

How well is Paediatric Pain Managed in a Private Hospital in London?  
An Evaluation of Paediatric Healthcare Providers' Pain Management Practices and Parents'  
Perception of Pain Management in their Hospitalized Children

By

Abidemi Oladoyinbo (1415891)

MPhil Palliative Medicine

Supervisor: Dr Michelle Meiring

Co- Supervisor: Dr Patricia Luck University  
of Cape Town

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## ABSTRACT

**Background:** Optimal pain relief in a healthcare setting relies heavily on actual pain management practices rather than just on the healthcare practitioner's knowledge of this. Understanding parents' perceptions of pain management practices are very important in identifying areas of concerns and in developing plans and strategies for improvement. Although research has examined these practices in various public healthcare settings, no research has been carried out within the private sector.

**Aims/Objectives:** This study aims to evaluate pain management practices of paediatric healthcare providers and parental perception of these practices within a private hospital in London. Its main objectives to evaluate paediatrics health care providers' pain management practices against the recommended standard within the UK.

**Methods:** Using a Mixed method study design, 10 healthcare providers were observed and data was collected on pain management of 10 children over a period of 10 months (14 shifts). Interviews were also conducted with the corresponding 10 parents/caregivers of children involved in the study.

**Results:** The median age of child participant and health care providers were 3 and 32years respectively. Greater than half of the parent participants were Arabic while there was a fairly equal representation of white, Asian and black racial distribution among the health care providers. Although all healthcare provider could speak English, almost half of them could speak other languages, while greater than half of parent participant speaks Arabic.

Pain assessment is routinely documented when the vital signs are checked, but recorded score may not correlate with the actual pain score of the child. This is due to lack of consistency and appropriate use of a validated pain tool for age. A potential lack of knowledge on how to utilise the various assessment tools may also contribute. Most parents were satisfied with the pain management of their child. They did indicate, however, the need

to improve healthcare providers' competencies and knowledge in the use of pain relieving devices as well as in the provision of supportive information for parents.

**Conclusion:** Overall, pain management practices in Harley Street were found to be satisfactory. Parental satisfaction with care provided could be attributed to the team approach utilised by healthcare providers in pain management.

It is recommended that Harley Street Clinic needs to implement a paediatric specific pain management guidelines with regular auditing of pain management practices in the hospital. A review of pain management information given to parents of cardiac patients, as well as the provision of pain management information brochure in relevant languages may help improve care.

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## **ABBREVIATIONS/TERMINOLOGIES**

Agency Staff –Temporary staff that has a contract with a temporary worker agency and work temporarily for and under the direction and supervision of the hirer

APA – Association of Paediatric Anaesthetists of Great Britain and Ireland

Bank Staff – Staff who provide cover for planned and planned shortfalls in staffing, covering vacancies and staff absences as well as bringing special required skill

BNF- British National Formulary

CA – Clinical Audit

O – Observation

NSAID - Non-Steroidal Anti- Inflammatory Agent

RCN – Royal College of Nursing

RMO – Resident medical officers are doctors working in different specialties in private hospitals in the UK

PEWS – Paediatric Early Warning Signs

WHO – World Health Organisation

PICU – Paediatric Intensive Care Unit

PCA - Patient Controlled Analgesia



# CHAPTER 1: INTRODUCTION

## *1.1 Background*

Hospitalized children experience pain daily.<sup>1</sup> This occurs as one of the commonest symptoms in any specialist paediatric care setting, either as a disease-related symptom or as a complication of diagnostic or therapeutic procedures. Paediatric healthcare providers therefore, in addition to specialist care, have the very important duty of providing optimal pain management using best-practice methods. Although there has been an increase in knowledge about pain, and guidelines<sup>2,3</sup> to support pain management are available, less is known about whether practices have improved in line with these.<sup>4</sup> Therefore, exploration of paediatric healthcare providers' actual pain management practice in all paediatric care settings is of paramount importance in the provision of optimal pain relief.

One of the key elements of quality paediatric pain management is the incorporation of the views and perceptions of parents and caregivers, who are valuable assets in pain assessment and treatment.

## *1.2 Problem Statement*

No paediatric pain audits have been conducted in Harley Street Clinic paediatric ward in London. There is no baseline study in this setting that has highlighted the quality, strengths, and weaknesses of paediatric pain management practices of staff members. The current pain management guidelines do not cover the management of paediatric pain and healthcare providers are advised to adopt principles of pain management from the current adult guidelines while the specific guidelines for paediatric patients are being developed.

Beyond providing excellent specialist oncology and surgical care for children with cancer and congenital heart diseases, there is also the need to provide optimal pain relief using best pain management practices. The following is therefore of utmost importance:

- Identifying areas of strength and weakness, thereby highlighting focus points for the development of strategies to inform specific paediatric clinical practice guidelines for the management of pain in the study site to improve quality of care and health outcomes.
- Exploring parental perceptions of these pain management practices to provide insight into their satisfaction with these, which is an accepted indicator of the quality of care.

*“Parents should be listened to and their views respected as part of providing patient-centred care”.*<sup>5</sup>

### ***1.3 Research Aim***

The aim of the study is to evaluate paediatric healthcare providers’ pain management practices and parental perception of these in a London private hospital.

### ***1.4 Research Objectives***

- To investigate pain assessment practices among paediatric healthcare providers.
- To assess pain management practices among paediatric healthcare providers.
- To evaluate paediatric healthcare providers’ current pain management practices against the recommended standard practice within the UK (World Health Organisation, Association of Paediatric Anaesthetists of Great Britain and Royal College of Nursing guideline<sup>3,5,7</sup>).
- To explore parental and caregiver perception regarding these pain management practices.

### ***1.5 Research Questions***

- What are the actual pain assessment and management practices of nurses and doctors involved in the care of oncology and post-cardiac surgery paediatric patients in a private setting?
- What are the parental and caregiver perceptions of these pain management practices?

### ***1.6 Outline of the Dissertation***

This study is primarily based on 5 core chapters. The first chapter is focused on introduction of the study.

The second chapter is focused on review of relevant literature that has been published.

The third chapter is focused towards demonstrating the research methodology that has been utilised for conducting this study.

The fourth chapter demonstrates the current findings and analysis with the use of charts and tables to provide clear context.

The fifth chapter summarises the context of the study as well as provide the limitations of the study along with some recommendations for the future work on the relevant topic of this study.

## **CHAPTER 2: LITERATURE REVIEW**

### ***2.1 The importance of pain control in children***

Provision of pain relief in children is a fundamental human right, and healthcare providers have an obligation to recognize, assess, monitor and treat pain as high priority.<sup>2</sup> Pain, which is synonymous with agony or suffering has been defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in term of such damage.<sup>6</sup>

Best pain management practices involve pain assessment (pain history, diagnosis, identification of source and intensity using a standardized tool), which is the first step, followed by pain relieving interventions using pharmacological and non-pharmacological strategies whenever possible.<sup>3,8,9,10</sup> Children's pain should be assessed and documented, and appropriate action taken.<sup>7</sup> The whole child must be considered when evaluating the clinical features of pain as pain is an outcome of an interaction of many factors.<sup>3</sup> Optimal pain management cannot be attained if all dimensions of total pain are not addressed. Effective pain relief therefore follows acknowledgement as well as management of the psychological, social, physical emotional and spiritual dimensions.<sup>11</sup>

Communication with children and parents during assessment and pain relief is crucial as is appropriate documentation. Children's pain should be assessed, documented and appropriate action taken.<sup>7</sup>

Consequences of poor pain management practices are delayed recovery, prolonged hospital admissions, poor wound healing, anxiety, impaired sleep, development of chronic pain and increased cost of healthcare.<sup>12,13</sup> In addition to direct consequences, poor pain management in children frequently leads to hidden costs, places a burden on family caregivers and can decrease productivity in the home.<sup>2</sup>

### ***2.2 Prevalence of Pain in Hospitalized Children***

Studies have identified high prevalence of pain in hospitalized children. A study by Cummings et al conducted in a tertiary paediatric setting in Newfoundland, Canada, found that 49% of hospitalized children experienced significant levels of pain during inpatient stay and that the most frequent sources of pain were related to disease and surgery as well as intravenous lines.<sup>1</sup>

Pain in children with cancer is caused by disease, diagnostic and therapeutic procedures, and side effects of surgery, chemotherapy and radiotherapy.<sup>3</sup> A study of prevalence of pain in a paediatric and young adult cancer population by Miser et al demonstrated that 75% had pain at diagnosis. This study also revealed that 50% of hospitalized patients had pain, and therapy-related pain was more common.<sup>14</sup>

A study conducted in a paediatric oncology ward in Sweden by Ljungman et al, in which 55 children and parents were interviewed, showed that pain was common during the different stages of cancer treatment with pain evaluation being inadequate.<sup>15</sup> This prominence of pain during cancer treatment was also confirmed by a prospective study conducted over 12 months in children aged 10-18 with cancer in Memorial Sloan Kettering Cancer Centre, New York. A symptom assessment scale was used to assess a broad array of symptoms in addition to information from parents and medical records. This study showed that pain was the most prevalent symptom with moderate to severe pain being present in 86.6% of respondents and quite a bit to very much being present in approximately 52.6%.<sup>16</sup>

Post-operative pain in hospitalized children is also common. Post-operative interviews of children aged 8-12 years in a surgical ward in Finland revealed that most children reported their worst pain as moderate to severe in intensity.<sup>17</sup> This also applied to children who had thoracic surgery in the same setting.<sup>17</sup> Children who have had cardiac surgery as treatment for congenital heart disease will most likely experience pain from the surgery, various procedures such as pacemaker removal, chest drain removal, intravenous lines and frequent venepunctures.

### ***2.3 Pain Assessment***

Children's pain assessment is an essential part of effective pain management and optimal pain management begins with accurate and thorough pain assessment.<sup>3,5,7</sup> Good pain assessment has been found to contribute to early recognition of pain as well as effective management of pain.<sup>18</sup> However, difficulty in measuring pain has led to the creation of multiple pain measurement tools and scores for neonates, infants and children.<sup>19</sup>

The two main fundamental approaches to pain assessment in children are self-report, and physiologic response.<sup>1,20</sup> Although self-report is regarded as the gold standard and most

reliable assessment, its use is impossible in preverbal children and in children with impaired cognition.<sup>5,7,13</sup>

Self-report tools include the visual analogue and numerical rating scale that is validated for use in children 8 years and above as well as the Revised FACES pain scale that is valid for children of ages 3-18 years old.<sup>7</sup> Behavioural measuring tools for pain assessment in neonates includes the CRIES scale and the COMFORT scale while the FLACC (Face, Legs, Arms, Cry, Consolability) scale is widely used in practice for pain assessment in children aged 1-18 years old.<sup>5,7</sup> The paediatric early warning score (PEWS) is a specialized tool routinely used in the UK to monitor clinical progress of an hospitalized child.<sup>21</sup> It is a bedside track and trigger tools to help alert staff to clinical deteriorating children by periodic observation of physiological parameters (heart rate, respiratory rate, blood pressure and temperature).<sup>21</sup> Pain assessment are incorporated in the PEWS chart due to its addition into routine observation as the fifth vital sign.<sup>5</sup> Pain assessment tools for different age group are sometimes incorporated in the chart to facilitate usage by healthcare providers during pain assessment.

Assessment of pain requires effective communication between child (whenever feasible), their family or carers, and the professionals in the multidisciplinary team.<sup>7</sup> Effective pain assessment is better achieved by adequate training/preparation of healthcare professionals in the use of pain assessment tools as well as proficiency in using them.<sup>7,22,23</sup>

#### ***2.4 Research Methods to Evaluate Pain Management Practices***

Methods used to research pain management practices are important. Aside from the various studies that looked at pain prevalence and examined healthcare provider's knowledge of pain management, initial studies also explored analgesic prescribing and administration practices retrospectively through the use of questionnaires. Beyer et al's comparison of post-operative prescribing and analgesic administration practices following cardiac surgery between 50 adults and 50 children showed that children were prescribed significantly fewer analgesics and received only 30% of prescribed analgesics.<sup>24</sup> A national survey conducted in 1992 in the United States (US) explored how healthcare providers in US teaching hospitals assessed and managed children's pain.<sup>25</sup> Two-thirds of respondents were nurses while one-third were physicians. This study revealed that 27% did not use self-report scales and this was attributed to inadequate application of knowledge rather than lack of knowledge about paediatric pain. Inadequate doses of analgesics were given, and non-pharmacological techniques were used

by only one half of respondents.<sup>25</sup> The recommendation from this initial study was that there is crucial need to examine healthcare providers' practice of paediatric pain using observation plus chart review to have a view of real-life actual practices.<sup>25</sup>

Subsequent studies focused on nurses' pain management practices. A descriptive study by Jacob and Punctilio, conducted in northern California examined nurses' beliefs and perceptions of pain using a questionnaire and evaluated their pain assessment and management practices using their documentation. They reported that, despite belief that pain assessment is essential in relieving pain, their documentation did not indicate that all children were being assessed for pain.<sup>20</sup> The data for this study was collected retrospectively, so it was considered an indirect measure of actual practices as nurses might have completed a pain assessment, but failed to document this.<sup>20</sup>

A retrospective clinical audit of medical records over two years in a paediatric hospital in Australia in 2005 examined how nurses assessed and managed post-operative pain in children of 5-15 years who had surgery for correction of fracture of the lower limb. The study revealed 12% evidence of pain assessment using standardized tools. Pain was assessed less frequently and documentation of management was inadequate.<sup>26</sup> One of the limitation of this study was the uncertainty of actual practices and whether those things that were not documented were done. This study recommended future use of observational study methods to examine pain assessment and management practice in a natural setting.<sup>26</sup>

From 2000, researchers evaluating pain practices used observational study methods. An observational study conducted in England to establish how nurses manage post-operative pain in a children's surgical ward used structured and non-structured observational tools to record the pain management practices of 13 registered nurses provided in an actual clinical setting.<sup>5</sup> This study showed that the nurses' pain management practices did not conform to recommendations and neither routine assessment of pain nor use of non-drug methods of pain relief on a regular basis was provided.<sup>5</sup> More recent observation of all nurses working on shifts in two tertiary paediatric wards in England and chart reviews revealed that several areas of practices did not conform to the guidelines.<sup>27</sup>

## ***2.5 The Role of Parents in Pain Management***

Parents are valuable partners together with healthcare professionals in the effective assessment and relief of pain in children. Interventions to relieve pain involve

caregivers/parents working closely with a team of professionals (doctors, nurses, pharmacist, play therapist and others).

Parents are a valuable source of information regarding their child's pain.<sup>28</sup> Watt-Watson et al's study revealed that parents were able to identify non-verbal cues which indicated that their child was in pain.<sup>29</sup> A few study showed that parental rating of pain intensity correlates closely with the child's rating.<sup>29</sup>

Not all studies, however, found that parents were good at assessing their own child's pain. Chambers et al, found when he examined agreement between child and parent-rated pain following minor surgery that parents demonstrated a low level of sensitivity when their children were experiencing clinically significant pain.<sup>30</sup> Another qualitative study in a community-based hospital also demonstrated that nurses felt that a parent's report of a child's pain often does not match the child's behaviour.<sup>31</sup> Despite this parent are still important in provision of high-quality services for children who require pain assessment and in the provision of patient-centred effective pain management.<sup>5</sup> Parents are well aware of their children's history of pain and their usual way of coping with it.<sup>32</sup> They are also a source of comfort to the child in the hospital.<sup>32</sup>

Parents' view on how well their child's pain was managed have been explored in only a few studies. Interviews of 22 parents at the King Hussein Children's Cancer Centre in Jordan revealed that parents expected their child's pain to be managed.<sup>33</sup> These parents also expressed that they would like to be involved in decision making process regarding their child's pain management .<sup>33</sup> This corroborated an earlier study in the late 90s where parents expressed desire for more information on pain and its treatment.<sup>17</sup>

Watt-Watson et al examined seventy one parent's perceptions of their child's acute pain experience and revealed that majority of parents identified a lack of information about painful procedures and of effective comfort measures for their child .<sup>29</sup> Simon et al also found that parents felt they needed more information on their child's pain management.<sup>34</sup>

Exploration of parental perceptions of children's pain management after major and moderate surgery in the UK showed that parents felt that their involvement in their child's pain management was superficial and limited.<sup>35</sup> Another study by Twycross on how well parents felt their children's acute pain had been managed during hospital admissions found that

parents were the main initiators of pain management discussions with nurses.<sup>27</sup> The final report revealed that though 18% of parents reported that nurses did not adequately discuss their child's pain management with them, most of the parents still appeared relatively happy with the quality of their child's pain management.<sup>27,35</sup>

A focus group discussion explored nurses' perception of factors that would help them in assessing and managing pain more effectively.<sup>36</sup> The nurses felt that if parents verbalized their concerns about their child's pain, informed them when they felt their child was in pain and got involved in pain care then their child's pain management could be optimized.<sup>36</sup> Nurses also indicated that parents have a role in distracting their child from their pain through comforting, playing, watching TV and talking with them.<sup>36</sup>

## ***2.6 Barriers to Pain Management***

There are several barriers to effective pain assessment and treatment in children apart from healthcare providers' lack of knowledge, as pain management requires a complex interaction between patient, parent, families, healthcare providers and healthcare systems.<sup>37</sup> Parental barriers to effective pain management include non-compliance with healthcare providers' suggestions for pain management and refusing pain medication as well as interfering with and answering for the child.<sup>36</sup> A qualitative study by Susanne et al that investigated barriers to pain management in adolescents with cancer reported that fear of addiction and worry about communicating pain to parents and providers potentially impaired effective pain management in this age group.<sup>38</sup>

## ***2.7 Cultural influences on pain management***

Culture is the way of life of a group of people and it encompasses the attitudes, beliefs and customs that distinguishes a particular group of people from another. It is commonly regarded as a factor in pain behaviour and experience.<sup>39</sup> Only a few studies have focused on the specific impact of culture on children's pain.<sup>40</sup> Study by Finley et al which examined some of the research regarding the cultural influences on the assessment of pain in children revealed that cultural implications of pain assessment in children remain elusive because the empirical evidence is limited and often based on ambiguous conceptualization of culture and relatively weak methodologies.<sup>39</sup> It was discovered that much of the research that invokes cultural variations concerns different racial groups living in the same geographical region of North American or Europe, who go to the same schools and are exposed to the same popular culture.<sup>39</sup> The final report revealed that although there are little

evidence that pain perception is modified by culture, pain expression by children as well as interpretation by care givers may be affected by the culture of the child or the caregiver.<sup>39</sup>

## ***2.8 Knowledge gap***

Most studies have observed nurses' pain management practices because they are at the forefront in assessment and implementation of pain management, and most of these studies were conducted in public paediatric care settings. This leaves a gap in our knowledge of paediatric pain management practices within the private hospital environment.

All healthcare providers contribute to ineffective pain management.<sup>18</sup> The implementation of best pain management practices rests on healthcare providers working as a team collaboratively with the parents/caregivers whether in public or private paediatric settings.

There is a need to ascertain the actual pain management practices of not only nurses but also doctors in every paediatric care setting to know what the actual practices are and whether healthcare providers work together, while also considering the parents (who are also part of the team) by exploring their perceptions of pain management.

## **CHAPTER 3: METHODOLOGY**

### ***3.1 Design of the Study***

This was a mixed-method study design. The study designs used were an observational cross sectional study design and semi-structured interview.

The details of the mixed-method study design used in this study are provided below:

To answer question one of this study, an observational cross-sectional study design method was used to explore pain assessment practices and relieving practices among paediatric healthcare providers in the study site. Healthcare providers who participated in the study were observed first hand by the researcher (participant observer) for pain management practices. The findings from the observation were entered in an observational tool that the researcher used for the data collection (observational data collection tool by Alison Twycross, March 30<sup>th</sup>, 2011 version, see appendix A for detail data elements in the tool).

Additional data on pain assessments and practices were also collected from the study site. Data sources, such as the medical notes, computerized nurses' notes for patients, and drug charts and vital sign charts (paediatrics early warning chart and IPOD device where vital signs were recorded). The paediatric early warning chart for the study site has FLACC( suggested for age 2month -7years), revised FACES( recommended for children>4 years) as well as the analgesic ladder incorporated in its last page as a guide for healthcare providers for pain assessment during routine observation. These data sources provided data about prescription practices, analgesics given during observations and how doctors and nurses documented these. These were recorded on the spaces allocated specifically on the observational collection sheets for additional information and used as field notes:

A qualitative study design method was used to answer question two. Semi-structured interviews were conducted for the parents/caregivers of the children whose pain management practice was previously assessed in the study prior to discharge to explore their perception regarding pain management practices (see appendix B for interview guide).

### ***3.2 Site of the Study***

The study site for this research project was the Harley Street Clinic, an independent private hospital in London that has a paediatric section which mainly offers specialist cancer (solid tumours, haematology oncology) treatment, cardiology and cardiothoracic surgery for

children with congenital heart disease. The clinic also offers some general paediatric services as well as neurological and orthopaedic surgery for children aged 0-17. This study was carried out in the 16-bedded ward which has individual rooms for admission of oncology and post-operative cardiac cases that were transferred from intensive care. The bone marrow unit was proposed initially as a site in the study, but it was closed during the time of the study due to internal reorganization, so the study site was constrained to the general ward alone. This setting provides care for indigenous UK patients and an appreciable number of patients from Russia, Arab countries, Greece, Europe, Africa as well as other countries around the world.

### ***3.3 Study Population***

There were two study populations. The first study population was nurses and doctors who took care of oncology and postoperative cardiology patients on the paediatric ward for the first research question. The second study population was the corresponding parents/caregivers of children who were post-operative cardiac patients and oncology patients admitted to the ward for disease-related or therapy-related pain.

#### **Inclusion Criteria:**

##### 1st Study Population

- Nurses and RMO doctors (Resident Medical Officers in paediatrics) working with paediatric cardiac patients and oncology patients on the ward
- Nurses and doctors in the above group who consented to participate
- Nurses and doctors who were employed as full or bank staff for >1 month ( need to use bank staff who work regularly in the hospital so to be able to observe for up to 2 shift)

##### 2nd Study Population

- Parents/caregivers of postoperative cardiac and oncology patients admitted into the ward and for >72 hours
- Parents/caregivers who consented to participate

#### **Exclusion Criteria:**

##### 1st Study Population

- Nurses and doctors (Resident Medical Officers) who were agency staff

- Nurses and doctors who did not consent to participate
- Nurses and doctors employed for <1 month
- Nurse administrator uninvolved in clinical work
- Doctors who were uninvolved with pain management

The 2nd study population

- Parents/caregivers of post-operative and oncology cases who did not consent
- Parents/caregivers who could not be interviewed because of language barrier (if there was no available interpreter or another mode of translation)
- Parents/caregivers of cardiology and oncology cases who were critically ill (haemodynamically unstable patient admitted directly to ICU who didn't require pain management on the ward)

### ***3.4 Sampling Method***

A purposeful consecutive sampling method was used whereby a focused selection of nurses and doctors (RMOs) who worked with oncology patients and post-operative cardiac patients were recruited for the study. Matched purposeful consecutive sampling was also used for the parents/caregivers of oncology patients (with the disease- or therapy-related pain), and post-operative cardiac patients requiring up to 72 hours of hospitalization. Seventy-two hours duration was used to ensure participants could be observed for at least 1-2 shifts as well as to give consideration for the cardiac surgery patients, who would spend at least 48-72 hours in the intensive care unit before coming to the ward where the study was being conducted. The fact that there is only one researcher with associated time constraint also made the duration of 72 hours more manageable.

Where either professional or caregiver refused permission to participate, another matched pair was identified until total matched and consenting pairs had been identified. Purposeful sampling was used because the study involves identifying individuals that meet the predetermined criterion of importance to the study. Purposeful sampling is a technique used for the identification and selection of information-rich cases for the most effective use of limited resources.<sup>41</sup>

### ***3.5 Sample Size***

Healthcare providers: 9 nurses and 3 doctors = 12

Parents: 12 parents – n = 12

The above sample size was considered the appropriate size to be used based on consideration of all the following factors listed below:

1). Multiple samples within one study: <sup>42</sup>

Two samples consisting of healthcare providers and parents/caregivers of patients.

2). Heterogeneity of study population: <sup>42</sup>

The study site contains both multicultural healthcare providers and parents/caregivers. There was also heterogeneity in terms of the patients whose pain management was being assessed (oncology and cardiology patients). The estimated sample size made data collection less labour intense.

3). Types of data collection methods: <sup>42</sup>

Using a participant observation and interviews at the same time requires more rigorous processes. Studies that used more than one method are found to require fewer participants. <sup>43</sup>

4). Budget/resources available: <sup>42</sup>

This research was self-funded so a smaller sample size of 12 was considered in consultation with the researcher statistical advisor to be more practical.

5). Availability of participants:

The study site is a private setting which only contains 18 beds for general paediatrics, oncology, cardiology and other specialties. Therefore 12 participants would be two thirds of what was available for the study period.

6). Compare sample size with that of previous similar studies:

The sample size chosen falls within the range reported to have been used in other similar studies. Other similar studies were found to have used a sample size of 10-13. <sup>4,27,35,44</sup>

### ***3.6 Data Collection Tools***

*3.6.1 Structured Observational Data Collection tool* (appendix A). Permission to use this tool was obtained from the author Allison Twycross (Appendix H). The tool was validated prior to use in other previous studies. <sup>44</sup> The tool was created by sending questionnaires to

Delphi respondents, who were asked to list observable behaviours/clinical skills that would indicate competency in areas identified in an earlier Delphi pain study.<sup>44</sup> Respondents (paediatric nurse educators and paediatric nurse managers) were also asked about pain assessment in neonates, preverbal children, school-age children and adolescents in order to consider difference in pain management practice between different age groups.<sup>44</sup> To ensure reliability of the tool, a clinical nurse specialist in pain management also coded the questionnaires to identify observable behaviours that were specific to pain.<sup>44</sup> The questionnaire was used along with the clinical guidelines on the recognition and assessment of pain in children (Royal College of Nursing ) and guideline from the USA Agency for Health Care Policy to create the observational tool.<sup>44</sup> The tool was created such that it has four sections relating to neonates, preschool children, school-age children and adolescents.<sup>44</sup> The tool has been used in other pain management studies. The structured observational chart contains the lists of possible pain management practice tasks that were assessed during observation.

For each of the standard practices domains on the observational tools, the domains stated below were observed and assessed/graded using a standardized scoring system:

\* Note – CA stands for clinical audit. O Stands for Observation.

#### Pain Assessment

- A pain history is obtained from each child (CA)
- Pain assessment takes place using a validated pain assessment tool (CA/O)
- Pain is reassessed following the implementation of pain-relieving interventions (CA/O)

#### Partnership in Care

- Healthcare professionals discuss the child's pain management with their parents/guardians (O)
- Healthcare professionals involve the child in decisions about their pain management (O)

#### Analgesic Drugs

- Child has analgesic drugs prescribed (CA)

- Dosage of analgesic drugs complies with hospital guidelines (CA)
- Analgesic drugs are administered as prescribed (CA)
- Analgesic drugs are administered if the child complains of pain (CA)
- Non-drug methods of pain relief are used (O)
- List non-drug methods used: (observed or recorded in notes)

#### Procedural Pain

- The child is prepared for painful procedures (CA/O)
- Analgesic creams are used for planned painful procedures (CA/O)

#### Documentation

- Pain assessments are recorded in a flowchart (CA)
- Pain-relieving interventions used are documented in the child's notes (CA)
- The effectiveness of pain-relieving interventions is documented in the child's notes (CA)

All the above-stated domains were graded using a standardized scoring system on the observation tools as defined below:

- Always carried out: carried out consistently each time necessary
- Sometimes carried out: carried out occasionally but not at all times when necessary
- Rarely carried out: carried out only once throughout observation
- Never carried out: not observed being carried out
- Not applicable: inapplicable due to age and other criteria

This tool contains the various tasks that were taken into consideration during pain management as recommended by clinical pain management guidelines (RCN Guideline and good practice in postoperative and procedural pain management).<sup>5,7</sup> The tool was reviewed by the researcher's supervisor prior to the commencement of study to verify whether it answered the question(s) posed by the research questions. (See appendix A for the observational tool.)

*3.6.2 Demographic Data Collection Sheet:* this was used to collect demographic data of healthcare providers who were participants (See Appendix I).

*3.6.3 Tape Recorder:* this was used to record conversations during the semi-structured interviews with parents/caregivers. The researcher familiarized herself with this tool prior to the commencement of the various interviews.

*3.6.4 Field Notes:* ample space already included on the structured observational tool was used for field notes to collect unstructured findings; communications between staff and the emerging practice patterns among this group that was not included in the structured observational section of the tool. Different field note was used during interviews with parents/caregivers to describe dynamics and context during each interview and to serve as back up if recording failed as well as record interview discussions in situations where the participant did not consent to tape recording during interviews.

*3.6.5 Interview Guide:* this was a semi-structured interview guide (see Appendix B) which was used for guidance during interviews with parents/caregivers for the second part of the study. It contains open-ended questions that were used to explore parental perceptions of pain management practices at the study site. Questions cover the following areas:

- Parental experience with regard to their child's pain
- Parental involvement in pain assessment
- Whether they had sufficient information with regard to pain management
- Any effective support from the care provider when their child was in pain
- Were the parents involved in decision making?
- Satisfaction with pain management and areas for improvement

The semi-structured interview guide (see Appendix B) consists of questions adapted partly from a previous study questionnaire that was used to explore parents' perceptions about quality of post-operative pain management.<sup>35</sup> The other source of ideas for appropriate questions included in the interview guide for assessing parental perceptions was also obtained from a literature review of Revised American Pain Society patient outcome questionnaire for

quality improvement of pain management in hospitalized adults.<sup>45</sup> The questions were then constructed by the researcher to reveal the highlighted areas above.

### ***3.7 Data Collection Procedures***

#### *3.7.1 Recruitment*

A meeting was held with the ward clinical manager of the study site first week in July 2015 before the first patient was recruited to provide information about the research after approval was obtained from the hospital committee. Each recruited healthcare provider was approached individually by the researcher who is also a Resident Medical Officer in the study site. The participating healthcare providers that fulfilled previously outlined inclusion criteria were all provided with the appropriate information sheet (appendix E) individually a day prior to or on same day of observation. The consent forms (Appendix J) were signed by participants for the first part of research on the same day after being provided with adequate information and having their questions answered. Each participating healthcare provider then had their demographic data documented, and a study number was assigned to individual participants.

Each parent/caregiver of a post-operative cardiac patient who fulfilled the inclusion criteria previously highlighted was approached individually after transfer into the ward from PICU while parents/caregivers for oncology patients were approached on the second day of admission. Information about the research, their roles and use of the tape recorder, and duration of interview and time and place of convenience for the interview was discussed.

Information sheet (appendix D) and signing of consent forms (appendix C) were done before each interview.

#### *3.7.2 Trial Run*

During the same week of meeting with the clinical manager, the primary researcher did a trial run using a tape recorder by interviewing one of the healthcare providers and one parent (whose child was on admission on the ward and who consented). This allowed the researcher to familiarize herself with the tools as well as obtain opportunities to clarify questions on the interview guide. Questions on the interview guide were also rehearsed to improve skills in asking open-ended questions. During the same week, one nurse was observed during one shift for the researcher to familiarize herself with being a participant observer. Methods were identified during this initial observation of the best way to observe without compromising or disrupting patient care.

### *3.7.3 Phase 1*

Participant observation was done over 10 months from July 2015 to May 2016 (due to very low caseload at the study site). The primary researcher assumed the role of a participant observer during the observation so that she could ask questions to clarify issues during observation. Each participant was shadowed intermittently for 12 hours per shift for 1-2 shifts as they undertook their normal duties in the clinical setting. Data were collected for 14 shifts; 6 were early shift and 8 were late shift with a total of 168 hours of observation.

Structured observational charts were completed during the process while field notes were used to capture other unstructured events such as conversations and unexpected behaviours that occur in relation to pain management practices. Field notes were made immediately after completing each observation section in a quiet room in the hospital away from the participant. Medical notes, drug chart and PEWS chart (paediatrics early warning score chart), IPODS and online notes which contain the documentation of pain assessment, analgesic given and intervention were reviewed while the nurse was on break or while attending to another non study patient.

### *3.7.4 Phase 2*

Concurrent parents/caregivers of post-operative cardiac patients and oncology patients who had consented were reminded a day before the interview. Each semi-structured interview was conducted within the hospital premises in a quiet room for 45 minutes with the aid of an interview guide while using an audio tape recorder for patients that consented. Field note was used to write about dynamics, contextual and emotional events that could not be captured on audio tape but were relevant to the interview. After each interview, the primary researcher clarified answers from the participant before finally ending the interview and turned off the audio tape while clarifying answers so as to assess whether having the tape on during the interview had affected initial response to questions. Transcriptions were done on the same day as each interview.

## ***3.8 Data Management and Analysis***

Data was analysed in several ways to obtain information on the pain assessment and management practices of the professionals as well as the parental perceptions of these pain management practices. Continuous data was presented using medians depending on data distribution (inter-quartile ranges) and frequencies and column percentages were used to describe categorical data.

Data from the first part of the study was analysed using categories in the structured observational chart as a framework. Additional information recorded in the field notes taken was also presented using the frame work from the chart. Observations noticed for each of the participants were then analysed under each of the themes while looking for similarities, patterns and peculiarities in practices. Analytical frame work analysis was used because this study has specific questions, and frame work analysis is better adapted to research that has specific questions, a limited time frame and a pre-designed sample.<sup>46</sup>

The second part of the study was analysed by starting verbatim transcription of interviews on the day of each interview. Framework analysis was used by following the key steps below:

- Familiarization: Review of transcription, reading of data and re-reading of data. Review of case one interview transcription was done with co supervisor while that of case two was done with Advance nurse practitioner who has Masters in palliative medicine.
- Identifying a thematic frame work: An initial coding framework was developed from initial issues prioritized in the semi-structured interview and emerging issues identified from the first step above.
- Coding: Specific pieces of data which correspond to differing themes were identified using contextual coding.
- Charting: Headings from the thematic framework would be used to create a chart that has each theme across all respondents.
- Interpretation: Patterns and associations, and concepts and explanations in the data were then identified.

### ***3.9 Ethical Considerations***

The research proposal was submitted to the research ethical committee of University of Cape Town for approval before commencing the research (approval number: 860/2014). Local approval was obtained from the clinical paediatric manager and paediatric matron of the hospital in August 2014. In addition, approval was given by the hospital Integrated Governance Manager who liaised with the National Research Ethics committee in the UK. Participants were given adequate information about the project, their roles and how their identity would be protected, through an information sheet. A signed freely given consent was obtained from each participant. Consent was also taken to use a tape recorder during the

interview. Each participant had their name assigned a study number before the commencement of data collection and no actual name appeared on the data to maintain confidentiality. Actual data was kept in a locker by the researcher to ensure confidentiality. A password-locked computer was also used to store data. During interviews, questions that could create distress were minimized, and an arrangement was put in place to stop the interview if the participant felt uncomfortable (see appendix F for distress protocol). An arrangement was also made with the nurse in charge of the ward during every observational study so that observation did not compromise patient care and to stop an observation to address any clinical incident practice noticed that could harm the patient. See appendices C, D and E for consent and information sheet for participants.

This study adhered to the listed ethical code below in accordance with principles outlined in the Helsinki declaration:

- Participants were debriefed about the aims and objectives of the study prior to primary data collection.
- Participation was voluntary without the use of coercion.
- Informed consent was obtained before involving participants in the study.
- Data protection and confidentiality was ensured.
- A plan for minimal risk to participants and possible satisfactory management of inevitable risk was made.
- The study was justified by the fact that patients stand to benefit from the knowledge that results from the research.
- The research proposal was submitted to the ethical committee prior to commencement.
- Possible methods for results dissemination have been made.

## CHAPTER 4: RESULT ANALYSIS AND DISCUSSION

### 4.1 Results

#### 4.1.1 Results: Part 1

Data were collected for 14 shifts; 6 were early shifts and 8 were late shifts with a total of 168 hours of observation over a 10-month period (patient loads that fulfilled the inclusion criteria were scanty).

Participants were shadowed for 1-2 shifts with each shift being 12 hours. A pain management checklist of the observational chart was used as a framework for content analysis while the results from the quantitative data were presented using tables.

#### *Study Population: Demographic and Clinical findings of Patient Participants*

Overall, 10 patient participants were enrolled in this study. The initially proposed number was contracted from 12 to 10 as a reorganisation within the hospital leads to the following:

- A new set of nurses being recruited while some older ones left and fewer numbers of permanent RMOs.
- The hospital beds were reduced from 18 to 16 and the bone marrow unit was closed.
- One of the recruited patients died in PICU so was deleted from the study.

The median age of presentation was 3 years and median weight of 8.6kg (range 25.1kg). The average hospital duration of admission was 7 days. Greater than half of the patients were Arabic while the rest were of Greek and black African origin. The majority of the patient participants had a primary diagnosis of cardiovascular-disease-related conditions (for example, congenital heart disease, double outlet right ventricle and aortic stenosis) while the remaining few had childhood malignancies (Alveolar rhabdomyosarcoma and neuroblastoma) as show in Table 1 below:

Study variables	Percentages
Gender	Male: 70%
	Female: 30%

<b>Race</b>	Arabic: 70%
	Greek: 20%
	African: 10%
<b>Primary diagnosis</b>	Congenital heart disease: 80%
	Oncology condition: 20%
<b>Caregiver relationship to child</b>	Mother: 90%
	Father: 10%

Table 1 Patient Participant Demographic and Clinical Profile

***Participating health care providers' demographic, clinical experience and types of employment profile***

The majority of healthcare providers were registered nurses, all were female and there was a fairly equal racial distribution as presented in Table below. (Table 2)

Percentages	
<b>Job titles</b>	RN: 60%
	SSN: 30%
	RMO: 10%
<b>Sex</b>	Female: 100%
<b>Racial profile</b>	White :40%
	Asian: 30%
	Black: 30%
<b>Language</b>	English language: 100%
	English/Asian language: 30%
	English/African language: 30%
	English/Spanish language: 10%

Table 2 Participating Healthcare Providers' Demography

The median age of the healthcare providers was 32 years (range of 23-63 years). The median total years of experience was 10 years, and paediatric focus working experience was seven years as shown in figure 1 below:

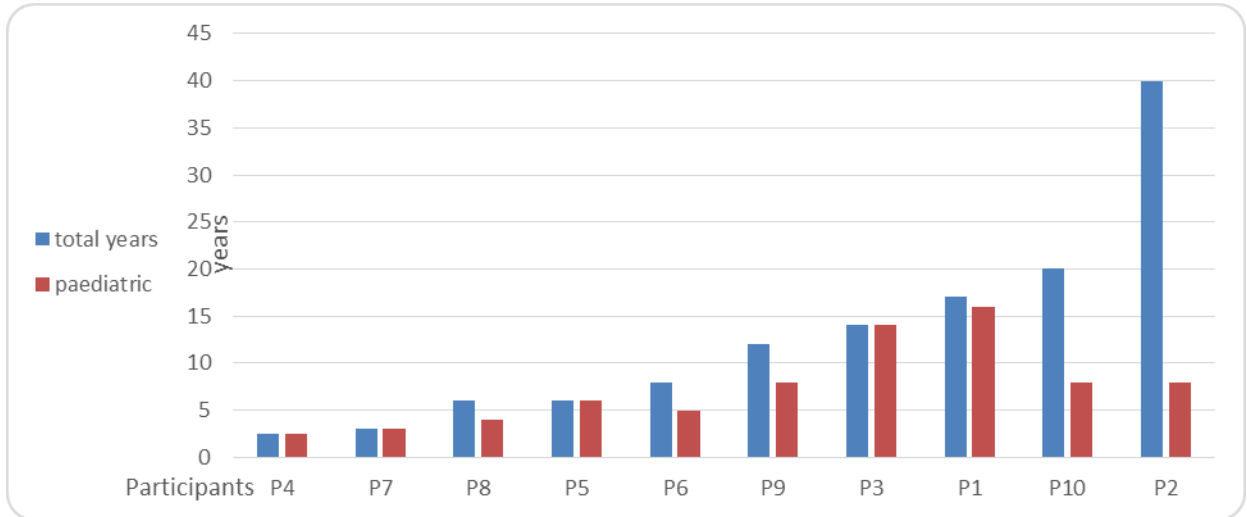


Figure 1 Participating Healthcare Providers' Years of Experience

Greater number of the healthcare providers that participated in the study were on a permanent contract arrangement with the study site while few were on a temporary/bank contract arrangement as shown in figure 2 below:

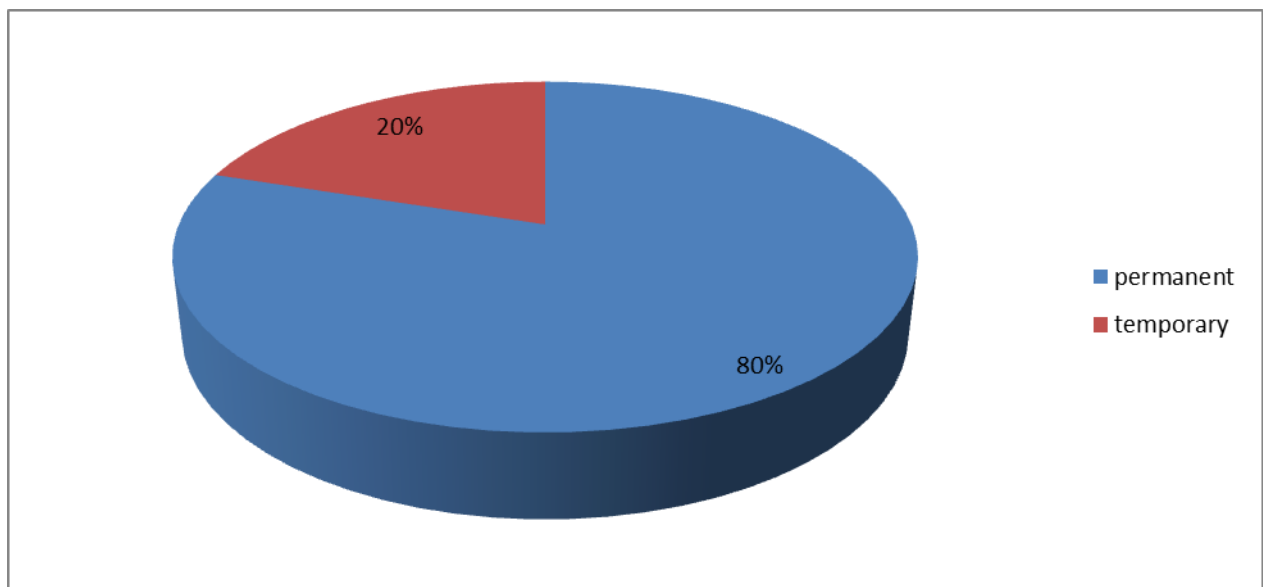


Figure 2 Healthcare Providers' Terms of Employment

***Pain assessment practices of healthcare providers***

Pain assessment practices of healthcare providers is presented in the table below.

<b>Study variables</b>	<b>Always carried out</b>	<b>Sometimes carried out</b>	<b>Rarely carried out</b>	<b>Never carried out</b>	<b>Not applicable</b>
<b>Pain history obtained from the child/caregivers</b>	20%	20%	60%	10%	0%
<b>Pain assessment with validated tool (CA/O)</b>	50%	40%	10%	0%	0%
<b>Pain reassessed following relieving interventions(CA/O)</b>	20%	60%	10%	0%	10%

Table 3 Pain Assessment Practices of Health care Providers

As can be seen, the majority of health care providers rarely obtained a history of pain from parents/caregivers. Equal number of health care providers always and sometimes obtained history of pain from parents/caregivers. Half of the health care providers always assessed patients using a validated tools, the majority of the remaining half sometimes assessed patients using a validated tool. More than half of the healthcare providers sometimes reassessed pain in patients following implementation of pain-relieving interventions whereas few healthcare providers always reassessed pain in patients following pain relieving interventions.10% of the healthcare providers rarely reassessed pain following implementation of pain-relieving interventions and the remaining 10% did not reassess pain because it was not applicable (the resident medical officer used the nurse’s assessment documentation following implementation of pain-relieving intervention).

A trend noticed from the field notes regarding history taking was that healthcare providers were not consistently taking a history of pain from parents of preverbal children whereas they consistently did so from the verbal child. The researcher observed one nurse shortly after the transfer of a preverbal child from PICU to the ward. No history of pain or pain experience

was discussed. The discussions centred on vital signs with more attention being paid to oxygen saturation and feeding. The researcher later observed that the child was quite unsettled; Mum told the healthcare provider she wasn't sure whether the child was in pain or hungry and suggested she wanted to give a feed first. No pain history was taken from the caregiver, despite the caregiver initiating a discussion regarding the possibility of pain (case 2, post cardiac surgery).

A history of pain was taken from a 10-year-old who had complained of worsening pain post cardiac surgery. The healthcare provider explored possible sources of pain, such as canular site, chest, and abdomen (case 1 field note). A nurse was also observed to have taken a pain history from the mum of a 9-year-old child during night could speak English as he could only speak Greek (case 6 field notes, oncology). There was no discussion with the child regarding his pain. This finding is an exception to a verbal child and suggests that language was clearly a barrier here. Pain assessment scores were recorded 4-hourly on iPod devices used for storing vital signs parameters. Two validated pain assessment tools, which are the FLACC (Face, Leg activity, Cry, Consolability) pain scale and the numerical scoring system used in this unit, are installed on the device, and the appropriate one forage is expected to be used while vital signs are being taken. These are also found on the PEWS chart.

The researcher observed a healthcare provider take a very good pain history from a 10-year-old child when she noticed the child looked unhappy; however, no pain measurement was done (case 1, post cardiac surgery) as a numerical scale could have been used at this point. Pain score was, however, recorded as 3 about a few minutes later while recording the vital signs, but this record appeared to be nurse estimation as no assessment tool was used (field note case 1). The observer, however, noticed on a different occasion during observation of the same case while vital signs were being taken that the numerical scale was used and the pain score was 6, which was then recorded and followed with appropriate actions.

Nurses found it easier to use the numerical scale. There were two occasions on which pain was assessed by proxy by asking the parent of preverbal children the pain score using the numerical scale rather than using the FLACC tool to directly assess the children's pain. The FLACC pain scale was used in most cases when the healthcare provider dealt with a preverbal child, but the 'cry' was, however, used as the sole criterion to arrive at a score rather than cry with the other required 4 parameters. "Nurse took vital signs and noticed child was crying. Mum commented that her 4-month-old child was upset and was unsure whether the

child was in pain or was hungry. The nurse then agreed to feed the baby. No pain assessment was done, and pain score throughout shift was recorded as 0-1; however, Nurse told the researcher that child was crying because he had just been transferred from PICU or because of hunger” (case 3, post cardiac surgery). There were seven other occasions on which nurses were noted to have used FLACC pain scale with the appropriate use of the 5 parameters.

Pain reassessments following implementation of pain-relieving intervention were usually clustered around the next observation/vital signs, which are done 4-hourly or during feeding. A preverbal child who was in pain was given analgesic; the reassessment for pain was done after 4 hours when the child was due for 4-hourly vital signs and NGT feeding (case2, post cardiac surgery). The reassessment was also done for a child after 2 hours of intervention because she went back for an NGT feed and Mum reported that the child was still in pain (case 7 field notes). Exceptions to this pattern are oncology patients who are on PCA; 1-hourly observations are done, and nurses have been observed to have gone to reassess pain after giving bolus morphine even before 1 hour has elapsed (cases 6 and 8 field notes).

***Partnership in Care Practices of Healthcare Providers***

Half of the healthcare providers always discussed the child’s pain management with their parents/caregivers while the remaining half sometimes did this as shown in table 4 below:

<b>Study variables</b>	<b>Always carried out</b>	<b>Sometimes carried out</b>	<b>Rarely carried out</b>	<b>Never carried out</b>	<b>Not applicable</b>
<b>Healthcare providers discuss child’s pain management with caregivers/child</b>	50%	50%	0%	0%	0%
<b>Healthcare providers involve child in decisions about their management</b>	20%	10%	0%	0%	70%

Table 4 Partnership in Care Practices of Healthcare Providers

As presented above the majority of the health care providers did not involve the child in decision about their management as not applicable (preverbal children). A few numbers of healthcare providers always and sometimes involved the child.

Most discussions with parent or child occurred during the time when vital signs were being taken or when medications were being administered. The researcher observed that most discussions were about what medication was being administered and more focus was placed on heart rate and oxygen saturation in most cardiac patients (case 4, post cardiac surgery). Parents initiated most discussion in preverbal children. Mum asked whether analgesic would be given before the child went to sleep (cases 6 and 7 field notes.). Nurses were observed to have initiated the conversation and asked a parent whether the pain medication given earlier had helped (case 3, post cardiac surgery). Doctors discussed pain treatment, options with parent and further enquired about what intervention had helped previously (case 5, post cardiac surgery).

Verbal children were involved in discussions regarding their treatment. It was observed that in a verbal child who was in pain, after taking a pain history the nurse discussed whether to give analgesic, the timing of medication and the preferred formulation (field note case 1). Language barrier was noticed in one of the cases (case 6), so communication was with only the mother, who could speak English, but there was no discussion with the verbal child.

### ***Analgesic Drugs and Non-Drug Methods of Pain Relief***

All the children had analgesic drugs prescribed, most of the prescriptions complied with the BNF (British National Formulary for children) while 10% never complied (sub therapeutic dose of paracetamol). Analgesic drugs were administered as prescribed in all the children. Analgesic drugs were also administered if the child/caregiver complained of pain in majority of the children while this was not applicable in 10% because the child/caregiver didn't complain of pain as shown in table 5:

<b>Study variables</b>	<b>Always carried out</b>	<b>Sometimes carried out</b>	<b>Rarely carried out</b>	<b>Never carried out</b>	<b>Not applicable</b>
<b>Child has analgesic drugs prescribed (CA)</b>	100%	0%	0%	0%	0%

<b>Dosage of analgesic drugs comply with British National Formulary(BNF)</b>	32 analgesic prescriptions 29(90.6%) comply	0%	0%	3(9.4%) prescriptions didn't comply	0%
<b>Analgesic drugs are administered as prescribed (CA)</b>	100%	0%	0%	0%	0%
<b>Analgesic drugs are administered if the child complains of pain (CA/O)</b>	90%	0%	0%	0%	10%
<b>Non-drug methods of pain relief are used (O)</b>	60%	40%	0%	0%	0%
<b>The child is prepared for painful procedures (CA/O)</b>	60%	0%	0%	0%	40%
<b>Analgesic creams are used for planned purposes</b>	80%	0%	0%	0%	20%

Table 5 Analgesic Drugs and Non-Drug Methods of Pain Relief

As can be seen, greater than half of the healthcare providers always used a non-drug method of pain relief while the remaining sometimes used this method. The majority of the healthcare providers always prepared the child for painful procedures whereas 40% did not need to because it was not applicable to patients under their care (no painful procedure during the period of observation). A greater number of the healthcare providers always used analgesic cream for planned painful procedures while few did not use analgesic cream

because it was not applicable to patients under their care (no painful procedure requiring analgesic cream during the period of observation).

All patients had analgesic drugs prescribed on their drug chart. The prescribed analgesic drug was observed to be given regularly as prescribed but sometimes given up to an hour late if the nurse was busy with another patient. Regular paracetamol was prescribed for all cardiac cases with morphine and ibuprofen on the as required side while oncology cases had regular morphine with paracetamol on the as a required side. One nurse was observed to have approached a doctor to change the paracetamol from a low dose to a therapeutic dose before administration after checking with another nurse. Low dose prescription of paracetamol was also noted on two other prescription charts. The researcher noticed that one of the low doses of the paracetamol prescription occurred during transcription of a PICU lower IV dose to oral on transfer to the ward (case 2 field notes). One nurse was observed to have been reluctant to give morphine written on as required side of prescription chart to a cardiac patient who was in pain. “A preverbal child was in pain, Nurse approached the Doctor for review and morphine was written on as required side, but Nurse, however, decided to give paracetamol on regular side of chart one hour earlier rather than give morphine that was prescribed” (field note case 3). However, in an oncology patient who was in pain, morphine was given easily without any hesitancy while paracetamol was considered only when the child was having a high temperature (Case 6).

Non-drug methods were used. Two nurses were observed to have given cold packs for children with abdominal pain (field notes for cases 1 and 6). Nurses were observed to have advised parents to distract their child during a dressing change and also involved the play therapist. Analgesics were used for planned painful procedures. Oral morphine was given 30 minutes before drain and pacing wire removal (field notes for cases 4 and 5). Preparations for planned painful procedures were carried out by nurses, doctor, play therapist, and physiotherapist. The physiotherapist discussed with the doctor about the timing of analgesics before physiotherapy (field notes cases 1 and 8). Nurses were observed to have applied analgesic cream prior to vein-punctures and canular insertions (cases 4, 8 and 9 field notes).

### ***Pain Assessment Documentation Practices of Healthcare Providers***

The pain assessment documentation practices of healthcare providers is presented in table below. (Table 6). Most of the healthcare providers always documented pain assessment

and recorded it on a flowchart while it is not applicable in 10% (RMO documented it in the patient’s case notes, but not required to record it on a flowchart).

<b>Study variables</b>	<b>Always carried out</b>	<b>Sometimes carried out</b>	<b>Rarely carried out</b>	<b>Never carried out</b>	<b>Not applicable</b>
<b>Pain assessment is recorded on a flowchart (CA)</b>	90%	0%	0%	0%	10%
<b>Pain-relieving interventions used are documented in the child’s notes</b>	80%	20%	0%	0%	0%
<b>The effectiveness of pain-relieving interventions is documented in the child’s notes (CA)</b>	40%	40%	20%	0%	0%

Table 6 Pain Assessment Documentation Practices

Pain assessment was documented by nurses on iPod and PEWS chart regularly after 4-hourly observations. The majority of the healthcare providers always documented pain relieving interventions whereas few sometimes did. An equal percentage of the healthcare providers always and sometimes documented the effectiveness of pain-relieving interventions while a few rarely carried this out.

A common phrase in nurses’ notes was “*paracetamol was given with good effect*” (field note for cases 1, 2, 3, 4, and 5) while in doctors’ notes it was “*pain well controlled on following list of drugs*” (field notes for cases 2, 3 and 4). One nurse documented use of a

nondrug method of pain relief and its effect “Icepack used for abdominal pain with good effect” (case 1 field note).

#### 4.1.2 Results: Part 2

Ten parents were interviewed consisting of 7 Arabic, 1 black African and 2 Greek.

There were 2 fathers and 8 mothers. Analysis of interview is as shown in table 7:

Theme	Subthemes	Quotes
<b>Pain experience</b>	Perception of intensity Most challenging time Effect on the child Pain expression	C2: Oh, well, starting from the time they brought him from downstairs he was in pain that night and he looked very uncomfortable.  C5: When he got to the ward I think the pain was a lot as he was crying all the time and not sleeping at all.  C4: When he got to the ward, I think he was so uncomfortable.
<b>Caregiver involvement</b>	Gives information to staff Support child	C1: They always look for moral support from the parent to actually help relax the child.  C3: They ask questions especially the nurses about what I feel when he is crying, whether he is hungry or in pain.  C2: They told me to play music for him on my IPAD when they were removing the drain.
<b>Support from healthcare providers</b>	Response of staff Giving medication Questioning	C9: They are swift and very responsive.  C5: They give her medicine and the medicine was good.

	<p>Advice</p> <p>Who provided support</p> <p>Non-drug pain-relieving methods</p>	<p>C2: They called the play therapist and they ask me to take him to the playroom. A psychologist came to see me one day and spoke to me about how I was coping.</p> <p>C1: All the nurses were courteous, and they were very polite and were always inquisitive as to the level of pain that he is having if any and trying to make him as comfortable as possible.</p>
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<p><b>Information sufficiency</b></p>	<p>Clarity of information</p> <p>People who gave information</p> <p>Adequate information</p>	<p>C1: They do ask us and tell us what they are giving him and for which purposes. “Mostly the nurses, not only the nurses but also the physiotherapist who tell him to do this and that because of this particular reason”.</p> <p>C1: They ask you to clarify or whether you need other clarification.</p> <p>C5: Nurses give me information and sometimes the doctors.</p> <p>C4: Well, they didn’t give enough information, but I always ask. I ask enough questions. They were doing their job, but I was the one asking “will he feel pain?”</p>
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<p><b>Satisfaction with pain management</b></p>	<p>Responsiveness</p> <p>Preparation for procedure</p> <p>Effect of interventions</p> <p>Staff presence/availability</p>	<p>C2: When they want to do something for the childlike when they want to remove the suture and wires, they prepare.</p> <p>C3: Most things they did helped him and today he is much better.</p> <p>C7: I am happy. The doctors and the nurses are good. When you call, the nurses come quickly to help, and my doctors come every day.</p>
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<p><b>Areas for improvement</b></p>	<p>Suggestions</p> <p>More information needs</p> <p>First-day transfer highlight</p>	<p>C6: There are some nurses who don't know how to use the equipment (PCA pump) that they use to give pain medication. I think they must learn better.</p> <p>I think they should always prepare for the first day the child will come from downstairs to upstairs.</p> <p>C3: I will have loved them to give me information on how to hold my child without causing him more pain.</p>
<p><b>Teamwork</b></p>	<p>Involved individuals</p>	<p>C1: Not only the nurses but also the physiotherapist who tell him do this and that because of this particular reason. Every one that comes.</p>
<p><b>Parental distress</b></p>	<p>Expressions</p>	<p>C6: It is frustrating and sad to me.</p>
	<p>Other factors</p>	<p>C1: It has affected me in more ways than one. Firstly, is the psychological trauma of seeing him going through a major operation and having to think how he is going to come out of it with the attendant risk. You must be there; you have to be strong as a man usually for the kids and rest of the family.</p>

Table 7 Interview Analysis

**Parental Experience of their Child's Pain:** Parents' discussion focused on the initial time of transfer of their child to the ward from PICU and indicated it as the most challenging time with regard to their child's pain. The time at which the pain was most intense was repeatedly mentioned by parents. The various ways in which children expressed pain were described by parents such as self-report, crying, discomfort, limited playing, altered sleeping pattern and feeding pattern. The possible consequences of pain in these children were also described by a parent during the interview.

*“He was in pain as I notice he was crying a lot, little movement, and not playing. He is breastfeeding more frequently than he used to do because of pain which makes him vomit more. I noticed that he wants to relax but he couldn't”* (C7-case 7, 16-month-old, post cardiac surgery).

**Caregiver Involvement:** Participants indicated they were involved in the management of their child's pain by healthcare providers in two major ways. Parents were engaged by staff in providing support for their children during painful procedures and reports from parents reflected that they were instructed to provide support by cuddling or by playing music on the IPAD. Healthcare providers also involved parents in the care of their children during pain assessment by asking parents questions to ascertain the intensity and location of pain as well as its effect on their child.

*“Mostly moral support, an example is when they were removing the pacing wire”*.  
*“They told me ‘Dad, do you want to hold his hands?’”*. *“They always look for moral support from the parent to actually help relax the child”* (Case 1, Post-cardiac surgery).

**Support from Healthcare Providers:** It was evident that participants described the support they received from healthcare providers with regard to the timing of response, mode of response of healthcare providers and actions taken during the time their child was in pain. Support provided by healthcare providers includes both medication administration and nondrug supportive measures such as distraction or play therapist involvement. Parents felt supported by the responsive actions of healthcare providers such as promptness in eliciting pain relief, enquiring about the welfare of the child and regular visits by healthcare providers.

*“When you called the nurse, they come quickly to help, and my doctor comes every day”*. – C7

**Information Sufficiency:** Findings suggested that participants were given information regarding their child's pain management. Eighty (80%) participants indicated that they received adequate information regarding their child's pain from healthcare providers but 20% of the parents who were parents of post-cardiac surgical patients stated that they didn't receive sufficient information.

*"I will say no because when he is crying they always come into the room and say 'carry him, Mama' and sometimes they say it as if I don't want to do that, but I feel that he screams and look more uncomfortable when I carry him, and I ask them, they say he will feel better and stop crying if I carry him. I ask them if it is okay for his chest to carry him after the operation and they say yes but I feel it is not okay". – C3*

Most information was from nurses and usually received during drug administration. It was evident that participants received information regarding their child's pain from not only the nurses and doctors but also other healthcare providers such as the physiotherapist in the study site.

**Satisfaction with Pain Management:** 91.6% of parents indicated they were satisfied with the pain care they received. Overall parental satisfaction in the interview reflected that satisfaction was best predicted by the swiftness of staff response when called, administration of medication, regular visits by doctors every day and staff preparation of the child prior to painful procedures. Furthermore, satisfaction with pain management also resulted from the positive effect of pain-relieving interventions initiated by healthcare providers (See figure 3).

*"I will say am okay and satisfied and I think they did their best. When they want to do something for the child, like when they want to remove the suture and wires, they prepare, they give him medicine 30 minutes before and there were two nurses so that it was done well. The play therapist was also there so it makes it easier and that was good for him" (Case 2).* Parental satisfaction was also influenced by comparison to the standard of practice in their countries.

*"Am satisfied with his care when I compare to where we come from".-C1*

- Swift staff response
- Medication administration
- Regular visits by doctors
- Preparation of the child before painful procedures
- Positive effect of pain-relieving intervention on the child

Figure 3 Factors Determining Parental Satisfaction

**Areas for Improvement:** Though most caregivers were satisfied, findings suggest that caregivers felt that certain areas of pain management needed improvement. Caregivers commented on the need to educate some of the nurses on how to operate PCA pumps that are used to administer pain medications, the need to provide more information for parents on how to handle their child after cardiac surgery without causing pain and the need to encourage appropriate preparation for optimal pain control on the first day of arrival on the ward after surgery.

*“Well, I think that is all, or maybe they should teach the parent how to hold child after the operation so that they will know how to do that without causing the child more pain. I think they should always prepare for the first day the child will come from downstairs to upstairs just as they do when they want to do any procedures and provide more support when they come from PICU so that the child is as comfortable as he was before coming up”.* – C2

**Team Work:** There was evidence that a team approach was utilised in pain management practice in the study site. Participants used the word “*they*” regularly during the interview and constantly mentioned reception of support from nurses, doctor, play therapist, physiotherapist and psychologist during hospitalization.

**Parental Distress:** Parents used emotive words and phrases such as frustrating, sad, stressful and afraid to express their own distress when their child was in pain. Parents expressed feelings of frustration, concern, anxiety, and fear during hospitalization. It appeared that parental distress was precipitated by fears of surgical risk, previous experiences with pain and other disease-related symptom.

*“I have been through a lot to have him. It was really hard and I and his Dad couldn’t sleep as we couldn’t put him on his side all through the night”.* – C4

## ***4.2 Discussion***

These results provide information on actual pain management practices of healthcare providers as well as parental perception of these practices in a private paediatric ward. This study found that pain histories were not consistently collected when the situation demanded more extensive assessment of the pain experience. This concurs with the findings of other studies.<sup>4,47</sup>

The two most common assessment tools used in the study site were the FLACC scale and a numerical pain scale. Healthcare providers appeared to be more comfortable with use of the numerical pain assessment tool even though the mean age of patients in this study was 3 years. It was sometimes used inappropriately instead of the FLACC scale to assess pain in preverbal children by asking the parent. While using the FLACC scale for pain assessment, healthcare providers used cry more frequently for scoring whereas the other 4 parameters were used but not consistently, so the final score was based on the intuition or perception of the healthcare provider. However, being an observational study, it was difficult occasionally to ascertain whether the parameters were assessed in detail. Earlier studies have demonstrated that despite tools being widely available, they were not always used well or consistently, as evidenced from this result.<sup>25,48</sup> As in other studies, the behavioural cue used most often for assessment in preverbal children was crying.<sup>4</sup> Physiological cues were not used consistently to assess pain as in other studies.<sup>4</sup> The explanation for this in the study site is because in cardiac patients the physiological indicators are used more to correlate to a cardiac cause rather than pain whereas in oncology patients they are regarded as more of an indicator of infection rather than pain. There is, however, little evidence to support the use of physiologic measures alone to measure pain, and these should be used in conjunction with other tools/measures to assess pain.<sup>7</sup>

Pain assessment was observed to be recorded regularly every 4 hours as it is part of the vital signs parameters required to be documented as per organizational policy on the PEWS chart or IPod device, but actual assessment using validated tools was not as consistent compared to the documentation. This explains in some instances why the documented pain score may not correlate with the child's actual pain score as the score might have been added as an afterthought to complete the routine chart format. Pain scores were also noticed to have been documented on some occasions some hours after other vital signs were taken during calculation of the PEWS score to complete the entries. Similar results with inconsistencies

between reported assessment and documentation have been produced by other studies.<sup>49</sup> This is an important finding as lack of correlation between actual pain and documented score could lead to suboptimal pain treatment in children. Previous studies demonstrated that under assessed and poorly documented pain could lead to children being under-medicated or their pain being poorly managed.<sup>50</sup> Although there is an established system in place to assess pain similar to vital signs in the study site as recommended by guidelines, health care providers however need to be trained in the techniques for assessing and grading pain with the available tools recommended on the PEWs chart.<sup>3,27</sup>

Reassessments 1-2 hours after intervention to reduce pain were not done consistently but usually during the routine 4-hourly vital signs or during other clinical activities such as feeding. Lack of consistent reassessment 1-2 hours after pain-relieving interventions indicate a stereotypic way of care rather than conceptualizing the care to each individual child as the need indicates. Pain reassessment should be done earlier than the four hourly routine observation after a pain relieving intervention in line with recommendations highlighted on the PEWS chart for any deteriorating child. Healthcare providers tends to increase frequency of observation (heart rate, respiratory rate, blood pressure and temperature) when there is slight derangement or in acute deterioration. There is a need to orientate healthcare providers to adopt a similar approach for the fifth vital sign after interventions to reduce pain. Lack of consistently conducting routine reassessment after pain-relieving intervention concurs with findings of earlier studies.<sup>4,51,52</sup> Oncology patients are more likely to be reassessed compared with cardiac patients. This may be explained by the fact that oncology patients are on regular morphine and those on PCA require one hourly observations. There may however be other explanations. A future study of healthcare providers' perception of pain management in both group of patient might give a better information on why the pain reassessment pattern differs.

Healthcare providers prepared patients for painful procedures using cream, play therapist and distraction technique, and this was a standard culture in the study setting. Utilization of music therapy, distraction technique with the iPad is unique to this unit. There is organized team work during planned procedures, and healthcare providers take advice and help from multidisciplinary team members. This differs from other studies that found that nurses tend not to seek advice from the multidisciplinary team about pain.<sup>25,26</sup>

Communication that occurs between healthcare providers and the parents is mostly focused on medication that is being administered by nurses while doctors tend to go into more detail in terms of the history of pain experience and options available for pain treatment. Most information was from nurses and was usually received during drug administration. Nurses' communication focus in this study was similar to findings from previous observational studies.<sup>4,26</sup> However, negotiation on timing of medication and choice(s) of formulation usually occurs, in contrast to previous study in which little negotiation was noted. This could be because the study site is a private setting and fewer patients compared to the public sector.

Good communication with regard to pain management, was observed not only between doctors and nurses but also inclusive of play therapists and physiotherapists. Parents also indicated that they received information from the multidisciplinary team. Parents of children who have had cardiac surgery however expressed the need for more information on how to carry out activities of daily living with their children post cardiac surgery without causing pain. Effective communication with this group of parents was lacking as although they were provided with instructions on how to support their children, the rationale for these instructions was not provided. Some earlier studies have also demonstrated inadequate information received by parents during hospitalization of their child for surgery.<sup>29,53</sup> There is, therefore, a need to provide information booklets on pain relief and care post-surgery for parents to address this concern.

Although there are adequate systems in place to breach language barriers(onsite interpreters during the day and 24 hours language help line, it is concerning that there are still instances where the available systems put in place were not utilized. Communication with a verbal child was inhibited by a language barrier, so it would have been difficult to assess the child's pain, and his involvement in decision making regarding the management of his pain would also have been impaired. Language barriers may affect pain assessment as well as effective communication between healthcare provider, child and parent. There are interpreters during the day time, but results from the study revealed that language is still a barrier as healthcare providers do not routinely use the helpline for interpretation at night. There is need for improved work-place practice regarding use of available language help.

Healthcare providers' practices conformed to best-practice guidelines in the areas of prescription of regular analgesics to all patients and administration of analgesic drugs.<sup>3,7</sup> This agrees with results of previous studies.<sup>4,27</sup> Opioids analgesic was used more regularly in

oncology patients compared with cardiac cases, and less paracetamol was used regularly in oncology cases. This is because cardiac cases usually have their intravenous morphine converted to oral on the as required side of the drug chart most of the time as their pain improves while paracetamol is written on the regular side prior to transfer to the ward. Oncology patients tend to have morphine on the regular side with paracetamol on the as required side of the chart most of the time as a way of keeping up with the culture of not masking fever in neutropenic patients with paracetamol administration. Non-steroidal anti-inflammatory agents were avoided in oncology patients due to their effect on platelets and in patient on chemotherapeutic agent that are nephrotoxic to avoid increased risk of nephrotoxicity. However oncology patients that are off chemotherapy and who have just had surgery usually have NSAID prescribed as part of first line analgesia. The knowledge of healthcare providers on pain management and the impact of this on practices and ward culture need further exploration.

Another area where healthcare providers conform to best practice in this setting is the prescription of analgesics in accordance with the British National Formulary (BNF). The only situation in which this differs is the erroneous prescription of a lower dose during conversion of intravenous paracetamol to oral resulting in a lower dose being administered. This is worrying as this can lead to suboptimal pain management. There is a need to evaluate the transcription of drugs from PICU charts to ward charts after transfer to ascertain frequency of occurrence to take appropriate actions to reduce prescription of sub-therapeutic doses of analgesics.

Healthcare providers utilized non-pharmacological methods of pain relief and also encouraged parents to utilize this method during painful procedures. It is a common practice in this setting. Distraction which is commonly used in this setting, has been found to be one of the most successful ways children deal with pain.<sup>54</sup> This contrasts with previous studies that indicated that non-pharmacological methods of pain relief are not often utilized.<sup>3,26,43,51</sup> The explanation for this could be changing pain management practice or improved knowledge of healthcare providers regarding non-drug methods of pain management.

Effectiveness of drug-relieving interventions were documented most of the time, but despite the judicious use of non-pharmacological methods in this setting, the documentation does not reflect the extent to which it is being used. Participants might not document these because

they assume other members of staff will document them or do not think the interventions are significant enough to warrant documentation.

The involvement of Parents by healthcare providers during pain assessment and in the provision of support during pain management, reflects an understanding of the roles of parents in pain management. Parents were utilized judiciously to provide support and non pharmacological methods of pain relief. This is a good practice as it invariably help parents to understand their role as well as acquiring of confidence in utilization of such non pharmacological methods after discharge from hospital. Parents needs to be actively encouraged to participate in pain management.<sup>28</sup>

Parental experience revealed that the intensity of pain in cardiac cases is highest on the first day on the ward after PICU transfer. This needs to be explored further to establish possible causes and corrective measures to improve quality of pain management.

Parents rated the support they received from healthcare providers with regard to timing of response, mode of response and actions taken when the child was in pain. Overall, parents were satisfied with pain management, which is similar to findings by previous studies.<sup>27,35</sup>. Participants were from overseas so the criteria used by some of the participants to arrive at their satisfaction level may be based on comparison of standard of care of the study site with the standard of care in their own countries rather comparison to required standard in the UK. This needs further exploration.

A certain number of parents described feelings of frustration and sadness as well as being really stressed during the period when their child was in pain. A previous study also demonstrated that feelings of fear, hopelessness, anxiety and depression were expressed by parents whose children were hospitalized.<sup>52</sup> Most of the participants were from overseas, so lack of usual family support, previous life experiences and other supportive mechanisms they have in their own countries may contribute to worsening emotional distress. There is need to explore measures that can be used to support parents during hospitalization as parental distress may reduce the ability to support their child during painful episodes.<sup>38</sup> Results from an earlier study showed that parents recommended supporting the child and parent on an emotional level.<sup>52</sup>

The ethnic and racial diversity of the participating parents and healthcare providers may influence pain expression as well as pain assessment outcome but there was no substantial

supportive evidence in the data that was collected. Another study demonstrated that health professionals' assessment of children's pain is subjected to a wide range of individual, social and contextual influence.<sup>55</sup> The effect of ethnic diversity on pain management needs further evaluation in this setting.

Even though up to 90% of parents expressed satisfaction with pain management, parents still felt that competences of healthcare providers in the use of PCA pumps need improvement as well as the aspect of information provision for parents whose children have had cardiac surgery. Earlier qualitative studies have produced similar results regarding parental desire for more information about care during their child's hospitalization.<sup>52</sup>

## **CHAPTER 5: CONCLUSION AND RECOMMENDATION**

### ***5.1 Conclusion***

This study evaluated the pain management practices of healthcare providers in a private hospital and parental perception of such practices. This is the first study to evaluate the pain management practices in the study site. Pain assessment is a crucial factor in providing effective pain management. Pain assessment is routinely documented with the other vital signs in line with hospital policy for the paediatric early warning scoring system; the recorded scores may not always correlate with the actual child's pain score. This is due to lack of consistency in using a validated tool for assessment and lack of appropriate use of assessment tool for age, especially in preverbal children. It could also possibly be due to inadequate theoretical knowledge on how to utilise some of the validated paediatric pain tools.

Parents were satisfied with pain management but suggested the need for improvement in knowledge and competency of healthcare providers in the use of pain-relieving devices. They also identified the need for healthcare providers to provide better information for them on effective ways of handling children post cardiac surgery to minimize pain. The results suggested that certain areas of practices conform to best- practice guideline while certain aspects need further in-depth evaluation and improvement.

### ***5.2 Limitations of the Study***

There are some limitations to this study.

- 1) The small sample used and collection of data on a small ward in a private hospital might limit the generalization of the results of this study. The sample size was limited also because of the paucity of patients that fulfilled the recruitment criteria during the period of the study. Some of the findings of the study, however, concur with those of previous studies and might be applicable in other similar settings.
- 2) The researcher, who is also a member of staff (RMO) in the hospital, is the only one who undertook all the data collection. There is a possibility that parents might not want to be seen to complain or report dissatisfaction for fear of upsetting the researcher, who is one of the healthcare providers.

- 3) The observation of staff could be a potential source of bias as they might behave differently while being watched. The researcher was a participant and observer, and there were rapid habituation and less observer effect as participants and healthcare providers viewed the researcher as someone inside their circle. The risk of loss of objectivity was also reduced by having a defined observational tool as a checklist and having a set time for each observation. Being a participant observer also afforded the researcher the ability to participate in an activity at a close angle and thus provide a good interpretation of the situation.
- 4) This was an observational study; therefore, it was difficult to interpret some of the behaviours by simply observing without knowing the thoughts of the parents or the healthcare providers. However, parental interviews were conducted, and this study evaluates the pain management practices of healthcare providers in this private hospital for the first time, leading to the emergence of key issues that need to be addressed to improve pain management and those that need further exploration.
- 5) Language barrier. Parents/caregivers who could not be interviewed because of difficulty with translation and unavailability of an interpreter during data collection were excluded. The use of language helpline was inappropriate as a patient would incur additional cost.
- 6) All participant healthcare providers being female might not give a good representation of the typical healthcare professional representation. Majority of the healthcare provider at the time of the study were female.

#### ***5.4 Recommendations***

- 1) There is a need to implement a specific paediatric pain management guideline for the study site as the 2014 pain management guideline is based on an adult guideline which does not cover the management of paediatric pain.
- 2) Regular auditing of pain management practices in this setting with attention to the following:
  - Paediatric pain guideline and protocol audit: paediatric pain guideline has been implemented in the study site in August 2016. One way that has been suggested for improving service is to have a protocol and guideline that are audited on a regular basis.<sup>56</sup>

- Pain assessment and documentation practices will provide information on possible areas of pain assessment and documentation practices that need improvement and eventually impact on quality of pain management.
- 3) A detailed review of pain management practices on the ward in the first 24 hours of transition from Intensive care will highlight the factors responsible for the higher intensity of pain described by parents during that period so that appropriate solutions can be implemented.
  - 4) Education and Training: Pain management training as part of induction courses for new staff as well as 1-2 yearly refresher courses for old staff members to improve pain management knowledge and skill in the use of PCA pumps and other devices that are used regularly for pain management.
  - 5) There is a need to further explore the distress parents experience when their child/children are in pain in this setting and develop strategies to assist parents with adequate coping mechanisms.
  - 6) There is a need to improve the adequacy of information given to parents whose children are having cardiac surgery regarding pain by providing information brochures on pain management post operation that are translated into different common languages.
  - 7) There is a need to create a booklet which would have a sample of common pain scale (FLACC, Numeric, Analogue, and Revised Faces Pain scale) and written pain descriptions interpreted into different languages.
  - 8) The Implementation of a flow chat for healthcare providers which provide a simple step by step ways of accessing language line is very important.

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## **APPENDICES**

- A) Structured observational tool chart
- B) Semi-structured interview guide
- C) Consent for parent/caregivers)
- D) Parent/Caregivers information sheet
- E) Healthcare provider information sheet
- F) Distress protocol
- G) Evidence of Local Approval
- H) Evidence of permission to use observational tool
- I) Healthcare provider demographic data sheet
- J) Consent for participant (healthcare provider)
- K) Assent form for children

*Appendix A*

Observational Data Collection Tool

	<b>Always carried out</b>	<b>Sometimes carried out</b>	<b>Rarely carried out</b>	<b>Never carried out</b>	<b>Not applicable</b>
<i>Pain assessment</i>					
A pain history is obtained from the child(CA)					
Pain assessment takes place using a validated pain assessment tool(CA/O)					
Provide information about the pain assessment tool used :( Which tool? Was it age and developmentally appropriate?)					
Pain is reassessed following the implementation of painrelieving					
How often pain was assessment/reassessed:					
	<b>Always carried out</b>	<b>Sometimes carried out</b>	<b>Rarely carried out</b>	<b>Never carried out</b>	<b>Not applicable</b>
<i>Partnership in care</i>					
Health care professionals discuss the child's pain management with their					

parents/guardians(O)

**Appendix A**

	<b>Always carried</b>	<b>Sometimes carried out</b>	<b>Rarely carried out</b>	<b>Never carried out</b>	<b>Not applicable</b>



## Appendix A

	Always carried out	Sometimes carried out	Rarely carried out	Never carried out	Not applicable
<i>Non-drug methods of pain relief</i>					
Non-drug methods of pain relief are used(O)					
List non-drug methods used:(observed recorded in notes)					
	Always carried out	Sometimes carried out	Rarely carried out	Never carried out	Not applicable
<i>Procedural pain</i>					
The child was prepared for painful procedures(CA/O)					
Provide some additional information about who undertook this preparation and how it took place:					
	Always carried out	Sometimes carried out	Rarely carried out	Never carried out	Not applicable
Analgesic creams are used for planned painful					
procedures (CA/O) <i>Documentation</i>	Always carried out	Sometimes carried out	Rarely carried out	Never carried out	Not applicable
Pain assessments are recorded on flowchart(CA)					
Pain-relieving interventions used are documented in the					
The effectiveness of painrelieving interventions is documented in the child's					

## Appendix A

### Additional Information for the child-CA/O

Case number(child and caregiver)			
Sex			
Race			
Language			
Date of admission			
Date of interview			
Primary diagnosis			
Treatment Received			
Surgery is done			
Other procedure			
Caregiver relationship to child			
Amount of time caregiver present at bedside- O	Always present	Sometimes present	Rarely present

**Additional information/Comment**

## Appendix B

SEMI-STRUCTURED INTERVIEW GUIDE

RESEARCH: Pediatric health care providers pain management practice and parental perception regarding pain management in a private hospital.

1) Introduction: greetings, familiarize, signing of consent

2) Demographic data: Can you tell me about yourself?

Probe: sex, relation to a child, length of admission and reason for admission and ethnic group.

3) Can you tell me about your experience regarding your child's pain during this admission?

Probe: - how much pain since admission and how much currently

-how has pain affected your child-sleep, play, eating and how has it affected you?

4) Were you involved with the staff in your child's pain treatment?

Probe: If yes: - Can you give me more details /examples of how you were involved

-involvement in assessment, decision making and other roles played during pain relief interventions and procedures

If No: can you elaborate why?

5) Were you given any information regarding your child's pain and treatment?

Probe: - can you give more details, who gave the information (doctor, Nurses, pharmacist and others).

-information sufficiency

6) What are the various sorts of supports you received during the periods when your child was in pain/painful procedure?

Probe: - medication

- Non-pharmacological interventions

- Psychological

7) How satisfied are you with the care and support you received as regards your child's pain.

Probe: - how well pain management practices meet child's pain care need, and which practice produces the best response.

-Views regarding healthcare providers competence in pain management.

8) How could we help well?

Probe: - In what areas do you feel we need to improve?

-what other things do you think we should know.

-do you have any other thoughts on these issues?

9) Clarify answers.

Thank you for your time and finally do you have any question you would like to ask me.

Note: additional and follow up questions would be asked as appropriate with each participant.

## Appendix C

### CONSENT FORM (PARENT/Caregiver)

Research Title: Pediatrics Healthcare provider pain management practices and parental perception regarding pain management in a private Hospital

I have been invited to participate in a research about paediatrics healthcare provider pain management practices and parental perception regarding pain management in a private hospital.

I.....have read the information sheet/it has been read to me. I have been given the opportunity to ask questions about the study and any questions I have asked has been answered to my satisfaction. I understand the purpose of the study and that I can withdraw at any time from the study without prejudice. Any information which might identify me will not be used in the report or published material.

I agree to participate in the study as outlined to me and in particular to be interviewed by the researcher.

Signature of Participant: .....

Date: ..... (Day/month /yes)

I agree with the interview being tape recorded:

Researcher:

I have accurately read out the information sheet to the potential participant and to the best of my ability made sure that the participant understands what is been done. I confirm that the participant was given an opportunity to ask questions about the study and all questions asked has been answered correctly to the best of my ability. I confirm that the participant has not been coerced into giving consent.

Name of Researcher: .....

Signature of Researcher: .....

Date: ..... (Day/ month/ year) Name

of witness.....

Signature of witness:

Date:..... ( day/month/year)

## **Appendix D**

### **INFORMATION SHEET FOR PARENT/CAREGIVER**

RESEARCH PROJECT: Pediatric Healthcare provider pain management practices and parental perception regarding pain management in a private hospital.

My name is Abidemi Oladoyinbo and I am working at the Harley Street Clinic. I am doing a research project as part of Master's program to assess pain management practice by healthcare providers and parental perception of this pain management so as to identify where weaknesses and strengths exist in practice and how we can improve if needed.

The aim of this study is to examine the current quality of our pain management practices and to get your opinion on these. This will ultimately help provide information that will guide pain optimal pain relieving practices and the development of specific guidelines for this.

You are being invited to participate in your experience as a parent/caregiver on how we managed your child's pain during this admission will contribute much to our understanding of our practice.

This research will require your participation in an interview .During the interview the primary researcher will ask your questions to ascertain your views on how we are doing from your own perspective with regards to treatment of your child's pain. The interview will be less than 1 hour. Although I will be taking some notes during the session, I cannot possibly write fast enough to capture all responses so I will be tape recording as well, so that none of your comments will be missed. As we tape record during the session please try to speak up so that none of your comments is missed. The interview will be conducted in a comfortable place at the clinic.

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. Non-participation will not impact negatively on the care of your child. You are free to cease participation at any time.

The risk may include recollection of unpleasant experience during child care and it is possible you may find answering some of the questions challenging. If during the course of the interview, you feel upset or emotional you may request for the interview/recording to be paused. Additional support and assistance will be provided by the hospital psychologist and then decide whether to continue or not. If you still find the interview challenging after this

then the interview will be terminated. If you register a complaint about the care of your child during the interview, I will report the incident and liaise with the duty manager who will subsequently have a discussion with you in order to address the shortcomings.

There will be no direct immediate benefit to you; however, your participation will help us to find out different areas in our pain treatment that can be improved to ensure better pain control for children while on admission at the clinic.

All responses will be kept confidential and this means the interview responses will not be shared with anyone else except members of my research team (supervisors). All information included in the final report/transcription will not identify you as the respondent. You don't need to give your child's name or your name and neither will you be identified by name on the Tape. The cassette will be coded and locked in a cabinet. It will be heard by only the researcher who will also be transcribing the recordings. Data will be stored in the researcher's password locked computer. The recording will be deleted 4 months after transcription.

The knowledge obtained from this research will be shared with the University of Cape Town and the Harley Street Clinic. You can have a summary of the result if you wish. There is also a possibility that the result will be published so that other interested people and hospitals may learn from the research.

Remember you don't have to talk about anything you don't want to though your opinion is highly important for this project. You may end the interview at any time even if you have agreed earlier.

If you have any questions, you can ask now or if you wish to ask later, you may contact the researcher using the contact details below;

Name: Oladoyinbo Abidemi

Mobile number: 07404060778

E-Mail address: aoladoyinbo@yahoo.com.

Research Supervisors:

Dr Michelle Meiring

Dr Patricia Luck

Palliative Medicine department, UCT

Phone: +447721035638

Phone: +27824087102

E-mail: [Patricialuck@me.com](mailto:Patricialuck@me.com)

E-Mail: [ma.meiring@uct.ac.za](mailto:ma.meiring@uct.ac.za)

If you have any questions or concerns about your rights and welfare as research participants, you may contact the Faculty of Health science Human research ethical committee, the University of Cape Town using the following contact details;

Telephone: + 27214066338

Fax: 0214066411

E-mail; [shuretta.thomas@uct.ac.za](mailto:shuretta.thomas@uct.ac.za)

## Appendix E

### INFORMATION SHEET FOR HEALTH CARE PROVIDERS

#### **Research Title: Paediatric Healthcare provider pain management practice and parental perception regarding pain management in a private hospital**

My name is Abidemi Oladoyinbo and I am working as a Paediatric RMO at the Harley Street Clinic. I am doing research towards a Master's Degree in Palliative Medicine at the University of Cape Town. My research is entitled "Paediatric Healthcare Provider Pain Management Practice and Parental Perception Regarding Pain Management."

I will be looking at how we manage pain, so this study will assess the pain management practices of doctors and nurses in this hospital to help identify strengths and weaknesses. The aim is to assess our current quality of pain management practices and to measure this against recommended standards. I am also interested in the opinion of a parent about this care. This will provide information for the development of specific paediatric pain management guidelines in our site to improve quality of care and thereby health outcomes.

You are being invited to participate in this research project. Before you make a decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the information provided carefully.

As a participant, you need to allow yourself to be observed by the primary researcher as you perform your normal clinical activities while taking care of oncology and post-operative cardiac patients that are in pain. You will be observed for 6 hours /shift, for 2 -3 shifts. Observed practices regarding pain management will be recorded and your relevant documentation noted.

Participation is completely voluntary and you are at liberty to withdraw at any time. The choice that you make to participate or not will have no bearing on your job or on any work-related evaluations or reports. Although there is no immediate benefit for you as a participant, it is hoped that the study will generate important information which will inform strategies and guidelines for optimal pain management. There is no risk for you in this study.

All observations and information about you will be kept strictly confidential. All data collected during observations shared with my research team member (supervisor) and all

information I include in the final report will not identify you as the participant as your names will not be mentioned. Data will be stored in a password locked computer and hard paper will be locked in a cabinet in the office. The project is being sponsored personally by the researcher.

The Report of the study will be submitted to the University of Cape Town electronic archive. The report will also be made available to the study site. You can also have access to this report if you wish.

I have received ethical clearance from the relevant institutions and the hospital management has also given permission for the study.

Please ask any questions to clarify anything that is not clear or if you wish to ask questions later, you may contact me or supervisors using the contact details below;

Researcher:

Abidemi Oladoyinbo

Mobile number/E-Mail: 07404060778, [aoladoyinbo@yahoo.com](mailto:aoladoyinbo@yahoo.com) Research

Supervisors:

Dr Michelle Meiring

Dr Patricia Luck

Department of palliative medicine

Phone: +447721035638

University of Cape

E- mail:patricialuck@me.com

Phone: +27824087102

Email: ma.Meiring @uct.ac.za

You may contact the Faculty of Health science Human research ethics committee at the University of Cape Town if you have any questions or concern about your rights or welfare as research participant using the contact details below

Telephone: +27214066338

Fax: 0214066411

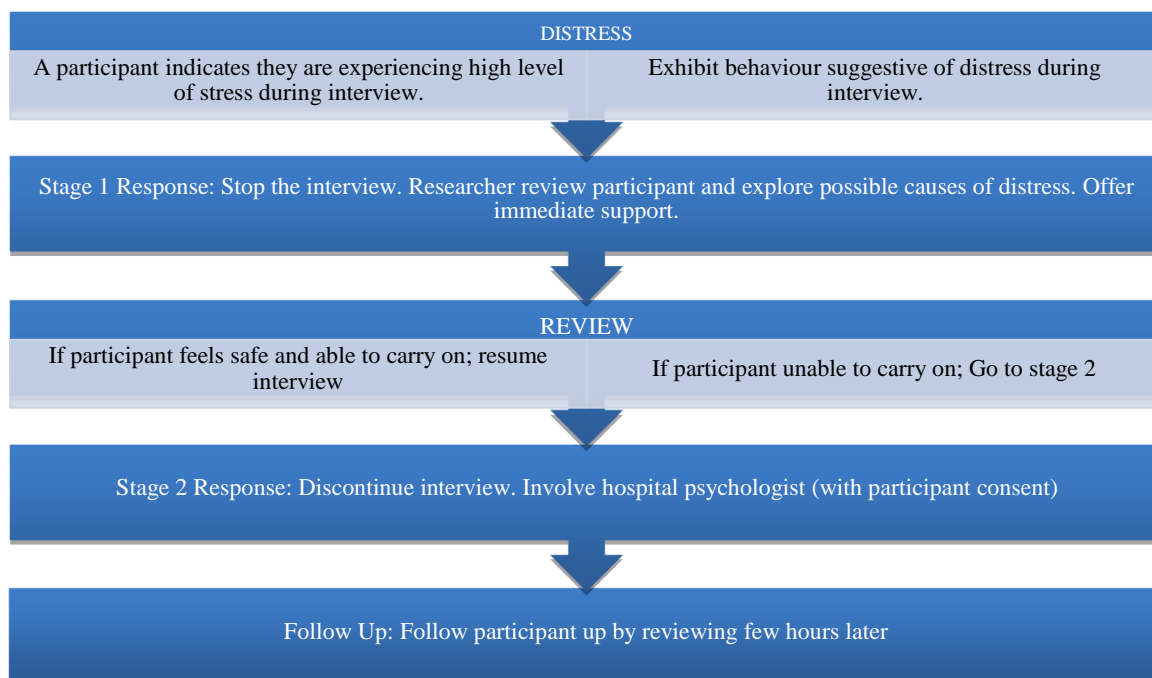
E-Mail: [shuretta.thomas@uct.ac.za](mailto:shuretta.thomas@uct.ac.za)

## Appendix F

### DISTRESS PROTOCOL

Research Title: Paediatrics Healthcare provider pain management practices and Parental perception regarding pain management in a private hospital

(Modified from Haigh C, Witham G. Distress protocol for qualitative data collection, Manchester Metropolitan University, Department of Nursing).



## Appendix G



## Appendix H

**Abidemi Oladoyinbo** <aoladoyinbo@yahoo.com> 3 Nov at 4:45 PM  
To aoladoyinbo@yahoo.com

Sent from my iPad

Begin forwarded message:

**From:** "Twycross, Alison" <a.twycross@lsbu.ac.uk>  
**Date:** 22 August 2014 at 14:43:14 BST  
**To:** 'Oladoyinbo Abidemi' <aoladoyinbo@yahoo.com>  
**Subject:** RE: Permission to Use Structured observational chart.

I have your email but have had a really busy week. I will send you the tool as soon as I am able.

Dr Alison Twycross  
Head of Department for Children's Nursing and  
Reader in Children's Pain Management  
Editor: Evidence Based Nursing  
Department of Children's Nursing  
Faculty of Health and Social Care  
London South Bank University  
103 Borough Road, London, SE1 0AA

**Tel:** +44 (0)20 7815 8419  
**Mobile:** +44 (0)778 552 5986  
**Email:** [a.twycross@lsbu.ac.uk](mailto:a.twycross@lsbu.ac.uk)

**From:** Oladoyinbo Abidemi [[mailto:aoladoyinbo@yahoo.com](mailto:mailto:aoladoyinbo@yahoo.com)]  
**Sent:** 22 August 2014 14:30  
**To:** Twycross, Alison  
**Cc:** [alisontwycross@hotmail.com](mailto:alisontwycross@hotmail.com)  
**Subject:** Fw: Permission to Use Structured observational chart.

On Wednesday, 20 August 2014, 13:31, Oladoyinbo Abidemi  
<[aoladoyinbo@yahoo.com](mailto:aoladoyinbo@yahoo.com)> wrote

On Monday, 18 August 2014, 15:58, Oladoyinbo Abidemi  
<[aoladoyinbo@yahoo.com](mailto:aoladoyinbo@yahoo.com)> wrote

Thanks for the reply. I would like to Use the observational tool you used for the study : Children's nurses' post operative pain management practices: An observational study. Please It will really be helpful if you can send me a copy. Thanks  
Regards  
abidemi

On Monday, 18 August 2014, 7:09, "Twycross, Alison"  
<[a.twycross@lsbu.ac.uk](mailto:a.twycross@lsbu.ac.uk)> wrote

Apologies for the delay in replying. I would be very happy for you to use my structured observational tool. I have more than one. Which one are you thinking of using? Do you need me to send you a copy?

Best wishes



I have been invited to participate in a research about paediatrics healthcare provider pain management practices and parental perception regarding pain management in a private hospital.

I.....have read the information sheet/it has been read to me. I have been given the opportunity to ask questions about the study and any questions I have asked has been answered to my satisfaction. I understand the purpose of the study and that I can withdraw at any time from the study without prejudice. Any information which might identify me will not be used in the report or published material.

I agree to participate in the study as outlined to me and in particular to be observed by the researcher.

Signature of Participant: .....

Date: ..... (Day/month /yes)

Researcher:

I have accurately read out the information sheet to the potential participant and to the best of my ability made sure that the participant understands what is been done. I confirm that the participant was given an opportunity to ask questions about the study and all questions asked has been answered correctly to the best of my ability. I confirm that the participant has not been coerced into giving consent.

Name of Researcher: .....

Signature of Researcher: .....

Date: ..... (Day/ month/ year)

Name of Witness:

Signature of witness.....Date:.....(  
day/month/year)

## Appendix K

### ASSENT FORM FOR CHILDREN >7 YEARS

Read and explain the following to the child in a language s/he can understand when s/he has assented to talk:

What is a research study? A research study helps us learn new things. We can test new ideas and receive answers to questions on how things are done.

Why are we doing this study? We are doing the study to find out about the treatment and care you are receiving for your pain during your hospital admission.

Who is doing this study? This study is organised by Dr Abidemi Oladoyinbo (Ola) as part of a research study.

Why is this study being done? This study is being done so that we can: Find out about the treatment and care you are receiving for your pain and identify the best ways to help other children who may be admitted in the hospital in the future to control their pain.

What will happen during the study? If you decide to be in the study, I will look at the way your nurses and doctor take care of you when you are in pain. I will examine your folder and drug chart and write detail information about the care you received while you were in pain. I may ask you question about your pain while watching how your doctors and nurses are taking care of you.

Who will know what I did in the study? Nobody will know apart from your parent/caregiver, those treating you and the few people involved in the study.

Can I decide if I want to be in the study? You can decide if you want to take part. You can say NO' or you can say YES'. Nobody will be upset if you say NO'. If you say YES', you can always say NO' later. You can say NO' at any time. We will take good care of you no matter what you decide. I will also ask your parent/caregiver to partake in the study and ask them questions about their experience of the care you received while you were in pain.

Are there good things and bad things about the study? The good thing about the study is that we will learn more about the care you received while in pain as well as the care you didn't receive and why. Someday we hope what we have learned from this study will help us know the best ways to help you and other children who have pain when in hospital. The bad thing is

that you may not like anybody to watch while you doctors/nurses are taking care of you or you might find questions about your pain hard to answer. I will try to make sure no bad things happen. If you feel pain at any time during the study we will report to the nurse in charge and your doctor so that steps will be taken to change to other pain medicine that will help in relieving your pain.

What else should I know about this study? You can ask questions at any time about this study. Being in this study is your choice and takes the time you need to make your choice. If you say 'Yes' and you change your mind later, please tell the research doctor at any time.

If you have any question about the study at any time you can talk to the following research team member listed below;

Dr Abidemi Oladoyinbo

Harley street clinic

Mobile No: 07404060778

E-mail [aoladoyinbo@yahoo.com](mailto:aoladoyinbo@yahoo.com)

Dr Michelle Meiring

Palliative Medicine Department, UCT

Phone: +27824087102

E-Mail: [ma.meiring@uct.ac.za](mailto:ma.meiring@uct.ac.za)

Dr Patricia Luck

Email: [patricialuck@me.com](mailto:patricialuck@me.com)

Mobile No: 07721035638

I have read this form or someone has read it to me. If I did not understand something, I can ask the doctor to explain it to me. I can always ask the doctor a question about the study if I don't understand something. I will be given a copy of this form.

Please tick one box:

**YES**, I want to be in this study and I know I can change my mind later.

**NO**, I do not want to be in this study.

Signature/Finger print

\_\_\_\_\_

Name: \_\_\_\_\_

Date of Signature: \_\_\_\_\_

Researcher: Tick the applicable box if child agrees to participate

The child is capable of reading and understanding the assent form and has signed above as documentation of assent to take part in this study.

The child is not capable of reading the assent form, but the information was verbally explained to him/her. The child signed above as documentation of assent to take part in this study.

The child had ample opportunity to have his or her questions answered.

Signature of researcher \_\_\_\_\_ Date \_\_\_\_\_

Name of researcher: \_\_\_\_\_