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Manifestation and parental assessment of children's cancer pain at home: an exploratory mixed methods study

ABSTRACT

Aims and objectives: To describe pain manifestation in children with cancer at home and understand how parents assess this pain.

Background: Pain is experienced by children with cancer throughout their cancer journey. Short-term, and into survivorship, pain has negative physical and psychological consequences. Changes in treatment location mean children with cancer spend more time at home. Little is known about pain experienced by children at home or how parents assess this pain.

Design: A mixed methods convergent parallel study was reported using STROBE.

Method: Parents of children with cancer on active treatment were recruited from one tertiary cancer centre. Parental attitudes towards pain expression were assessed using surveys. Parents recorded their child's pain manifestation in pain diaries kept for one month. Interviews captured a deeper understanding of pain manifestation and how parents assess this pain at home. Integration occurred after each data collection method was analysed separately.

Results: Predominantly children were not in pain at home. However, most children experienced at least one episode of problematic pain over the pain diary period. Surveys showed parents held misconceptions regarding children's pain expression. Interviews diverge from surveys and suggest parents used a range of information sources to assess pain.

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Conclusion: Children with cancer may differ from one another in the manifestation of pain at home resulting in multiple pain trajectories. Parents of children with cancer are able to adequately assess their child's pain using information from multiple sources.

Relevance to clinical practice:

- It is not currently possible to predict which children will experience problematic pain at home, so all parents require pain management education prior to discharge.
- Teaching parents to use bundled approaches to pain assessment may accelerate their learning.
- Healthcare professionals may benefit from using multiple information sources to assess pain.

INTRODUCTION

Worldwide estimates of annual childhood cancer incidence is around 300,000 per year (International Agency for Research on Cancer, 2016). Due to advances in treatments such as chemotherapy, radiotherapy, surgery, and bone marrow transplants, survival rates have increased (Clarke, Fletcher, & Schneider, 2005; Fortier, Wahi, Bruce, Maurer, & Stevenson, 2014). In England and Wales, survival rates have reached 82% for children (Cancer Research UK, 2015a) and 84% for teenagers and young adults (Cancer Research UK, 2015b). Contemporary treatments are associated with greater experience of side-effects and advances in symptom management have not matched advances in survival rates (Fortier, Sender, & Kain, 2011). As a result, children experience severe side-effects which reduce autonomy, physical and psychological wellbeing (Collins et al., 2000), and quality of life (QOL) (Hockenberry et al., 2017). Children's cancer pain originates from the disease itself, side-effects of treatment, and procedures (Fortier et al., 2014; Olson & Amari, 2015; Twycross, Parker, Williams, & Gibson, 2015). Pain is frequently reported as the most common, bothersome and distressing side-effect (Olson & Amari, 2015; Twycross, Parker, et al., 2015) which continues throughout the cancer trajectory (Fortier et al., 2014; Hedén, Pöder, von Essen, & Ljungman, 2013; Van Cleve et al., 2012).

BACKGROUND

Increases in outpatient care provision has enabled children with cancer to spend more time at home cared for by their parents (Fortier et al., 2011; Kazak & Noll, 2015). Children experience problematic pain at home which incurs the highest level of parental burden (Ferrell, Rhiner, Shapiro, & Strause, 1994) causing unendurable (Hellsten, 2000) anguish (Hedén et al., 2013) for parents who have to see their child in pain. This leads to helplessness, frustration (Ferrell, Rhiner, Shapiro, & Dierkes, 1994; Hellsten, 2000),

and parental distress (Hedén et al., 2013). One qualitative study reported that children's cancer pain at home impacts every area of family life (Ferrell, Rhiner, Shapiro, & Dierkes, 1994). Quantitative evidence suggests pain has the biggest impact on functioning in extracurricular activities followed by household, social, sleep, and academic domains (Fortier et al., 2014).

Whilst spending time at home is in line with patient and family preferences (Jibb et al., 2018), little is known of children's cancer pain manifestation outside healthcare settings. Furthermore, this trend incurs a shift in responsibility for pain management from healthcare professionals, who are trained in pain management, to parents, most of whom are not (Fortier et al., 2014; Twycross, Parker, et al., 2015). Understanding pain manifestation and parental assessment of children's cancer pain at home will enable appropriate interventions to assist parents in this context and reduce child pain.

METHODS

This paper presents findings from a larger mixed methods research study which investigated how parents of children with cancer manage their child's pain at home. The Theory of Planned Behaviour (TPB) (Ajzen, 1985) was used to guide a convergent, parallel, mixed methods design (Creswell & Plano Clark, 2011). Mixed methods were necessary as the research questions could not be answered adequately with either qualitative or quantitative methods (Dures, Rumsey, Morris, & Gleeson, 2011). The primary purpose for mixing methods was complementarity (Greene, Caracelli, & Graham, 1989) with additional secondary purposes of completeness (Bryman, 2006), offset (Bryman, 2006; Petros, 2011), and explanation (Bryman, 2006). Findings from two research questions are reported in this paper:

1. What is the pain manifestation of children with cancer at home?
2. How do parents assess their child's pain at home?

To answer research question one, pain manifestation was measured quantitatively in real-time using pain diaries and described qualitatively and retrospectively in interviews with parents. Research question two was answered quantitatively via a survey designed to measure parents' attitudes toward children's pain expression and qualitatively using interviews with parents. Using the Enhancing the QUALity and Transparency Of health Research network guideline, the Strengthening the Reporting of Observational studies in Epidemiology checklist was chosen to ensure accurate reporting of this research (Supplementary File 1).

DESIGN

Participants

Participants were recruited from a tertiary cancer treatment hospital within a large city. Participants were recruited from two wards: the children's inpatient ward and the children's day unit. The children's ward is an 18-bed ward, which provides care for children from age 1-15 years old. Treatments offered include chemotherapy, radiotherapy, phase I and II clinical trials, and stem cell transplant. The day unit has 22 beds/chairs and 7 cubicles. Annually it provides care for more than 5,000 outpatient children and young people aged 1-24 years.

The following inclusion criteria was used to select participants who 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 a child with cancer of any diagnosis, on active treatment, aged from birth to one day before their 17th birthday on day of recruitment.

Convenience sampling was used for survey and pain diaries. In consultation with a statistician, calculations using the exact method (Morris & Gardner, 1988), suggested a target sample of 100 participants would allow confidence intervals to be calculated with +/- 10% margin of error. For pain diaries, it was anticipated that due to a higher level of involvement, fewer parents would participate so a target sample of 40 was selected. A purposive sample of participants were recruited to interviews using a sampling frame which provided participants representing children with a range of ages and time since diagnosis (Table 1). Family needs evolve throughout treatment (Woodgate & Degner, 2003), so participants were selected to represent a range of treatment stages. It was important that children with a range of ages were represented as the way in which children experience, process, express, and communicate pain differs depending on their developmental stage (Gaffney & Dunne, 1986; Twycross, 1998).

Procedure

Healthcare professionals acting as gatekeepers assisted the lead author in identifying participants who were recruited from a tertiary cancer centre in the UK. Participants completed the survey first; a subset went on to complete pain dairies; and a subset of these participants completed interviews. Participants were free to progress through data collection methods at their own pace. Parents who were willing to be approached by a researcher were provided with written and verbal information and an opportunity to ask questions. Parents who expressed interest were provided with a copy of the survey to complete at their own convenience. Surveys were returned via collection boxes in ward areas to promote anonymity.

Ethical considerations

Healthcare professionals acting as gatekeepers ensured participants were not approached at a time which could be emotionally challenging. A process consent model was adopted (Dewey, 1929) with consent ascertained at each stage of data collection. Consent for survey was implied on completion. A “please contact me” form was provided at the end of the survey. Participants could complete this if they wished to participate in further phases. Written consent for pain diary and interview was collected prior to commencement. Interview consent was verbally confirmed prior to commencement. Ethical approval was granted from The Royal Marsden NHS Foundation Trust (AM1702/04) and the Health Research Authority (16/NS/0121, North of Scotland Research Ethics Service). Participants were given pseudonyms to maintain anonymity.

DATA COLLECTION

Each data collection method was piloted with three parents who met inclusion criteria. Following the pilot, no changes were made thus these data were included in this research.

Survey

The Parental Pain Expression Perceptions questionnaire (PPEP) was used to answer research question two by measuring parent pain assessment attitudes and misconceptions (Zisk, Grey, MacLaren, & Kain, 2007). The PPEP was developed by a group of experts using relevant research, literature, and clinical experience to produce nine items each rated on a seven-point Likert type scale. Reliability data was reported in a study with parents of children undergoing surgery, where Cronbach’s alpha reached 0.79 (Zisk et al., 2007) and 0.78 (Zisk, Fortier, Chorney, Perret, & Kain, 2010). A previous factor analysis resulted in three

sub-scales: active loud; quiet inactive; and attention seeking (Zisk et al., 2007). Reliability data is not available for subscales. This scale was originally developed in the United States (US) for postoperative pain in children but has been used in the United Kingdom (UK) general population (Twycross, Williams, Bolland, & Sunderland, 2015) and in the US with parents of children with cancer (Fortier et al., 2014). Child and parent demographic data were collected.

Pain diaries

Parents were offered either an electronic or paper copy of the pain diary. To answer research question one, parents made twice daily assessments of their child's pain over a one-month period. Parents recorded location and severity of their child's pain using an 11-point numerical rating scale (NRS) (Birnie, Hundert, Lalloo, Nguyen, & Stinson, 2019; Castarlenas, Jensen, von Baeyer, & Miró, 2017; Tsze, von Baeyer, Pahalyants, & Dayan, 2018). The validity of the NRS for assessing pain in children has been explored in several studies and systematic reviews. Most recently, Birnie and colleagues evaluated the NRS alongside other paediatric self-report pain measures (2019). A total of 21 studies which used the NRS were synthesised. Birnie and colleagues concluded that although reliability for the NRS ranged from poor to fair, it was one of only three paediatric self-report pain measures which they strongly recommended. Parents also recorded the location of, and what they thought had caused their child's pain.

Interviews

Semi-structured (McKenna, Hasson, & Keeney, 2010) interviews were used to answer research questions one and two. Background literature and TPB (Ajzen, 1985) were used to create the interview schedule which received face validity from three experienced researchers and eight experts by experience (Jones & Rattray, 2010; Parahoo, 2014; Teddlie & Tashakkori, 2009). In individual interviews conducted by one researcher (RP), parents were given opportunity to describe how their child's pain affected them, their child, and their family. Follow up questions prompted parents to describe how they knew their child was in pain. Interviews were conducted either face-to-face in hospital, the participants' home, or a public place, or via telephone. Setting and format of interviews determined by participants' preferences. All interviews were audio recorded and transcribed verbatim.

ANALYSIS

Initially each dataset was analysed separately and then integrated.

Survey

Survey data were analysed using SPSS (version 21, manufacturer IBM) and Microsoft Excel. Initially data were subject to a structured process of data checking and cleansing. By comparing characteristics of participants on the screening log to those who participated using a series of chi-squared tests, participant attrition was analysed. Descriptive statistics were used to analyse demographic characteristics of the sample. Cronbach alpha was conducted to assess reliability of pain scores. To identify responses of the sample as a whole, percentage agreement for each PPEP item was calculated by grouping 'strongly agree', 'agree', and 'slightly agree'. Similarly, 'strongly disagree', 'disagree', and 'slightly disagree' were grouped to calculate percentage disagreement. To identify how participant responses varied according to demographic characteristics, a mean score was calculated for each participant on each scale and subscale. Where data were missing, it would not be appropriate to replace missing values, so the mean score was not calculated for the relevant sub-scale and scale.

Comparisons of different groups with different demographic characteristics in scales and subscales were conducted using inferential statistics. Maximum pain in all groups with different levels of independent variables was normally distributed so parametric tests were used of analysis. Mean pain was analysed using non-parametric tests due to its non-normal distribution in

some groups with different levels of independent variables. Maximum pain was analysed using Student's t-test where the independent variable had two levels and ANOVA where the independent variable had more than two levels. Mean pain was analysed using Mann-Whitney U-test where the independent variable had two levels and Kruskal-Wallis where the independent variable had more than two levels (Myles & Gin, 2000). A Bonferroni post-hoc correction was applied to tests involving multiple comparisons to reduce type 1 errors. A corrected probability (p) value of <.05 was taken to indicate statistical significance. Correlations were considered small if $\leq .3$, medium if $> .3$ and $< .5$, and large if $\geq .5$ (Cohen & Holiday, 1982; Penn et al., 2008).

Pain diary

Similarly to survey data, statistical tests were chosen based on whether data were categorical, ordinal, or interval and whether data were normally distributed (Myles & Gin, 2000). As with survey data, a Bonferroni post-hoc correction was applied to tests involving multiple comparisons to reduce type 1 errors and a corrected probability (p) value of $<.05$ was taken to indicate statistical significance. Correlations were considered small if $\leq .3$, medium if $>.3$ and $<.5$, and large if $\geq .5$ (Cohen & Holiday, 1982; Penn et al., 2008).

Chi-squared tests were used to analyse attrition between survey and pain diary procedures. Data were analysed in terms of episodes with each individual data entry point analysed. In addition, on an aggregate level, each participants' data was summarised and compared. For each child, number of episodes of zero pain, pain of one or more, and clinically significant pain (pain score of more than three on the NRS) (Fortier et al., 2014), were calculated. Maximum pain and mean pain were calculated for each child and compared to diagnosis and time since diagnosis.

Interviews

Qualitative data were analysed using NVivo™ (Version 10, QSR International) following the six phases of thematic analysis (Braun & Clarke, 2006). Data were transcribed verbatim by the researcher which increased opportunity for reflexivity (Jootun, McGhee, & Marland, 2009; McKenna et al., 2010). Attention was given to ensuring data were represented as a whole whilst answering each research question.

Integration

Steps taken to achieve integration are displayed in Figure 1. Integration occurred in three phases. Firstly, integration was conducted by comparing aggregate survey, pain diary, and interview results utilising matrices (Creswell & Plano Clark, 2011; Fetters, Curry, & Creswell, 2013; Guetterman, Fetters, & Creswell, 2015): Inferences from each dataset were considered with reference to findings from the other datasets to distil inferences and facilitate step two. Secondly, datasets were integrated using a joint display which focused on research questions (Creswell & Plano Clark, 2011; Fetters et al., 2013; Guetterman et al., 2015). Finally, integration was concluded in the discussion which used a contiguous approach achieved through narrative (Fetters et al., 2013).

RESULTS

Surveys were completed by one hundred and one out of one hundred and sixty-one (62.7%) parents invited to participate. Pain diaries were received from 37/101 (36.6%) of these participants. With one exception, parents of children were recruited to interviews according to the sampling framework in Table 1: 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 of children represented in the sample are displayed in Table 2 and parent demographics are displayed in Table 3.

Chi-squared tests revealed no statistically significant differences found in gender and age of child, or parental relationship to child when potential participants were compared to those who completed the survey. Similarly, participants who completed only the survey were not statistically significantly different from those who completed the survey and pain diary.

SURVEY

Cronbach alpha for PPEP was found to be 0.80. Percentage responses for each PPEP item are displayed in Figure 2. Highest percentage agreement (86%) was for the statement "*children in pain have trouble sleeping*". Lowest agreement (24%) was for the statement "*children feel less pain than adults*". The inverse is true for percentage disagreement. Highest uncertainty (15%) was for the statement "*children exaggerate pain*", and lowest uncertainty (1%) was for the statements "*children always express pain by crying or whining*" and "*children who are playing are not in pain*". A statistically significant difference was found between ethnicity and PPEP (Asian and White [$h=24.2$, $p=.037$]) as well as PPEP active loud subscale (Asian and White [$h=31.5$, $p=.004$]). No statistically significant difference was found between PPEP scales, subscales and time since diagnosis.

PAIN DIARY

A pain score was recorded for 1769/2137 (82.8%) diary entries. Of these episodes, 465/1769 (26%) recorded a pain score of one or more. In 292/1769 (17%) episodes, clinically significant pain of three or more on the NRS (Fortier et al., 2014) was recorded. Pain score frequencies are displayed in Figure 3. Only six children (16%) did not have clinically significant pain on at least one occasion during the one-month pain diary period. Twenty-nine children (78%) had three or more episodes of clinically significant pain during the pain diary period. There were no statistically significant differences detected when comparing either maximum or mean pain score in groups of different diagnosis, different time since diagnosis, and pre and post-six months since diagnosis (Table 4).

Pain location was recorded for 492 episodes. In 36 of these episodes no pain score was recorded, in one episode pain was recorded as zero, and in two episodes pain was recorded as “?”. Table 5 displays frequency of pain locations for episode data and aggregated data. In 59 episodes, pain was reported in more than one location which meant intensity of pain for each location could not be calculated. For children who had a multimodal distribution of pain locations, the most frequent locations recorded by their parents have all been counted. Seventy-two percent of arm pain can be attributed to one child who had 23 episodes of arm pain.

A cause was recorded for 448 pain episodes. Table 6 displays frequency of causes of pain for episode data and aggregated data per child. In 60 episodes, pain was reported to have more than one cause which meant intensity of pain per cause could not be calculated. For children who had a multimodal distribution of cause of pain, the most frequent causes recorded by their parents have all been counted. All pain from disease can be attributed to one child, 50% of pain from procedures can be attributed to one child who had five episodes of procedure pain, and 56% of pain from infection can be attributed to one child who had 14 episodes of infection pain. Other causes of pain included specific daily activities like carrying a school bag, and avascular necrosis.

INTERVIEWS

Interview results are presented in two themes: pain manifestation and pain assessment. The concept that every child is different was key in parents’ responses in interviews and is threaded throughout. Parents

felt that their child had a unique pain manifestation and that their child's pain response to treatment could not be compared to other children. Similarly, parents felt that their child's pain expression was unique, and they developed bespoke strategies for assessing their child's pain.

"...every child is different. Every child is different. Every child responds differently" – Jana

Pain manifestation

In interviews, parents described both the presence and the absence of pain. They were able to distinguish different types of pain and its impact on the family. Children experienced pain in many parts of their body, with a variety of causes. Parents frequently described "bottom" and abdominal pain. This pain was mostly due to constipation and occasionally due to diarrhoea. Less common, but still frequent, children experienced mouth and throat pain due to mucositis. Other locations included jaw, head, arms, legs, and back. Parents frequently attributed their child's pain to chemotherapy and steroids. Parents also described pain from procedures such as bone marrow aspirates, lumbar punctures, or intrathecal chemotherapy, which happened in hospital but remained painful on discharge. Other causes included muscle weakness, infection, and rashes.

Parents recognised different types of pain, distinguishing between duration and intensity of pain:

"...intermittent [pain], these are moments, this is not kind of chronic pain that continues...there's debilitating pain, and there's just I don't feel quite right today I'm under the weather sort of pain" – Jackie

Parents reported that children experienced frequent low-level pain which resolved swiftly without intervention:

"...he'll just say, oh mummy my leg hurts, my hip hurts...it's just a random pain...But normally it's a passing thing where he'll moan about it for a few minutes and then it's gone." – Angie

Parents also described episodes of severe pain:

"...that weekend when everything hurt...Her eyes were sort of gone in a way. She was suffering that day. So that was 10 [out of 10] yes." – Ruth

In addition to describing the presence of pain, parents also described the absence of pain:

"...each drug has its own side-effect, but pain generally hasn't been one of them" – Angie

Parents were grateful for this and most referred to themselves and their child as "lucky". Their perception of themselves as "lucky" was drawn from comparisons to other children and parents who they perceived had experienced more pain. They were not specific about which families made them feel lucky:

"I think we're quite lucky in the fact that she wasn't in [pain], I know some children are in pain a lot and maybe if she was, I would have dealt with things differently" – Jackie

Parents often commented on age as both a positive and negative contextual factor. Parents of younger children described age as a barrier to helping children understand their pain, its cause, and how to resolve it. Below Suzannah described how she wished her child could understand the transient nature of her pain:

"...for that child to understand that their pain is a time in their lives, it's not forever, because children don't have a concept [of] time" – Suzannah

Parents of older children described their age as advantageous due to it providing their child with ability to reason:

"...old enough to be able to reason with it. You've got to do it cos it's going to make you better. So, he kind of does it." – Angie

Conversely, parents of older children worried about the psychological impact of pain on their child. One parent whose child had relapsed compared her child's different psychological responses to pain with age:

"...he's a little bit older and he's thinking about a lot more things...Whereas when they're younger, because they don't really know any better...he...coped a little bit better then, than he is now." – Priya

This potential for psychological damage caused by pain was recognised as a "blessing" in parents of younger children:

"But it's also been a blessing in terms of her not really being bogged down psychologically...An older kid would probably struggle with that a lot more. And so, the psychological benefit with being pre-school age...in the future she may not remember much or any of this which could be a blessing as well." – David

Pain also held psychological implications for parents. Many children experienced pain as a symptom of cancer prior to diagnosis, so when the child was in pain, parents feared their child may be relapsing:

"...the leg pain I thought oh my god why can't she cycle down the street? She could cycle down the street last week. Why can't she do that this week? Oh my god could it be the leukaemia?" – Suzannah

Pain assessment

"Like I said, every child is different and probably one more child with leukaemia will have a different, a different behaviour" – Natalia

Parents' response in the intervention phase was to assess their child's pain. As Natalia describes above, the child's uniqueness affected their pain expression behaviour and consequently pain assessment. Accurate pain assessment enabled parents to select an appropriate intervention. At times, pain assessment was easy as some parents reported their children telling them when they were in pain:

"...when he's in pain he lets me know, he will let me know" - Elena

More frequently, parents reported their child would not articulate their pain:

"And it's a question of second guessing and working out what she needs cos she's not that explicit about saying what works for her." – Margret

Parents occasionally admitted not knowing whether their child was in pain:

"Well you don't always, that's the thing about feeling helpless. You don't know but you just try and make a good guess really." – Beth

This uncertainty was in part caused by stoic children who appeared to have high pain thresholds and did not cry. Parents suggested reasons for this stoicism which differed with age. Older children often preferred not to talk about pain and wanted to cope without intervention. Pauline describes James choosing to "ride it" in the quote below:

"I feel he does have pain but it's not a pain enough to make him say, he will just ride it for a few hours...he will think...I'll just wait it out and he'll just ride the pain to a certain extent" – Pauline

In the middle age group, parents felt their child was aware that if they admitted to being in pain, their parent would give them medication or take them to hospital. Children tried to hide their pain because they did not want these interventions:

"...I think she was probably in more pain and...she didn't want to talk. I think she didn't want the medicine" – Jackie

"... not trusting that she was covering stuff up because she knew that if something hurt, we were going to end up back in hospital..." – Georgia

Parents of younger children felt unsure of their child's pain due to their child's inability to express pain:

"I suppose obviously at her age, particularly a bit earlier on, she's a bit older now but at the start of the process obviously her ability to communicate or articulate, in a way that an older child would be able to do is a challenge" – David

Despite challenges, parents developed alternative ways of knowing when their child was in pain including attending to their child's unique behavioural cues, mood, body language, verbal cues, and circumstances. Several parents reported that their child became quiet and did not talk or play, often withdrawing physically and trying to be alone:

"We can tell because normally Raj's quite a chatty person...we know he's going through something...when he doesn't want to talk to you" – Priya.

"She'll go to be on her own...try and hide" – David

For some children behavioural cues like being rude, moody, or angry were signs of pain:

"He'll snap at me go 'what' things like that which I know that's not him" – Pauline

*"She normally starts being moody and getting...then she'll say oh my legs are really achy"
– Lisa*

"Throwing stuff like being angry with others...even though he needed me all the time he was very angry with me at the same time because it was...you was supposed to look after me" – Jana

Body language was another way parents assessed their child's pain. As with behavioural cues, body language was specific to the child. David described how his daughter would:

"Collapse her shoulders a bit and droop" - David

Suzannah described her daughter as:

“Tense and clutching [her] stomach” – Suzannah

Elena described a unique position which her child assumed when in pain:

“...fold his leg over the other one kind of like a pretzel...was his little, his safeguard” – Elena

Some parents observed their child extensively and learned to assess their child’s pain through creative attention to detail:

“I...learned a lot from watching her play and...knowing how she was, how much she was hurting...if she was saying to the dolly oh you need this because you’re feeling like this...children can only go on what they’ve learned or what they know so if she’s saying that that dolly’s in pain cos this is how much it hurts and that’s what’s happened to her.” – Jackie

In the excerpt below, Pauline describes how she could identify the intensity of her son’s pain by noticing whether he was watching YouTube or using his PlayStation:

“...he’ll just watch YouTube he won’t even go on the PlayStation cos I can tell when he’s really wanting to rest and can’t focus on the PlayStation game that will go and he’ll lie down in bed and just watch, just watch YouTube or he’ll put a video or a film on or something. And I will know then that he’s still not quite well enough” – Pauline

Differentiating between fear and pain was a further challenge to pain assessment as children in this sample experienced many fear-provoking circumstances:

“...is it fear causing the pain? Is it anticipation of pain? Are these anxiety related symptoms?” – Suzannah

Whilst parents generally felt their child’s pain was genuine, a few parents, particularly of younger children, alluded to their child pretending to have pain to gain attention. These parents used circumstances to determine pain authenticity:

“...she may be in trouble so she she’ll say oh my finger when it’s nothing to do with her finger” – Stacey

INTEGRATION

The matrix of findings (Table 7) led to an examination of reasons for divergence between datasets. This matrix suggested the meta-inference that the PPEP may not be able to detect all forms of pain expression due to every child with cancer being different. Meta-inferences stemming from pain diary findings (Table 7.5) suggested that, due to convergences, pain diary and interview data collection methods measure the same phenomena. These meta-inferences confirm the most frequent location and causes of children's pain. Although children were frequently reported as not being in pain, it was difficult to tell from the matrices whether this was due to parents being unable to assess pain. Interview findings presented via the matrix revealed convergence between pain diaries and interviews which suggested they were measuring the same phenomenon. Once again meta-inferences regarding pain assessment were unclear. Divergences result either from parents not being able to assess their child's pain, or PPEP not being able to detect children's unique pain expressions.

Table 8 displays findings from each data collection method as they relate to each research question. Pain diary and interview data were convergent on pain locations and causes but had within-method divergence on pain prevalence. Chemotherapy toxicity was the most frequently cited reason for pain as measured by pain diaries, followed by constipation and diarrhoea, mucositis, and other treatment drugs. Interview data were qualitative and therefore cannot quantify the most frequent causes of pain, but similar causes were regularly mentioned in interviews so results from data collection techniques are considered convergent. The overall meta-inference stemming from this finding was that pain for children with cancer at home is primarily caused by treatments. Abdominal pain, followed by leg, mouth/throat, head, and then bottom pain were found to be the most common locations for pain as measured by pain diaries. Although interview data cannot quantify most frequent pain locations, regular mentions of each of these sites throughout interviews with potentially more emphasis on bottom pain, suggests general convergence between datasets. Pain diaries and interviews had within-method divergence regarding the prevalence of pain: both datasets simultaneously found pain to be present and absent. Data from pain diaries and interviews suggest children with cancer are not often in pain at home. Conversely, in most of the interviews, parents described distressing episodes of pain and indicated that some children experienced clinically significant pain for long durations as evidenced in pain diaries.

Survey and interview data diverged on how parents assess their child's pain at home. Surveys found that parents held negative attitudes and misconceptions towards children's pain expression which did not

change with time suggesting parents are not able to adequately assess their child's pain. Conversely, interview results suggest parents can assess their child's pain. Due to the effort parents put into learning, with the objective of knowing their child, parents understand their child's unique pain expression and feel they are able to identify when their child is in pain.

DISCUSSION

Survey results suggest parents of children with cancer hold misconceptions regarding pain assessment which do not change over time. In pain diaries parents reported children's pain location, cause, and intensity. Parents listed similar pain locations and causes in interviews and described both the presence and absence of pain. Parents provided detailed descriptions of their pain assessment strategies and reported that every child is different in both pain manifestation and expression.

WHAT IS THE PAIN MANIFESTATION OF CHILDREN WITH CANCER AT HOME?

Parents' perspectives of pain manifestation were recorded in pain diaries and described in interviews. Datasets converge on causes and location of pain but there was within-method divergence on prevalence of pain for children with cancer at home.

Causes of pain in children with cancer at home

This research found treatment to be the primary cause of pain experienced by children with cancer at home. Conversely, a recent study in Lebanon of inpatient and outpatient children with cancer, found tumours and metastases were the most frequent causes of pain (Madi & Clinton, 2018). In that study no significant differences were found in pain intensity between pain caused by cancer, treatment, and procedures. Children were asked to choose between a predetermined list of potential causes of pain and authors suggested this method may have biased or limited children's responses. Treatment as the major source of cancer pain in children is otherwise widely corroborated (Hanmod & Gera, 2016; Ljungman, Kreuger, Gordh, & Sørensen, 2006). Our findings are in line with a historical trend toward more pain from treatment and less pain from the disease itself (Twycross, Parker, et al., 2015).

Location of pain in children with cancer at home

Most frequent pain locations for children with cancer at home were the abdomen, legs, mouth/throat, head, and bottom. Comparison with other literature is hindered by different ways of reporting pain location. In a study reporting on an app designed for managing cancer pain at home, a small sample

(n=12) of outpatient children made no mention of abdominal pain when using a body diagram (Fortier, Chung, Martinez, Gago-Masague, & Sender, 2016). In concordance with our findings, both abdomen and legs were within the top five pain locations in a sample of outpatient children though the mechanism of recording is unknown (Fortier et al., 2014). A sample of inpatient and outpatient children similarly reported abdomen and head to be in the top five pain locations using a body diagram (Madi & Clinton, 2018). When given four options to choose from, parents of inpatient and outpatient children with cancer both on and off treatment, reported legs to be the most frequent location of pain (Tutelman et al., 2018).

Prevalence of pain in children with cancer at home

Pain diaries and interviews both had within-method divergence regarding the prevalence of pain: each dataset simultaneously found pain to be present and absent. Many pain diaries and interviews suggest children with cancer are not in pain at home very often. The absence of pain as a finding of this research suggests one of two scenarios: either children with cancer do not experience pain at home very often, or parents are limited in their ability to detect their child's pain. This research did not use self-report measures of pain making it difficult to ascertain which scenario is true. However, previous research using self-report of pain intensity concluded that children generally do not experience severe pain at home (Fortier et al., 2014). Combining these results, it can tentatively be suggested that the first scenario is more likely: children with cancer do not experience pain at home very often. Greater confidence in this explanation stems from an analysis of how parents assess their child's pain at home.

In most interviews, parents described distressing episodes of pain and in pain diaries parents reported that some children experienced clinically significant pain for long durations. Despite what appears to be within-method divergence, these findings may not be mutually exclusive. A potential explanation is that there may be not be a single pain trajectory: children's cancer pain at home may be best described by heterogeneous pain trajectories. For example, there may be a subset of children who experience no pain at home, a subset of children who experience frequent pain at home, and a subset of children who experience occasional pain at home. This is corroborated by the key finding from interviews that "every child is different".

Due to data quality, statistical confirmation of heterogeneous pain trajectories could not be performed using pain diary data so evidence from literature will be used to support this potential explanation. A longitudinal study of children with cancer, provided evidence of two heterogeneous symptom trajectories which included pain: less severe and more severe (Wang et al., 2017). Another study in children with cancer found evidence of four symptom and function profiles and related this to children having another medical condition (Buckner et al., 2014). Both studies predicted each child's symptom trajectory using criteria which are frequently unavailable in clinical practice and authors of these studies emphasised difficulties predicting profiles based on demographic criteria. This suggests healthcare professionals (HCPs) in clinical practice may be unable to detect which children will experience more pain at home. An educational checklist has recently been developed which includes a list of topics for nurses to address with parents of children newly diagnosed with cancer prior to initial discharge (Rodgers et al., 2018). On this list, pain and pain management are considered primary topics which only require attention if applicable. Our research found that when children did experience pain, it was often clinically significant. Clinically significant pain episodes occurred at least once for 84% of children which implies this topic should be addressed in the vast majority of cases and it may not be appropriate to address this topic only as required. As it is currently not possible to predict which children will experience pain and when (Buckner et al., 2014; Wang et al., 2017), pain education prior to discharge must be a universal consideration for parents of all children with cancer regardless of their pain experience in clinical settings.

HOW DO PARENTS ASSESS THEIR CHILD'S PAIN AT HOME?

Data integration revealed divergences between datasets regarding how parents assess their child's pain at home with survey data suggesting parents are not able to assess their child's pain at home and interviews indicating the reverse. Potential parent-based and method-based explanations for this divergence are considered.

Parent-based explanations for divergent findings

Two possible parent-based explanations will be discussed. Firstly, parents may be mistaken in their perception that they are able to assess their child's pain. It is not possible to say for certain whether parents' pain assessments are accurate, as this research did not include a self-report measure of pain. Many studies reveal concordance between parent and child reports of pain. In qualitative work, child and parent perceptions of cancer pain have been found to be compatible (Ljungman et al., 2006). A congruent

relationship between parent and child reports of cancer pain was found in studies relating to procedure pain (Badr, Puzantian, Abboud, Abdallah, & Shahine, 2006), and longitudinal symptom assessment (Baggott, Cooper, Marina, Matthay, & Miaskowski, 2012). Conversely, literature reports divergence between parent and child reports of pain. A meta-analysis which investigated dyadic concordance for all types of childhood pain concluded that despite moderate effect sizes, parent reports should only be considered an estimate of their child's pain (Zhou, Roberts, & Horgan, 2008). This meta-analysis included 12 studies, of which four investigated postoperative pain, and five procedural pain. Both of these pain manifestations are short-term, and parents may be less used to assessing their child's pain in these circumstances compared to parents of children with cancer. One study investigating children with cancer, found parents' retrospective recall of pain, amongst other symptoms, was higher than children's recall which is contrary to suggestions of under recognition of pain in this population (Zhukovsky et al., 2015). This combined evidence suggests parent and child reports of cancer pain are congruent and parents are able to assess their child's pain.

An examination of the accuracy of parents' pain assessment can be made by considering the trustworthiness of proxy reports of children's pain using wider literature and the content of interviews. Assessment of the trustworthiness of proxy report of children's pain is made on the assumption that self-report is the gold-standard in pain assessment (Baggott, Cooper, Marina, Matthay, & Miaskowski, 2014; Finley, Kristjánsdóttir, & Forgeron, 2009). When a measure is considered gold-standard, this suggests it is accurate and should be unquestioned, but there are many reasons why clinicians and researchers may question the use of self-report as gold-standard (Twycross, Voepel-Lewis, Vincent, Franck, & von Baeyer, 2015; Versloot, von Baeyer, & Craig, 2013). Evidence suggests children give different self-reports of pain to different people (Versloot, Veerkamp, & Hoogstraten, 2004; Versloot et al., 2013). One explanation is the concept of "display rules", where a child is likely to display a behaviour (i.e. pain expression) if they perceive it will lead to a positive outcome (Versloot et al., 2013). Display rules are evidenced in our research by parents' descriptions of children not wanting to admit to their pain due to fear of having to take pharmacological interventions which they found unpalatable, thinking pain would mean going to hospital, and not wanting to think about pain. It is, therefore, possible that any self-report measures of child pain utilised in this research may have been less accurate than parents' proxy report.

Current academic thinking suggests self-report should be considered the primary, but not sole source of information for pain assessment (Twycross, Voepel-Lewis, et al., 2015). Instead, it is suggested that approaches in which several aspects of child pain are simultaneously considered and weighed against one another may be more beneficial. These methods are termed “bundled approaches”. One example of a bundled approach is the CARES (Context, Assessment, Risk, Emotion, Socio-cultural) approach. This is considered a bundled approach because, as with other care bundles, it uses several different strands of information to make an assessment and deliver an intervention.

Parents reported using circumstances surrounding the pain episode, children telling them when they were in pain, behavioural cues, considering emotions by differentiating between fear and pain, and considering their child’s age and developmental stage. Parents balanced risks of analgesic drug administration and non-pharmacological interventions, and used their own background and family preferences in managing pain. Parents reported combining several elements of information in their assessment of their child’s pain which constitutes using a bundle. In short, pain assessment as conducted by parents of children with cancer closely matches pain assessment as advised by current world experts in paediatric pain (Twycross, Voepel-Lewis, et al., 2015).

Overall, this evidence suggests that whilst parents’ pain assessment should be considered only an estimate of pain, it can be considered a good estimate. It is unlikely parents are mistaken in their understanding of their ability to assess their child’s pain. Our research identified bundled approaches as an accurate way of measuring pain in children with cancer which researchers may find useful when designing future research and HCPs may find useful when assessing children’s pain in clinical settings.

A second parent-based explanation is that, on average, interview participants may have been better at pain assessment compared to those completing the survey. Using a sampling frame for interviews ensured a range of participants in terms of age of child and time since diagnosis but it did not attempt to include parents with a range of pain assessment abilities. Participants’ prior pain assessment knowledge or education received from HCPs was unknown. A recruitment strategy which ensured a range of participants in terms of pain assessment abilities would have been difficult to design and may have biased data collection if the researcher was aware of participants’ pain assessment abilities when conducting

interviews. Although a balanced interview sample is not guaranteed, inspection of the PPEP scores of interview participants revealed a range of pain assessment scores which indicates biased sampling may not be the cause of divergence between datasets. In conclusion, neither parent-based explanations appear to be the cause of divergence between datasets in this context.

Method-based explanations for divergent findings

Two possible method-based explanations exist. Firstly, closer examination of the PPEP, suggests some questions may be misleading for parents. For example, parents who agree with the statement “children in pain have trouble sleeping” will be scored as having a misconception. Whilst being asleep does not mean that a child has no pain, children with pain resultant from a variety of causes do have trouble sleeping (Fortier et al., 2014; Haraldstad, Sørnum, Eide, Natvig, & Helseth, 2011; Lynch, Dimmitt, & Goodin, 2018; Palermo, Law, Churchill, & Walker, 2012; Palermo, Wilson, Lewandowski, Toliver-Sokol, & Murray, 2011). Similarly, parents who agree with the statement “children who are playing are not in pain” will be scored as having a misconception. Although playing does not mean the child has no pain, problems with social functioning are associated with acute (Roth-Isigkeit, Thyen, Stöven, Schwarzenberger, & Schmucker, 2005) and chronic pain (Fortier et al., 2014; Palermo, 2000) in children so it may be possible that parents had misunderstood the question. It may not be appropriate to classify parents who agree with statements such as these as having a misconception in the context of children’s cancer pain.

Secondly, the PPEP may not be sufficiently nuanced to detect the uniqueness of each child’s pain expression. Interview results were focused around the key theme “every child is different”, which describes how each child’s uniqueness impacts parents’ pain management. Due to the chronic nature of cancer pain in children (Fortier et al., 2014), parents have time to learn their child’s unique pain expression. Quantitative, closed-question data collection methods, such as surveys, may lack the sensitivity required to measure nuances of pain assessment in children with a chronic condition. Conversely, open-ended data collection methods, such as interviews, allow parents to describe their child’s unique pain expression and their unique method of pain assessment. Whilst there is evidence of PPEP reliability from acute settings (Zisk et al., 2010, 2007), its validity in measuring pain assessment in a context where parents have opportunity to learn their child’s unique pain expression is unknown.

STRENGTHS AND LIMITATIONS

Analysis conducted to embrace rather than ignore divergences has strengthened this study (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2009). Had this research not embraced between-method divergences, different conclusions may have been drawn. As demonstrated in this study, mixed methods produces findings which are more than the sum of their parts (Teddlie & Tashakkori, 2009).

Age, gender, and diagnosis distributions of this sample roughly match UK figures for children with cancer (Children with Cancer UK, 2018; Irvine, 2017). Mixed methods sampling (Teddlie & Yu, 2007) which involved combining a small qualitative sample to obtain depth of data, with a larger quantitative sample to obtain breadth of data, strengthened this study (Creswell & Plano Clark, 2011). Sample size and inclusivity may have increased due to participants being offered flexibility to participate according to their time capacity and interest for research (Newington & Metcalfe, 2014).

Use of purposive sampling for interviews enabled data to be gathered from a broader range of participants in relation to the research question (Heavey, 2014). Interview sample should not be considered generalisable as there remains a possibility that participants who expressed interest in completing an interview may be biased (Parahoo, 2014). Survey and pain diary samples should not be considered representative of the population as convenience sampling was used for both (Etikan, Musa, & Alkassim, 2016; Parahoo, 2014). Generalisability was limited by recruitment of participants from just one UK tertiary cancer centre. UK paediatric cancer services are organised to allocate children with cancer one tertiary cancer centre and one shared care centre (NHS England, 2017). As a result, recruiting from a tertiary cancer centre has meant parents recruited to this study represented children receiving care from a range of shared care centres.

This was an exploratory study aiming to provide an in depth, illustrative information on the situation parents face at home. Thus, this study was not powered to examine a regression relationship between study variables. However this study will aid future researchers to guide sample size calculation that might facilitate multiple regression analysis. This research will aid with establishing sample size calculations for future research.

Acceptable, non-burdensome research methods have been demonstrated by a response rate of 63%. Pain diary recruitment was only three shy of target. Both survey and interview sample targets were met. Homogeneous sampling enabled meta-inferences generated through integration of data collection methods to hold greater authority. Recruitment relied on HCPs acting as gatekeepers to ensure potential participants were not approached at times when recruitment may have incurred additional distress (Creswell and Plano Clark, 2011; Teddlie and Tashakkori, 2009). This strategy was a safety mechanism designed to reduce distress and overcome a potential ethical barrier. However, it is not possible to say definitively whether HCPs fully understood potential participants' needs in these circumstances or the impact of research on participants. Paternalistic HCPs may have prevented potential participants from experiencing potential benefits of involvement in research (Coombs et al., 2016).

CONCLUSION

Children with cancer experience pain in a range of locations primarily caused by treatment. Pain intensity may differ between children who may have heterogeneous pain trajectories. Literature is currently insufficiently developed to predict which children will have more severe pain trajectories. Consequently, it is important that all parents of children with cancer are prepared for their potential pain management role.

Divergence between datasets on pain assessment can be understood by examining parent-based and method-based explanations. Lack of self-report may mean the true nature of children's cancer pain at home is not fully represented. Evidence of child disclosure of pain being limited by display rules suggests self-report may not represent an unquestionable gold-standard in this context. Parents' use of several aspects of child pain expression is in line with expert recommendations to use bundled approaches to pain assessment. This evidence suggests parents are not mistaken in their understanding of their ability to assess pain.

Participants who chose to complete interviews may be more attuned to their child's pain leading to a biased sample but inspection of interview participants' PPEP scores suggests this is not the case. Some PPEP questions may have misled parents and exaggerated misconceptions in pain assessment. Finally, because "every child is different", the PPEP may be insensitive to children's unique pain expression. Integration suggests method-based rather than parent-based explanations are more likely the cause of

divergence. Not only are parents able to adequately assess their child's pain but use of bundled approaches means they are in line with current expert thinking on children's pain assessment. Although parents experience challenges in pain assessment they overcome these and can confidently assess their child's pain.

RELEVANCE TO CLINICAL PRACTICE

Children with cancer experience pain in a variety of locations primarily caused by treatment. These children may have heterogeneous pain trajectories, but research is unable to identify which children will experience more severe pain so all parents of children with cancer should be equipped to manage their child's cancer pain at home.

Parents use bundled approaches to adequately assess their child's pain. Healthcare professionals may benefit from using these approaches in clinical practice. In addition, parents of children newly diagnosed with cancer may benefit from being taught about bundled approaches.

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Table 1: Purposive sampling for interview participants

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

Table 2: Demographic characteristics of children represented in the sample

Child demographic data n (%)		Survey (n=101)	Pain diary (n=37)	Interview (n=18)
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)
	M	60 (59.4)	23 (62.1)	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)	
Note: Totals vary due to missing data				

Table 3: Demographic characteristics of parents represented in the sample

¹ Parent demographic data n (%)		Survey (n=101)	Pain diary (n=37)	Interview (n=18)
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)
Note: Totals vary due to missing data				

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

Table 4: Comparisons of maximum and mean pain scores in different groups with different demographic characteristics

Independent variable	Dependent variable	Testing values	p-value
Diagnosis	Maximum pain	ANOVA (F(4,32) = 1.833)	0.147
	Mean pain	Kruskal-Wallis (H(4) = 3.786)	0.436
Time since diagnosis	Maximum pain	ANOVA (F(4,32) = 0.412)	0.799
	Mean pain	Kruskal-Wallis (H(4) = 0.010)	1.000
Pre- and post-six months since diagnosis	Maximum pain	Student's t-test (t(35) = -0.232)	0.818
	Mean pain	Mann-Whitney U (U = 158)	0.925

Table 5: Frequency of pain locations

Location	Number (%) of episodes (n=492)	Number (%) of children for whom this is the most frequent pain location (n=37)
Abdomen	123 (25.0)	11 (29.7)
Legs	104 (21.1)	11 (29.7)
Mouth / Throat	99 (20.1)	4 (10.8)
Head	71 (14.4)	5 (13.5)
Bottom	66 (13.4)	1 (2.7)
Arms	32 (6.5)	1 (2.7)
Back	30 (6.0)	4 (10.8)
Other	21 (4.2)	3 (8.1)
Don't know	15 (3.0)	1 (2.7)

Chest	10 (2.0)	2 (5.4)
Note: Totals vary due to missing data and due to the decision to count all of the most frequent locations for children who had multimodal distribution of pain.		

Table 6: Frequency of causes of pain

Cause	Number (%) of episodes (n=488)	Number (%) of children for whom this is the most frequent cause of pain (n=37)
Chemo-toxicity	120 (24.5)	9 (24.3)
Constipation / diarrhoea	90 (18.4)	7 (18.9)
Other	62 (12.7)	3 (8.1)
Mucositis	60 (12.2)	2 (5.4)
Drug side-effects	46 (9.4)	3 (8.1)
Don't know	27 (5.5)	4 (10.8)
Unwell / infection	25 (5.1)	2 (5.4)
Surgery	25 (5.1)	2 (5.4)
Being active	25 (5.1)	3 (8.1)
Nausea	23 (4.7)	2 (5.4)
Procedure	10 (2.0)	2 (5.4)
Disease	4 (0.8)	1 (2.7)
Note: Totals vary due to missing data		

Table 7: Meta-inferences generated through matrices

Survey inferences	Pain diary convergence	Pain diary divergence	Interview convergence	Interview divergence	Meta-inference
Misconceptions about pain assessment	Children frequently not in pain. Parents who had better scores on PPEP quiet-inactive scale also reported their child experienced more pain and recorded more episodes of analgesic drug administration.	Several aspects of PPEP showed no statistically significant differences when compared to pain diary.	Few parents felt their child would occasionally fake pain.	Parents described in detail how they knew their child was in pain and put effort into understanding / assessing their child's pain.	"Every child is different" therefore PPEP may not be able to detect unique pain expressions. Parents are mistaken in their belief they are able to assess pain.
No improvements in pain assessment over time	No significant differences in maximum or mean pain score time since diagnosis.	None	Stoicism, not wanting pharmacological interventions / hospital, age of child prevented parents knowing.	Parents described using behavioural cues, mood, body language, verbal cues, and circumstances to assess pain.	Interview sample are better at pain assessment than survey sample. Survey is misleading to parents.
Children frequently not in pain	None.	Sample endorsed many misconceptions on PPEP.	Parents described themselves as "lucky" due to the lack of pain their child had experienced.	Some parents commented that taking part in interviews made them realise their child was in regular low-level pain. Most parents could recall times when their child had severe pain at home.	Either children with cancer infrequently experience pain at home or parents have limited ability to detect pain.

Pain diary inferences	Survey convergence	Survey divergence	Interview convergence	Interview divergence	Meta-inference
Children frequently not in pain	None.	Sample endorsed many misconceptions on PPEP.	Parents described themselves as “lucky” due to the lack of pain their child had experienced.	Some parents commented that taking part in interviews made them realise their child was in regular low-level pain. Most parents could recall times when their child had severe pain at home.	Either children with cancer infrequently experience pain at home or parents have limited ability to detect pain.
Frequent pain locations	n/a	n/a	Similar locations.	Bottom higher emphasis in interview. Few mentions of headaches.	Pain diary and interview measure same phenomenon. Children with cancer experience pain most frequently in abdomen, legs, mouth/throat, head, and bottom.
Cause of pain	n/a	n/a	Similar causes.	None	Pain diary and interview measure same phenomenon. Most frequent causes of pain in children with cancer are: chemotherapy toxicity, constipation/diarrhoea, mucositis, and other drugs.
Interview inferences	Survey convergence	Survey divergence	Pain diary convergence	Pain diary divergence	Meta-inference

Pain manifestation	n/a	n/a	Frequent pain locations and cause of pain match interview. Children frequently not in pain.	None	Pain diary and interview measure same phenomenon.
Know your child	None	Sample endorsed many misconceptions on PPEP.	n/a	n/a	"Every child is different" therefore PPEP may not be able to detect the uniqueness pain expressions necessary for pain assessment. Some parents do not learn to assess their child's pain. Interview sample are better at pain assessment than survey sample. Survey is misleading to parents.
Pain assessment	None	Sample endorsed many misconceptions on PPEP.	n/a	Children frequently not in pain.	Either children with cancer infrequently experience pain at home or parents are unable to detect pain children's pain. Some parents do not learn to assess their child's pain. Interview sample are better at pain assessment than survey sample. Survey is misleading to parents.

Table 8: Joint display of integration structured around research questions

Survey	Pain diary	Interview	Meta-inference
What is the pain manifestation of children with cancer at home?			
n/a	<i>Cause</i>		
	Most frequent causes were chemotherapy toxicity, followed by constipation and diarrhoea, mucositis, and other treatment drugs.	Frequent mentions of chemotherapy toxicity, constipation, diarrhoea, mucositis, and other treatment drugs.	Convergence Pain in children with cancer is most frequently caused by treatments.
	<i>Location</i>		
	Most frequent locations were abdomen, followed by legs, mouth/throat, head, and bottom.	Frequent mentions of pain in abdomen, legs, mouth/throat, head and bottom.	Convergence Pain in children with cancer is most frequently in abdomen, legs, mouth/throat, head and bottom.
	<i>Prevalence</i>		
Children had no pain in 74% of episodes.	Parents reported being "lucky" with lack of pain, low level of pain, fleeting pain.	Within-method divergence Potential explanation:	
Clinically significant pain occurred at least once for 85% of children.	Parents described episodes of pain at home which could not be resolved.	- Heterogeneous pain trajectories	

How do parents assess their child's pain at home?			
<p>Parents hold many negative misconceptions regarding pain assessment which do not improve over time.</p>	<p>n/a</p>	<p>Each child has a unique pain expression. Parents know their child and use many techniques to make accurate assessment of their child's pain.</p>	<p>Between-method divergence Potential explanations: - Parents are mistaken in their belief they are able to assess pain. - Interview sample are better at pain assessment than survey sample. - Survey is misleading to parents. - Survey is insensitive to individual child pain expression.</p>

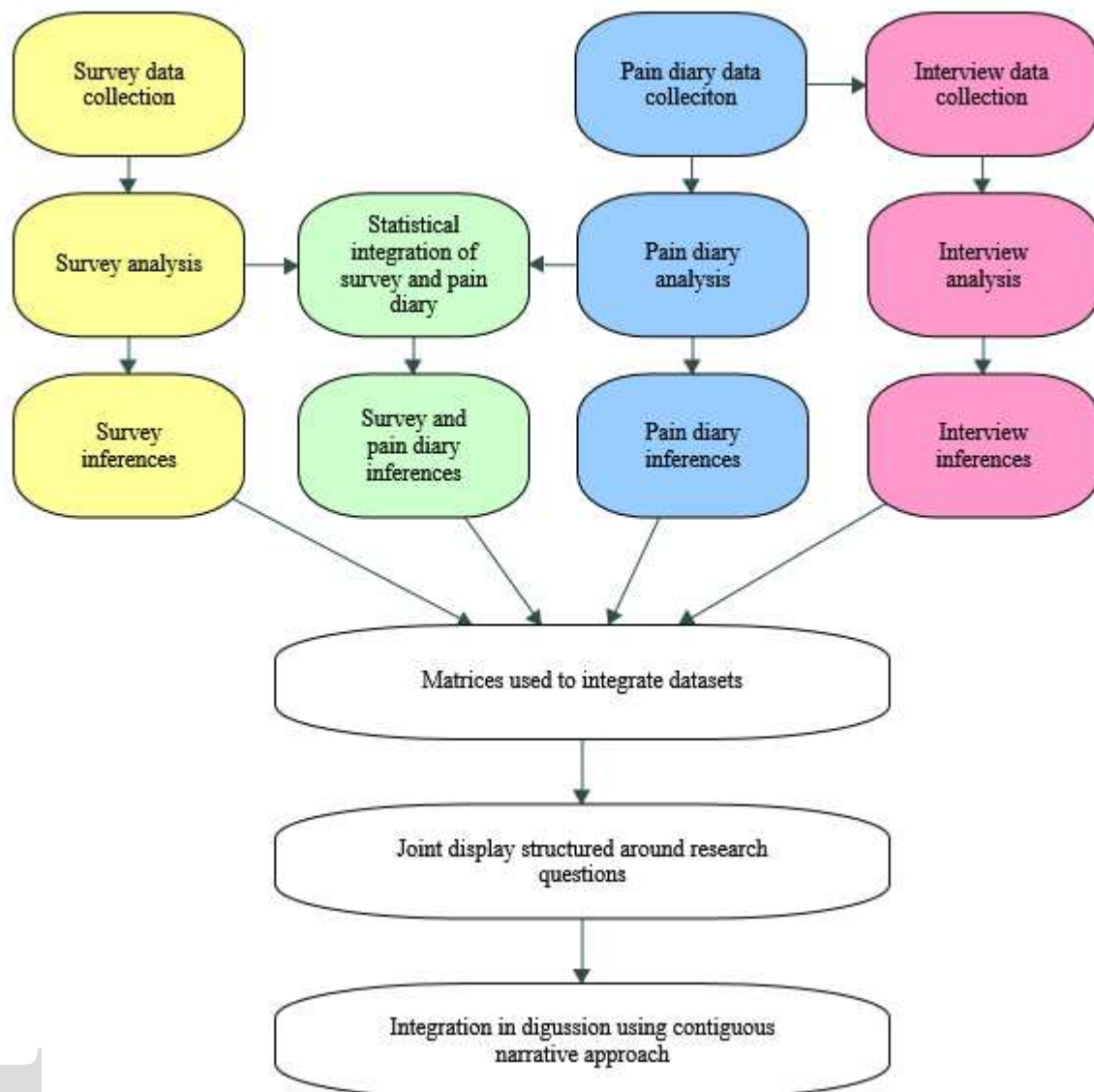


Figure 1: Analysis process and meta-inference generation

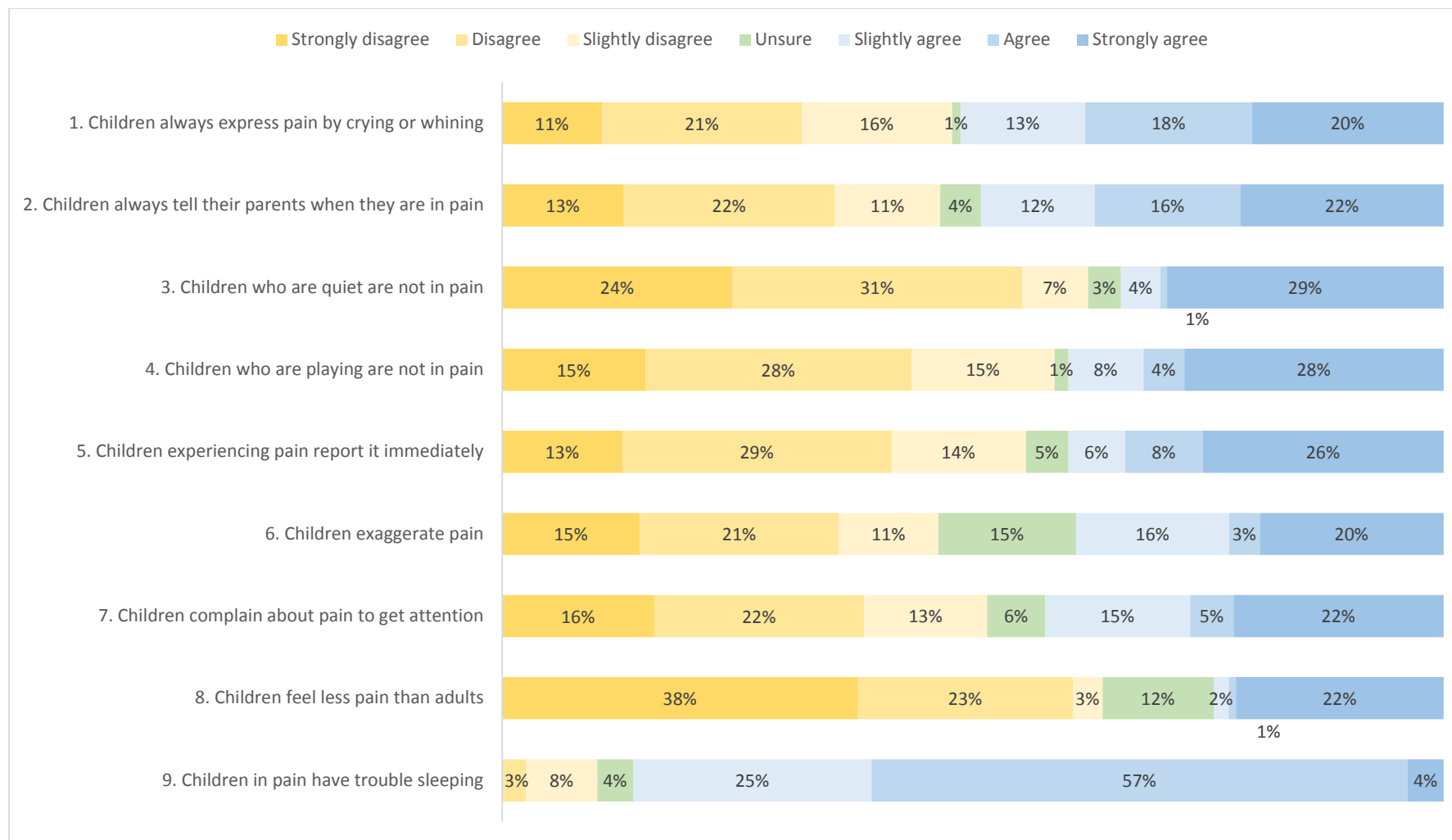


Figure 2: Percentage response for MAQ items

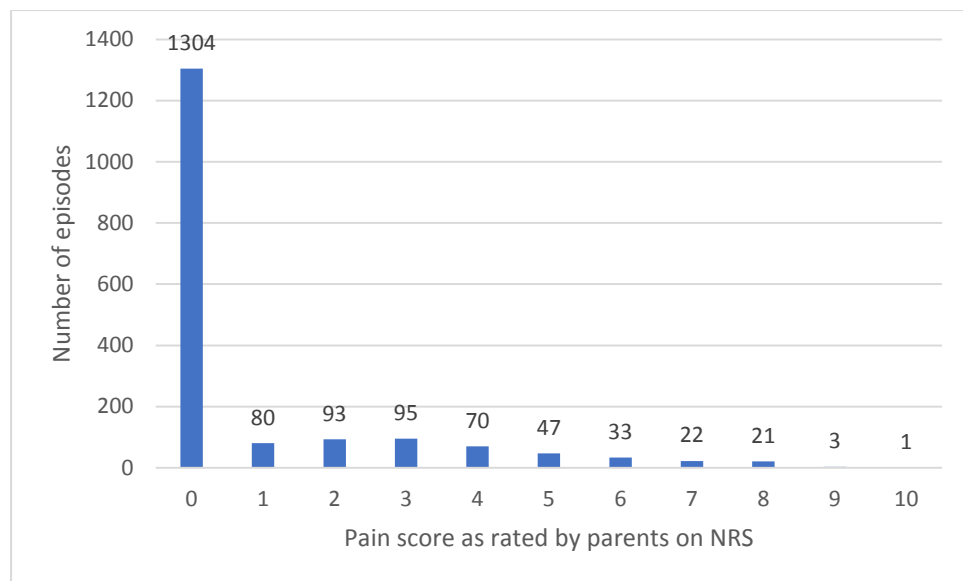


Figure 3: Frequency of pain scores as reported by parents on NRS