, even if their child's temperature was within safe parameters. In a similar study, parents of children with acute lymphoblastic leukaemia on and off treatment, reported in interviews fear of administering paracetamol even when their child was not neutropenic (Bettle, 2015).

Parents reported hesitancy over morphine administration due to fear of exacerbating existing symptoms of nausea and constipation. Although hospital policy acknowledges these side-effects (Cheng & Tattermusch, 2014; Hanmod & Gera, 2016; Patterson, 1992), to our knowledge, this is the first study to report the impact these have on parents' management of children's cancer pain.

This analgesic context may have altered parent's MAQ responses. For example, parents who agree with the statement "Pain medication has many side-effects", are considered to be expressing a negative attitude towards medication. Similarly, parents who disagree with the statement "There is little need to worry about side-effects from pain medication" are considered to be expressing a negative attitude towards medication. Although masking a temperature is not medically classified as such, many parents may consider it to be a side-effect. If parents consider masking a temperature to be a side-effect of paracetamol, given its potentially fatal consequences, it is unsurprising that many would show negative attitudes to these statements. It may be that the MAQ is detecting practical barriers rather than attitudinal barriers which may explain why parents in this study appear to show more negative attitudes on MAQ than non-cancer populations (Twycross, Williams, et al., 2015; Zisk et al., 2010, 2007).

To compound this, parents also reported that when they wanted to administer analgesic medications, children found medications non-palatable and frequently refused them. Children refusing medication as a barrier to parental management of children's cancer pain has been reported elsewhere (Bettle, 2015; Fortier et al., 2014; Mariyana, Allenidekania, & Nurhaeni, 2018). Mothers of children with cancer described this as a major challenge which is time-consuming and associated with physical and psychological side-effects (Clarke et al., 2005).

Integration of several data collection methods used in this research can explain conflicts found elsewhere in literature. This research distinguished between attitudinal barriers and practical barriers. Due to the analgesic context – frequent

contraindication and non-palatability of medication – the MAQ may be detecting the practical barriers to analgesic medication which continue throughout the cancer diagnosis. This analgesic context meant parents felt they had an “empty toolbox”, leading to frustration, helplessness, an inability to manage their child’s pain, and feeling stripped of parenting skills.

Attitudinal and practical barriers to analgesic medications, reveal the importance of non-pharmacological interventions for parents managing their child’s cancer pain at home. Use of physical and psychological strategies to manage children’s pain at home was far more than a helpful adjunct to analgesic drug interventions. Physical and psychological strategies allowed parents to re-stock their “empty toolbox” and regain their ability to manage their child’s pain at home effectively.

### Strengths and limitations

Convenience sampling was used for recruitment to this study for both surveys and pain diaries. Although this facilitated recruitment of a sample size sufficient for statistical analysis, it means this sample should not be considered representative of the population (Etikan, Musa, & Alkassim, 2016; Parahoo, 2014). Purposive sampling was utilised for interviews, which allowed data to be gathered from a broad range of experiences related to the research question (Heavey, 2014).

Participants were recruited from just one UK tertiary cancer centre which limited generalisability. Due to the organisation of UK paediatric cancer services, children with cancer will be allocated one tertiary cancer centre which conducts specialist aspects of treatment and one shared care centre which conducts general aspects of

treatment closer to home (NHS England, 2017). Recruiting from a tertiary cancer centre meant this research includes parents whose children were receiving care from a range of shared care centres.

A further strength of this study is the way in which analysis was conducted to embrace, rather than ignore divergences (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2009). Findings which stemmed from between-method divergences would not have been revealed had this research not embraced divergences derived from mixed methodology. Had any one method been absent from this study, different conclusions would have been drawn. This research demonstrates how mixed methods produces findings which are more than the sum of their parts (Teddlie & Tashakkori, 2009).

## Conclusion

This study is the first to use mixed methods to investigate how parents manage their child's cancer pain at home and what influences parents' choice of intervention. Quantitatively measured attitudinal barriers suggest parents of children with cancer hold many negative attitudes towards analgesic medications which do not change with exposure to healthcare settings. Qualitatively measured attitudinal barriers suggest parents resolve their negative attitudes towards analgesic medications. The analgesic context, coupled with children finding analgesic medications non-palatable, create practical barriers towards analgesic administration which may explain the divergence between quantitatively and qualitatively gathered data. The MAQ may be detecting practical barriers rather than attitudinal barriers. Practical barriers result in

an “empty toolbox” of pain management interventions which parents stock effectively with non-pharmacological interventions.



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