CONCERNS OF CAREGIVERS OF PAEDIATRIC PATIENTS REGARDING ANAESTHESIA AT AN ACADEMIC HOSPITAL IN JOHANNESBURG

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Declaration

I, Janani Ayshwaryah Yogeswaran, declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in the branch of Anaesthesiology, in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

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Presentations arising from this study

This study was presented in the form of a poster presentation at the 19th annual Paediatric Anaesthesia Congress of South Africa (PACSA), on the 7th of November 2015.

It achieved a highly commended clinical excellence award.

Abstract

Studies show that anxious children experience negative post-operative outcomes, and that anxiety in parents, leads to anxiety in children. Addressing issues related to caregiver anxiety in the peri-operative period may be beneficial in reducing anxiety in paediatric surgical patients, thereby potentially avoiding a host of undesirable outcomes.

The concerns of caregivers' of paediatric patients presenting for surgical procedures at Chris Hani Baragwanath Academic Hospital (CHBAH) were not known. Gaining insight into caregiver's concerns, and what they fear about anaesthesia, allows us to address these concerns in a constructive manner, and thus improve the quality of the experience.

This study explored the concerns of caregivers of paediatric patients presenting for surgery, in an attempt to alleviate these concerns, and thus reduce anxiety.

This qualitative, explorative research project was conducted amongst caregivers of paediatric patients presenting for surgery at CHBAH. Semi-structured, in-depth interviews were conducted until data saturation occurred (n = 20). The interviews were audio – recorded, and then transcribed verbatim, after which thematic analysis was used to analyse the data.

Major concerns identified included a fear of death, pain and surgical and anaesthetic complications. The fear of death was influenced by factors including personal and community experiences, media influences and the perceived risk of surgery.

The findings of this study show that a singular event can be experienced, and thus interpreted, differently by different individuals. This '*Weltanshauung*' (world view) needs to be borne in mind by anaesthetists when interacting with caregivers prior to surgery, in order to deliver holistic care of the highest quality.

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Chapter 1: Overview of the study

This chapter will provide a brief synopsis of the entire study, and constructs an outline which will be developed further in subsequent chapters. A broad overview of the subject is provided in order to contextualize the study, and includes a background to the research problem, which forms the basis of this study. A brief outline of the study methodology is also provided, although this will be elaborated upon in later chapters.

1.1 Introduction

The first public demonstration of anaesthesia by ether inhalation was conducted in 1846 by William Morton, and is considered the beginning of anaesthesiology as a speciality in its own right. In the years following this demonstration, there have been numerous advancements in knowledge, technology, drugs, instruments and equipment, resulting in the highly scientific field of anaesthesia as we know it today (1). Despite these momentous advancements, various myths and misconceptions exist in the general public with regards to both anaesthesia and anaesthetists, resulting in many fears and concerns regarding the perioperative period (2, 3).

Considering that caregivers enrolled in this study were adults, a review of the literature was undertaken which focused on adults' experiences. A large amount of research has been conducted to explore the nature of fears and concerns in adult patients in the perioperative period. The most common fears identified include "waking up during anaesthesia" (4-8) and "not waking up from anaesthesia" (4, 5, 7, 9). Specific concerns about the anaesthesiologist qualifications, experience or activities in theatre were only expressed by a small percentage of patients (9), or were only expressed after being specifically questioned in this regard (8).

A recent Nigerian study conducted on the subject in 2007, provided some information within an African context. Of the participants in this study, 80% had no previous exposure to any form of anaesthesia. Fears identified in this population include death, brain damage, memory loss and intraoperative awareness (10).

In recent times, the psychological effects of anaesthesia and surgery on the parents of paediatric patients has been explored.

Three studies investigating anxiety in parents whose children underwent a surgical procedure, found that parents had anxiety levels that were in keeping with an illness state (11, 12), or that met the DSM-IV criteria for acute stress disorder (13). Factors identified as contributing to the stress and anxiety experienced by parents, include issues such as lack of information, and the consequent feeling of insufficient preparation (14), concerns about their children experiencing pain or discomfort (15, 16) and the feeling of losing control (17).

Ogilvie (15) in 1990, utilised in-depth interviews and participant observation, to explore factors that parents perceived as sources of stress in the perioperative period. Concerns expressed by parents included those of their children experiencing pain, and the risks of the surgery. Parents also worried whether they had made the right decision in allowing their child to undergo surgery.

A qualitative study published in 2006 looked at parents' experiences of their child's first anaesthetic (17) . In keeping with findings from other studies on the subject, parents in this study also reported worry and anxiety in the perioperative period (11, 13, 14). Patterns that emerged upon analysis of the interviews showed that parents experienced a range of emotions in the perioperative period, ranging between relief (the period of illness/pain that the child experienced will soon be over because the operation is being done) and worry (about risks of the surgery and anaesthesia), and report a sense of powerlessness (17).

These studies have shown that anxiety is prevalent in parents whose children undergo surgical procedures (11-17). Understanding specific concerns that parents have allows targeted interventions by the anaesthetists during the preoperative consultation, which is vital in enhancing trust and confidence in the anaesthesiologist, for the patient (18). One of the important objectives of this consultation is to identify and allay concerns that patients have (18). By understanding the specific concerns and fears in different populations, the anaesthetist can provide targeted education, counselling and reassurance during the preoperative visit.

A 2010 study conducted in Jordan found no significant relationship between parental anxiety and anxiety in paediatric patients in the preoperative period (19). However, this is in contrast to other studies conducted in Canada, Australia and the United States, which found a positive relationship between the two variables (20-22).

Furthermore, it has been shown that children with higher anxiety levels before surgery, experience a range of postoperative problems, including increased post-operative pain, and subsequent analgesia consumption, general anxiety, and problems sleeping and eating in the post-operative period (23). Emergence delirium, maladaptive behaviours (22) and negative behavioural changes in the postoperative period, including apathy, withdrawal, general anxiety, separation anxiety and aggression towards authorities (24), have also been identified.

Based on these studies, addressing issues related to parental anxiety in the perioperative period may be beneficial in reducing anxiety in paediatric surgical patients, thereby potentially avoiding a host of undesirable outcomes.

1.2 Problem statement

Much of the identified literature with regards to caregivers' concerns in the perioperative period was based in the developed world (11-14, 17, 25, 26), with no literature identified within an African setting.

The South African context is unique, with a diverse patient population. Patients vary in their levels of formal education, their cultural and religious backgrounds, their socio-economic circumstances, and their family and community dynamics (27). With such diverse backgrounds, the experiences of caregivers during anaesthesia for their children, may also be a diverse one. It is imperative that the anaesthetists understand the nature of these fears, so that they can provide targeted education, counselling and reassurance in the preoperative visit.

The concerns of caregivers of paediatric patients presenting for surgical procedures at Chris Hani Baragwanath Academic Hospital (CHBAH) was not known. Gaining insight into patients concerns, and what they fear about anaesthesia, allows us to address these concerns in a constructive manner, and thus improve the quality of the experience.

1.3 Aim

This study aimed to describe the concerns of caregivers whose children were undergoing anaesthesia at Chris Hani Baragwanath Academic Hospital, and to explore the factors that contribute to these concerns.

1.4 Objectives

The objectives of this study were to:

- describe caregivers concerns related to their child's anaesthesia
- explore factors that contributed to these concerns.

1.5 Research assumptions and definitions

The following definitions were used in this study.

Caregiver: Individual primarily responsible for the wellbeing of the paediatric patient undergoing surgery, and who may not necessarily be the parent of the child.

ASA classification: Criteria published by the American Society of Anaesthesiologists to determine fitness of a patient for surgery (28).

ASA I	A normal, healthy patient
ASA II	A patient with mild systemic disease
ASA III	A patient with severe systemic disease
ASA IV	A patient with severe systemic disease that is a constant threat to life
ASA V	A moribund patient who is not expected to survive without the operation
ASA VI	A declared brain-dead patient whose organs are being removed for donor purposes.

Anaesthetist: Any qualified doctor working in the department of anaesthesiology including interns, medical officers, registrars and specialist anaesthetist (anaesthesiologist). The term anaesthesiologist and specialist anaesthetist are used interchangeably in the literature, and will be used as it appears in the literature.

1.6 Demarcation of the study field

CHBAH is an approximately 3 000 bed academic hospital, affiliated to the University of the Witwatersrand, located in Soweto. It serves this area, but also functions as a referral centre for other hospitals. The hospital has a paediatric surgical unit, which performs a wide range of surgical procedures.

The interviews for this study were conducted in a private room located in the operating theatre complex of CHBAH.

1.7 Ethical considerations

Approval to conduct the study was obtained from the relevant authorities at the University of the Witwatersrand and the Gauteng provincial authorities. Identified caregivers were invited to participate in the study, and issued with information letters. Those agreeing to participate in the study were asked to sign an informed consent. An additional consent was obtained for audio-recording of the interview. Anonymity and confidentiality were maintained. The study was conducted in adherence to good clinical research practice as outlined in the South African Good Practice Guidelines (29), and the Declaration of Helsinki (30).

1.8 Research methodology

1.8.1 Study design

This study utilised a qualitative, explorative research approach, employing in-depth interviews with caregivers.

1.8.2 Study population

The study population comprised caregivers accompanying paediatric patients for surgery at CHBAH.

1.8.3 Study sample

A purposive sampling method was employed for this study. Inclusion and exclusion criteria for the study were defined. Interviews were conducted until data saturation occurred, which resulted in a sample size of twenty participants.

1.8.4 Data collection

The interviews were conducted at CHBAH, in a private room in the theatre complex, whilst the child was undergoing surgery. Semi structured, in depth interviews were conducted over a period of three months, using an interview guide. Interviews were audio recorded.

1.8.5 Data management

The audio recordings of the interviews were transcribed verbatim by an external party, after which the accuracy of the transcription was confirmed by listening to the original audio recording, and comparing it to the transcription.

1.8.6 Data analysis

This study utilised thematic analysis to analyse the data according Braun and Clarke's six phases (31).

Data analysis was facilitated by a computer based program, MAXQDA 11 ©.

1.9 Trustworthiness

Trustworthiness was ensured by using the four principles proposed by Guba (32), namely credibility, transferability, dependability and confirmability

1.10 Significance of the study

The concerns of caregivers of paediatric patients presenting for surgical procedures at CHBAH were not known. Gaining insight into caregiver's concerns, and what they fear about anaesthesia, allows us to address these concerns in a constructive manner, and thus improve the quality of the experience.

Addressing issues related to caregiver anxiety in the perioperative period, may be beneficial in reducing anxiety in paediatric surgical patients, thereby potentially avoiding a host of undesirable outcomes.

This study provides some insight into whether caregivers in our hospital population experience similar degrees of anxiety when compared to their international counterparts, and has identified particular fears and concerns related to the anaesthesia.

Whilst the results of the study cannot be generalised to the entire patient population of South Africa, it provides some insight into the caregiver's experiences, and provides a platform upon which further research can be conducted in this area. It also allows anaesthetists to be more aware of potential concerns that caregivers may be harbouring, and thus allows a more detailed, targeted preoperative consultation.

1.11 Report outline

This research report will be presented in the following chapters.

Chapter 1:	Overview of the study
Chapter 2:	Review of the literature
Chapter 3:	Research methodology

Chapter 4:	Results and discussion
Chapter 5:	Summary, limitations, recommendations and conclusion of the study.

1.12 Summary

This chapter provided a brief synopsis of the entire study, and constructed an outline which will be developed further in subsequent chapters. A broad overview of the subject was provided in order to contextualize the study, and included a background to the research problem, which formed the basis of this study. A brief outline of the study methodology was also provided, although this will be elaborated upon in later chapters.

Chapter 2: Review of the literature

This chapter contains a critical appraisal of international literature available on the subject, and forms the foundation of this study. The review of the literature provides a context for the study, and identifies gaps in the current body of knowledge that this study aims to fill. Examining study designs and methodologies used in previous research, and understanding their flaws and benefits, directs the successful development and implementation of the present study.

This chapter begins by discussing various anaesthetic myths and misconceptions that have persisted through the years, and that may prove to be a source of anxiety around the peri-operative period. Anxiety regarding anaesthesia in the general adult population is reviewed. This is followed by a focus on concerns experienced by caregivers of paediatric patients presenting for surgery. The effect of parental anxiety on the anxiety of children presenting for surgery, and the negative post-operative consequences of pre-operative anxiety in children is briefly explored. This chapter concludes by briefly exploring the role of the pre-operative visit by the anaesthetist.

2.1 Anaesthesia: myths and misconceptions

The very first “anaesthetic” was given to reduce the pain associated with dental extractions and minor surgery. In 1846, the first public demonstration of anaesthesia by ether inhalation was conducted by William Morton, and is considered the beginning of anaesthesiology as a speciality in its own right. Prior to 1846, Greek and Roman surgeons performed a range of surgical procedures, without an effective way to protect the patient from pain. Primitive methods for pain control include the use of wine, alcohol fumes and sponges soaked in opium, sulphuric ether and scopolamine, but patients still experienced intense pain and suffering. The years following the ether anaesthetic demonstration in 1846 have seen numerous advancements in knowledge, technology, drugs, instruments and equipment, resulting in the highly scientific field of anaesthesiology as we know it today (1).

Despite the momentous advancements that have resulted in modern day anaesthesia, various myths and misconceptions exist in the general public with regards to both anaesthesia and anaesthetists. An internet search of the subject *anaesthesia myths and misconceptions*, reveals sites dedicated to quelling these misconceptions. Common myths

identified include anaesthesiologists leaving the room once the patient is asleep, and the idea that induction of anaesthesia still occurs through inhalation of ether or chloroform (33). Other misconceptions are that anaesthesia is a form of sleep, and that anaesthesiologists are not highly trained professionals (2). Within an African context, a Ugandan websites notes that many people fear side effects of anaesthesia, and others associate it with death (3).

2.2 Do patients fear anaesthesia?

A literature review was conducted to establish the different concerns and fears adult patients' experience, with respect to anaesthesia. The review focused on adult patients, as the target population for this study are adult caregivers.

While appraising the literature available on this subject, it was noted that a number of different tools have been developed which are used to assess anxiety levels in a population. The studies reviewed used various different tools, in various combinations, in order to assess the levels of stress and anxiety in their studied populations. The lack of a single standardised tool makes it difficult to compare results across different studies. Tools that are commonly used in relevant studies identified in this literature review are:

- State – Trait Anxiety Inventory (STAI) (22, 34)
- Leeds Self - Assessment of Depression and Anxiety (11, 12)
- Hospital Fears Inventory (HFI) (21)
- Visual analogue Scale (VAS) (21, 35)
- Amsterdam Preoperative Anxiety Information Scale (APAIS) (35)
- Global Mood Scale (GMS) (19, 21)
- Modified Yale Preoperative Anxiety Scale (mYPAS) (20, 22).

A study conducted in New York in 1991 surveyed the knowledge, attitudes and concerns, regarding anaesthesia, of 800 patients. Whilst this paper is over 20 years old, the sample population is one of the largest identified in various studies on this topic. Additionally, this study employed both questionnaires and open ended interviews with the participants, to collect their data. A portion of the study focused on the perceptions that the patients had of anaesthetists (in terms of their training and role in the perioperative period) and their

preference for anaesthetic management, but of particular relevance to this study is the extensive exploration of patients' concerns (8).

Patients in this study were asked the question, "what are you most concerned about?" (8). The use of an open ended question allowed patients the freedom to express their own primary concerns, without being confined by the limited options available on a questionnaire. Whilst the literature available in this field would have guided the conception of such a questionnaire, it could not claim to be a surrogate for a patients' own words.

Following this open ended question, patients were given a questionnaire containing written statements regarding concerns related to the perioperative period. Each participant then had to rate the intensity of their concern for each statement, using a Likert scale. A Likert scale is a commonly used tool for scaling responses on a survey, and asks participants to evaluate a criterion, generally by indicating the level of agreement or disagreement with that criterion.

Factor analysis of patient responses allowed the concerns to be grouped into four big groups. Factor analysis is a statistical method of data analysis, used to identify a limited number of factors that can be used to represent relationships between groups of interrelated variables. The four factors identified were specific anaesthesia complications, anaesthesiologists' characteristics, anxiety about hospitalisation and pain. A comparison between the two sets of information gathered shows that most patients spontaneously expressed concerns regarding "not waking up", pain or disability, whilst concerns regarding the anaesthesiologist (e.g. qualifications, experience and presence in theatre) were only expressed following specific comments on the questionnaire (8).

This study went on to explore the relationship between variables in the patients' history and their concerns. Neither past anaesthetic experiences, nor the type of anaesthetic received previously, was related to patients concerns in a statistically significant manner. A relationship, however, was established between specific concerns and type of anaesthetic received. Patients receiving general anaesthesia expressed more concerns about "not waking up", whilst in patients undergoing neuraxial anaesthesia, pain was a more common concern. The authors also found that patients undergoing major/non-ambulatory surgery were less likely to deny concerns (8).

Laffey *et al* (4) recruited 300 inpatients admitted for a range of elective surgeries, for a study exploring patients' knowledge of care in the perioperative period. Patients who were suspected of having an above-average knowledge of or insight into the role of anaesthetists, were excluded from the study. The patients were divided into three groups; patients who were surveyed pre-operatively prior to being seen by a health worker, patients who were surveyed an hour or two after a routine but non-standardised anaesthetic visit, and lastly, patients who were surveyed two to three days post-operatively. Patients were issued multiple choice questionnaires (4).

The study found that similar proportions of patients in each of the three groups admitted to fears relating to the surgery itself, pain, intra-operative awareness and dying during surgery. There was no difference in the number of participants who feared the surgery itself, both before and after the surgery. Females and patients under the age of 35 years, indicated the most fear for intraoperative awareness (4).

A unique method of data collection was utilised by a Canadian study, conducted in Alberta, in 2001. An annual telephonic survey 'The Alberta Survey' is conducted by the Population Research Laboratory, which is a research unit of the University of Alberta. The aim of the survey is to gather a wide range of information, which is then utilised by various organisations to gain some insight into a variety of public policy issues. The researchers used this already established instrument to determine the attitude of the general public towards preoperative assessment and the risks associated with general anaesthesia (5).

A total of 1 126 people participated in the study, of whom 80% had been exposed to an anaesthetic previously (other than dental anaesthesia). Perceived common fears were divided, based on severity of concern, into three categories: "very concerned", "somewhat concerned" and "not at all concerned". A major concern for participants was the risk of awareness intra-operatively (47.5% when the "very" and "somewhat concerned" groups were combined). Other prevalent concerns included the risk of brain damage, memory loss and intraoperative death, pain, and post-operative nausea and vomiting (5).

Sharma *et al* published a study conducted in India in 2007 and found that 30% of the 200 patients who participated in the study by means of a multiple choice questionnaire, were more afraid of the anaesthesia than of the surgery. The most commonly identified fear in

this study was that of waking up/awareness during surgery, with 34% of patients admitting that this was their worst fear. Only a small proportion of participants (12%), had concerns regarding the qualifications of their anaesthesiologist (9).

Of particular interest to this research project, because of its African context, is a Nigerian study that was published in 2007. The study issued questionnaires to a targeted sample of people who did not work in the medical field. In addition to collecting demographic information, participants were requested, in a manner similar to the Canadian study above, to select one of four choices relating to intensity of concern they felt for various perceived fears. Of the 61 participants, 80% had no previous exposure to any form of anaesthesia. Upon combining the two categories, "very" and "somewhat concerned", fear of death was recognised to be the biggest concern for participants (82%), followed by fear of pain (75.4%), brain damage, memory loss and intra-operative awareness. (10) The findings in this study, conducted in what is considered a developing country, show remarkable similarity to the previous study by Matthey *et al* (5), set in Canada, which is considered a developed country. Another interesting fact to consider is that whilst 80% of the Nigerian sample had had no previous exposure to anaesthesia, 80% of the Canadian sample had experienced an anaesthetic previously, which may suggest that the fears experienced by patients seem to be generalizable, and not grounded in past experiences (5, 10).

A cross sectional study published in 2010, aimed to discover the most anxiety-provoking aspects of general anaesthesia in 460 patients, and attempted to establish anxiety alleviating interventions. Factor analysis revealed patterns of association, namely; preoperative anaesthetic information, anaesthetic catastrophizing, final support, personal support, imminence of surgery, possible adverse events and final perioperative experience. Statistical analysis of the data revealed that there was a significant correlation between increased anxiety levels on the day of surgery and the following factors: preoperative anaesthetic information , anaesthetic catastrophizing and imminence of surgery (6).

Important issues found to influence the "preoperative anaesthetic experience", were the preoperative visit by the anaesthetist (including an explanation of events by the anaesthetist), being informed about the expected duration of the surgery, and the nurse explaining events to the patient (6).

Thoughts pertaining to death whilst under anaesthesia, not waking up, trusting strangers and a mask being placed over one's face, were all identified as important contributors to the factor, "anaesthetic catastrophizing". Again, the fears in this category are comparable to those found in the studies discussed above. 'Imminence of anaesthesia', was associated with the immediate preoperative period, and the preparation for theatre (6). Reassurance in this stage, and re-iteration of the information provided in the preoperative visit may prove to be beneficial to the patient in alleviating anxiety, but work still needs to be done to explore the receptiveness of patients in this stage just prior to administration of anaesthesia, and the surgery.

A Brazilian paper published in 2011, explored perceptions about anaesthesia and anaesthesiologists, and used multiple choice questionnaires to explore the subject in 518 patients. This study examined patients' perceptions of the anaesthesiologist and the anaesthetic itself, before and 24 hours after the surgical procedure, in order to determine whether these perceptions had changed. It was found that 29.3% of the patients interviewed expressed pre-operative concerns. However, as the question regarding concern was phrased as a multiple choice question, details regarding the nature of these concerns was not established. In the post-operative interview, 7.1% of patients expressed postoperative concerns, whilst 38.5% of patients did not express concern. Noticeably, the largest proportion of patients, 54.4%, did not answer this question. No explanation was provided for this in the paper. While it is significant that almost a third of patients expressed preoperative concerns, one is not able to establish the nature of these concerns, which limits the interpretation of this data (36).

A similar study conducted in Turkey in 2013, also looked at the perceptions of 250 patients attending an anaesthesia clinic. The bulk of the research, after collecting demographic information, explored patients' knowledge regarding the role of the anaesthesiologist in the perioperative period. However, of particular interest is a small focus of the study, which explored patients' fears regarding anaesthesia. Results showed that the majority of patients were concerned about "not waking up" from anaesthesia (31.2%), waking up during the anaesthetic (22.8%) and "not being completely asleep" (21.6%). Other concerns related to "saying unintended things", experiencing pain, and postoperative nausea and vomiting. Again, the data in this study was obtained via questionnaires, and as the questions were

presented in a multiple choice format, patients' responses were limited to the choices provided. Also, the nature of the questionnaire, did not allow the researchers to delve further into contributing factors for these concerns (7).

In 2012, Matthias *et al* explored preoperative anxiety in surgical patients in a government hospital in Sri Lanka. This study utilised the APAIS and VAS tools in questionnaires, to assess anxiety levels amongst their patients. The APAIS contained six questions – four concerning patients' anxiety around the surgery and anaesthesia, and two questions which determined their need for information. The questions were then scored on a 5-point Likert scale by participants. The VAS is a graphical assessment of the degree of anxiety experienced by a patient for various factors in the perioperative period. Patients were presented with a ten cm line, with one end labelled "no anxiety", and the other labelled "maximum anxiety", and asked to place a mark on the line that represent their own anxiety level. The researchers then analysed the questionnaires in three components: anaesthesia-related anxiety, surgery-related anxiety and information desire (35).

The study found that the prevalence of anxiety in the sample population was 76.7% when the APAIS score was ≥ 11. The authors suggest that this higher prevalence of anxiety in the Sri Lankan population, when compared to other international literature, could be related to the fact that it is considered a developing country, and government hospitals provide care to poorer members of society. The authors also note that "trust and respect for surgeons is inbuilt in the local culture", and therefore patients tend to avoid questioning doctors. As a result of this perceived social barrier, patients may not feel comfortable discussing their fears with doctors, and inadvertently conceal their fears and anxiety (35).

2.3 The perspective of a parent whose child undergoes anaesthesia

This study aimed to explore the experiences of adult caregivers, whose children underwent surgical procedures. From the review of available literature, it has been established that anaesthesia is a stressful experience for adult patients, and the literature clearly identifies commonly held fears and concerns. The experience of a parent, or caregiver, of a child undergoing a surgical procedure, is clearly not identical to that of an adult patient who is about to undergo surgery themselves. The dynamics of a parent-child relationship are complex, and beyond the scope of this study, however determining the prevalence of

anxiety in caregivers, and understanding their nature of their fears, will assist anaesthetists in providing appropriate education and counselling in the perioperative period.

Two similar studies, conducted in the preoperative period, in Hong Kong and Scotland, and published in 1996 and 1998 respectively. Both studies tried to identify sources of anxiety in a group of one hundred parents of children under the age of thirteen admitted as inpatients for elective surgery. Parents were issued a Leeds Self-Assessment of Depression and Anxiety questionnaire, a validated tool that identifies individuals with significantly elevated levels of anxiety (11, 12).

The Hong Kong study (12) found that 47% of parents experienced anxiety within an illness range, and there were higher anxiety levels in parents whose children underwent major surgery .

In the Scottish study (11), sources of significant anxiety identified included both the surgery and the anaesthesia, postoperative pain and the hospitalisation process itself. Similar to the Hong Kong study, it was found that 42% of parents had measured levels of anxiety that could be regarded as being in keeping with an illness state, and mothers were found to be more likely than fathers to have pathological anxiety levels.

A qualitative study done in Canada in 2006, explored parents experiences of their child's dental surgery, during which the children all received general anaesthesia. Whilst a large proportion of the study focussed on parent's knowledge and feelings of oral health and hygiene, one of the interview questions was, "what were you thinking and feeling when your child was asleep and being worked on by the dentist?" Most of the 11 parents who participated in the study described emotions such as "fear", "worry" and "concern", both when they first discovered the need for a general anaesthetic, and again whilst they were in the waiting room during the surgery (25).

A 2009 Italian paper by Scrimin *et al* (13), aimed to assess the levels of anxiety and symptoms of acute stress in 154 parents, 24 hours after their children had undergone a range of elective surgeries. Participants completed questionnaires containing various different tools to assess levels of parents' anxiety. The study showed that all parents manifest high levels of state anxiety, which is anxiety related to the perioperative

experience, with 46.8% of parents experiencing levels of anxiety which were 1-2 standard deviations above the normal level of anxiety in the adult Italian population. Parents showed higher levels of anxiety with major surgeries, compared to day surgery, and mothers appeared more anxious than fathers. Of the respondents, 27.9% reported symptoms found in at least one of the four acute stress disorder (ASD) categories, with 16% of parents meeting the DSM-IV criteria for ASD. The type of surgery was also significant, with more parents exhibiting clinically significant state anxiety for major surgeries.

All these studies show that anxiety is prevalent in parents whose children undergo surgical procedures. Understanding specific concerns that parents have, allows targeted pre-operative consultations by the anaesthesiologist, with the intention to allay these fears and concerns as far as possible.

A qualitative study done in 1990 by Ogilvie (15), attempted to explore those factors that parents perceived as sources of stress in the perioperative period. The author interviewed nine families whose children were admitted for elective surgery. Convenience sampling was used, with the only other criteria used being proficiency of the English language, and living within a 10-mile radius of the city. The author used a combination of in-depth interviews, and participant observation in the study. Participants were observed during stressful periods in the perioperative period (admission to the ward, late afternoon on the day prior to surgery, blood tests, premedication, exit from the ward for surgery, and return to the ward after surgery). Parents were then interviewed twice, first whilst the child was in theatre, and later, 5 to 20 days after discharge, at the child's home (15).

The parents interviewed had a range of responses when questioned about the most stressful aspects of their child's hospitalisation for surgery. Parents expressed concerns about their child experiencing pain, whilst others, mainly mothers, expressed concerns about the risks of the surgery. Parents identified hospital equipment as a source of anxiety, mentioning intravenous equipment most frequently. Another common emotion that parents reported experiencing was guilt – related to feelings of neglecting their other children, housework not being done etc. The parents also found waiting to be stressful. This also extended to periods before the peri-operative period, such as waiting to be booked for surgery. Some parents questioned whether they had made the right decision to allow their

child to undergo the surgery, and other emotions identified during the interviews included anger, fatigue, boredom and a feeling of anonymity and depersonalisation (15).

A qualitative study published in 2012 by Andersson *et al*, looked at parents' experiences of their child's first anaesthetic. In this Swedish study, interviews were conducted with six parents whose children had been anaesthetised for day surgery, and the interviews took place within three weeks of the surgery. Inclusion criteria for participation in the study were parents of children under the age of 18 years, who presented for their first day surgery, and proficiency in the Swedish language. All the children who participated in the study had received ear, nose and throat surgery (17).

Patterns that emerged upon analysis of the interviews showed that parents experienced a range of emotions in the perioperative period, ranging between relief (the period of illness/pain that the child experienced will soon be over because the operation is being done) and worry (about risks of the surgery and anaesthesia), and the reported a sense of powerlessness (17). In keeping with previous findings (11, 13, 14), parents in this study also reported worry and anxiety in the perioperative period. Parents felt that they needed sufficient information in order to help them cope with the process, and it is interesting to note here, that they wanted more information specifically regarding the anaesthetic process itself (17).

Litman *et al* (34) examined the relationship between parental anxiety and variables such as the age of the child, history of previous surgery for any children in the family, and parental gender and level of education. State-Trait Anxiety Inventory questionnaires were issued to six hundred parents of children aged between two months and sixteen years in the port-operative period. The results of this study shows that parental anxiety was increased when the child less than one year old, and when it was the child's first surgery.

In a Swiss study, a survey analysis was performed on 368 parents whose children underwent day surgery over an 18 month period at a tertiary hospital. A questionnaire, containing structured questions addressing a range of perioperative issues, was distributed to patients prior to discharge on the day of surgery. Of the participants, 13% and 3% admitted to experiencing stress associated with the surgery as moderate and severe respectively. Factors identified that had a significant association with parental stress included feelings of

insufficient preparation for day surgery, insecurity with nursing care at home and post-operative complications at home such as fever, vomiting, pain and problems sleeping and eating (26).

Day surgery, or ambulatory surgery as it is also known, has been found to have many advantages. Both the child and the family are happier, with less separation anxiety experienced by children. There is a reduction in the nosocomial infection rate, as the child is not exposed to micro-organisms found in the hospital for extended periods of time, and the system is very cost-effective for hospitals, as expensive hospital admissions are avoided. (37). However, despite the increase in popularity of day surgery, in recent times, and the numerous identified benefits, the majority of concerns experienced by parents in this study involved the postoperative care of the child back at home, and a feeling of being insufficiently prepared for this (13). Whilst day surgery clearly presents numerous advantages to the health care system, this is possibly an indication that not enough work is being done to educate and prepare parents for the post-operative care of their child, which contributes significantly to their anxiety in the perioperative period.

A study by Tonz *et al* found that parents who spoke a foreign language felt that they were significantly less prepared for surgery (21%, $p<0.0001$), than their counterparts who did not (6%) (26). Considering that South Africa is a very diverse country with 11 official language (27), it is a possibility that language barriers between the patients and anaesthetist exist, and may influence parental stress levels, due to a lack of communication and understanding.

A follow up study by the same authors, which was published in 2005, analysed the effects of interventions implemented following the initial study. These implementations included the development of an interactive CD-ROM, designed to prepare parents and children for surgery, and an information booklet, which were distributed to parents prior to admission for the surgery. The CD-ROM provided the family with information regarding the perioperative period in a playful manner, portraying the story of a child undergoing surgery, and was distributed from the third time period. The data collection followed a similar pattern to the previous study, and data was collected over three defined time periods (14).

Following the intervention, significantly fewer parents felt under prepared for the surgery (2% and 3% in the second and third data collection periods respectively), when compared to the original study (9%). Of all the participants, 16%, 9% and 19% experienced moderate to severe stress in the three time periods respectively. Once again, in two of the three periods, non-German speaking parents felt significantly less prepared than their German speaking counterparts ($p< 0.0001$ in both these periods). In the original study, a lack of information and subsequent feeling of insufficient preparation were identified as factors causing significant parental stress. However, even after the implementation of an instrument to better prepare parents for their child's surgery, the degree of stress experienced by parents did not significantly decrease. This finding raises the concern of whether the wrong information is being conveyed, or that the stress just may not be preventable (14).

2.4 Are these fears founded?

A commonly identified fear in the literature appears to be that of "waking up during the operation", or intraoperative awareness. Awareness is defined as the postoperative recall of events that occur during general anaesthesia. An American study looking at 19 575 patients who received general anaesthesia at seven different academic medical centres in the country, found the incidence of intraoperative awareness to be 0.13%, at a rate of 1 to 2 cases/1 000 patients (38). A Swedish study published in the Lancet in 2000 also explored the incidence of intraoperative awareness in 11 785 patients, and found the incidence to be 0.18% in cases which used neuromuscular blocking agents, and 0.10% in cases which did not (39). Similar findings were demonstrated in an Australian study, with an incidence of 0.11%, and intraoperative awareness was found to be one of the variables that had a strong correlation with patient dissatisfaction (40). The incidence of intraoperative awareness in the paediatric population, mirrors that of the adult population, as a 2005 Australian study proved. The authors found an incidence of intraoperative awareness of 0.8%, in a population of 864 children (41).

Another commonly identified fear in the literature is that of death, or "not waking up after surgery". A recent systematic review and meta-analysis published in 2012, investigated perioperative and anaesthetic-related mortality, and found that mortality solely related to anaesthesia has declined dramatically over the years, from an incidence of 357 per million patients before the 1970's, to 34 per million patients between 1990 and 2000. The rate of

decline has been greatest and most consistent in developed countries (42). A South African study conducted at Groote Schuur Hospital in Cape Town, showed an incidence of 0.19 deaths per 1 000 anaesthetics administered. Whilst this data was for a 30-year period, prior to 1987 (43), the findings still mirror international trends.

Whilst it is clear from the literature that these fears are experienced by a large number of patients, numerous publications have proved that the actual incidence of intraoperative awareness and mortality due to anaesthesia, is very low. It is not clear from the literature what has led to these fears in patients, but understanding contributing factors may assist the anaesthetist in addressing these concerns in the preoperative interview.

2.5 Does parental anxiety have any effect on the children?

Some studies reviewed in the literature have found a relationship between parental anxiety and anxiety in children. These are discussed further below.

A 2006 Australian publication examined risk factors for anxiety in 1250 paediatric patients at induction of anaesthesia (20). The modified Yale Preoperative Anxiety Scale (mYPAS) was used to assess the level of anxiety in the children at the time of induction. High levels of anxiety were identified in 50.2% of the sample, with high anxiety being defined as a mYPAS score > 30. The authors note that comparisons with other studies using the same tool may be limited due to variable use of the mYPAS, with respect to different scores being used to define “high anxiety”.

The study also found numerous risk factors that had a weak correlation with increased anxiety prior to anaesthesia, including younger patients, procedures lasting longer than 30 minutes in duration, and more than five previous hospital admissions. The findings of this study showed a link between anxious parents, and higher anxiety levels in the child, although this was not statistically significant (20). These finding are similar to those in the two studies discussed below (21, 22).

A Canadian study which was published in 2009, explored the notion that anxiety in the preoperative period in parents, predicted behavioural and emotional responses of children at induction of anaesthesia (21). The study looked at 134 patients, aged between 2 to 10

years with ASA classifications of I or II, and separated the children and their parents into two groups, one group where the parent was allowed to be present at induction (treatment), and the other group were the parent was not present (control) (21). Although parental presence at induction of anaesthesia has been extensively studied, the discussions surrounding this subject are beyond the scope of this study, and the subject will not be explored further here.

The children and their parents levels of anxiety was assessed both before, and one week after surgery. The children were assessed with the Hospital Fears Inventory (HFI), a tool that contained eight items thought to elicit fear in a normal population of children (e.g. visit to the doctor) with graded visual responses to represent level of fear, and the Behavioural Questionnaire, a list of 28 questions complied from observed changes in psychological symptoms (e.g. enuresis, night terrors etc.), which the parents assessed on a 5-point Likert scale. Parents were assessed by the Parents Questionnaire, a 16-question tool that assesses parental anxiety in relation to the child's hospitalisation, as well as assessing the parents past levels of general anxiety. Assessment of the parent's anxiety and their child's behaviour on arrival for surgery and at induction of anaesthesia was done with the Visual Analogue Scale, and the Global Mood Scale, respectively. The GMS is an observational tool, based on a 7-point scale, which is used to assess the patient's mood at induction, and was performed bay trained nurses in the operating room (21).

The results of this study show that children who were most upset at induction of anaesthesia, were those who were accompanied by the most anxious parents, and the level of parental anxiety pre-operatively was reflected in the children behaviours and fears one week after surgery. The authors recommend that highly anxious parents should be excluded from accompanying their child at induction of anaesthesia, and should be offered additional counselling and support (21).

A study by Kain et al (22) published in 2004, attempted to find a relationship between preoperative anxiety and postoperative emergence delirium and maladaptive behaviours in children. As the authors had conducted a series of prospective studies over the preceding six years on this subject, children from eight studies who met a list of criteria were identified

for this study (i.e. ASA I-II, general anaesthesia utilising oxygen/nitrous oxide and sevofluorane) (22). The study used the following tools to determine anxiety levels:

- State-Trait Anxiety Inventory
- EASI Scale of child temperament
- Modified Yale Preoperative Anxiety Scale

In addition to other findings, a positive relationship was established between parents with high anxiety levels in the preoperative period, and postoperative events such as emergence delirium and maladaptive behaviours in the children. Whilst a definitive association between these variables could not be established, it is clearly necessary to identify and address parental anxiety in the preoperative period, as the authors point out.

An earlier study by the same author (44) also concluded that situational anxiety in the mother was one of the variables that predicted pre-operative anxiety in the child. The authors concluded that although negative behavioural responses were noted to develop in some children, the majority of these changes were limited, and not long term.

A 2010 study by Al-Jundi *et al* (19) done in Jordan, looked to assess children's anxiety and distress during different stages of general anaesthesia for dental surgery, and to determine the effect of various variables, including parental anxiety, on the children's anxiety and behaviour. The study also assessed factors affecting parental distress, and the parents' attitudes towards accompanying their child to induction. The study recruited 118 Jordanian children between the ages of 2 to 12 years, undergoing day case dental surgery under general anaesthesia, with ASA I or II classifications. The Global Mood Score was used to assess anxiety in the children during three phases – phase 1, in which the parent and the child were waiting in the day care unit, phase 2, during which the parent and the child left the day care unit to their arrival in the induction room, and phase 3, the time of induction of anaesthesia. Immediately after the child woke up after surgery, parents were given a questionnaire, which used a three point Likert scale to assess the distress and attitude of the parent during the procedure (19).

In contrast to the study by Kain *et al* (22), no significant relationship was found between parental anxiety, and anxiety levels in the child. The only statistically significant factor that

affected parental distress in his study was when their child was less than five years old, and even that was only for the moment of separation.

2.6 Anxious children and negative postoperative outcomes

As discussed, Kain *et al* (22) conducted a study to establish a relationship between preoperative anxiety and postoperative emergence delirium and maladaptive behaviours in children.

It was found that the odds of a child having marked symptoms of emergence delirium increased by roughly 10%, with a 10 point increase in the child's state anxiety score (the anxiety related to an event, which in this case is the perioperative period). Also, there was a 12.5% increase in the odds that a child would have one or more new-onset maladaptive behavioural changes after surgery, with a 10 point increase in the state anxiety score. Characteristics found in children at high risk of experiencing emergence delirium or developing maladaptive behaviours post-operatively include younger, less social and more emotional and impulsive children. As discussed, these children's parents were significantly more anxious in the holding area, and on separation prior to surgery (22).

The authors note that while it is possible a relationship exists between anxiety and postoperative events, a cause-effect relationship between these variables cannot be established, due to the design nature of this study (22).

Another paper by Kain *et al* (23) in 2006, tested the hypothesis that children with higher anxiety levels pre-operatively, had a more complicated postoperative course. The study took place at a children's hospital in Connecticut over a five and a half year period. The authors identified flaws in previous studies that explored the effect of preoperative anxiety on post-operative outcomes in adult patients, including that the populations used in these studies were inhomogeneous with respect to surgical procedures and anaesthetic management. In order to obtain a homogenous sample, consecutive outpatient children between the ages of 5 and 12 years, with ASA I-II classifications, scheduled to undergo general anaesthesia for elective outpatient tonsillectomy and adenoidectomy were eligible for enrolment in this study. Two hundred and forty one children were enrolled in this study. Anaesthetic management on the day of surgery was also standardised for all participants.

Various exclusion criteria were identified in order to maintain a homogeneous sample with standardised care (23).

The study followed the children and their parents for a period of five days prior to surgery, and 14 days after surgery, with the primary outcome measure being the child's postoperative pain, which was determined through the use of pain-assessment tools (for both the parent and the child) and an objective parameter, analgesic consumption. Secondary outcomes include the child's postoperative behaviour, as assessed independently by nurses and parents (23).

Results showed an association between children with increased anxiety levels in the preoperative period, and negative postoperative outcomes. These postoperative problems include increased postoperative pain, analgesic consumption, general anxiety, and problems with eating and sleeping. Although it was noted that most of these outcomes did not last beyond three days, this are still significant findings (23).

Another paper by some of the same authors found that as many as 67% of children may develop negative behavioural changes in the postoperative period, including apathy and withdrawal, general anxiety and separation anxiety and aggression towards authorities. Whilst the authors note that these behaviours generally resolve over time, concerns exist that this may not be true for all children, and that the perioperative experience may have a long term negative impact on their future interactions with the healthcare system (24).

2.7 The relationship between the anaesthetist and the patient, and the function of the preoperative consultation

The preoperative visit by the anaesthetist is a critical event, and has many important functions. The Practice Advisory for Preanethesia Evaluation, developed by the American Society of Anesthesiologists (ASA), defines the preoperative visit by the anaesthetist as "*the process of clinical assessment that precedes the delivery of anesthesia care for surgery and for non-surgical procedures, and is the responsibility of the anaesthetist*" (45). The Association of Anaesthetists of Great Britain and Ireland published safety guidelines in 2010 outlining the role of the anaesthetist in the preoperative assessment and preparation of surgical patients (18). The preoperative assessment by the anaesthetist is designed to minimise risk for patients, identify patients at high risk for morbidity and mortality in the

perioperative period, reduce the number of cancellations on the day of surgery and the subsequent economic benefits thereof, and reduce complication rates and mortality. The safety guidelines note that the preoperative consultation is important to enhance trust and confidence in the patient, for the anaesthetist, and it is important that the anaesthetist takes the time to answer any questions about the perioperative period that the patient may have, and thus attempt to allay any fears. The preoperative visit is therefore a key component in improving the patient's experience of their hospital admission (18).

In order to address the anxiety that patients may be experiencing in the perioperative period, the anaesthetist must be aware of perceptions, fears and concerns that patients have, regarding anaesthesia. Understanding the nature of these fears will allow targeted education, counselling and reassurance during the preoperative visit.

2.8 Answering the South African questions

A review of the literature has shown that anxiety experienced by parents in the perioperative period is a significant problem, and appears to be multi-factorial in its origin. There is some evidence to show that anxiety experienced by parents, is detected by their children, and in turn leads to increased anxiety levels in the paediatric surgical patients prior to the induction of anaesthesia. This increased level of anxiety in the children, has in turn shown to contribute towards a range of negative postoperative outcomes.

Understanding the specific concerns that caregivers' experience, can assist anaesthetists in alleviating anxiety in the perioperative period by addressing these concerns in the preoperative consultation, thereby preventing the vicious cycle of events that ensue from an excessively anxious caregiver. The literature review failed to identify any studies that took place within a South African setting, and this study was conducted to address this knowledge gap.

2.9 Summary

This chapter reviewed the relevant literature available on this subject, and provided the context in which my study was conducted.

Chapter 3: Research methodology

This chapter discusses the design and methodology employed in this study. The review of the literature had identified various different study designs which had been employed to explore this subject in the past. Understanding the flaws and benefits within each of these studies, has allowed the development of a study design that is suited to answer the research question.

3.1 Problem statement

Much of the identified literature with regards to parents' concerns in the perioperative period is based in the developed world (11-14, 17, 25, 26), with no literature identified within an African setting.

The South African context is unique, with a diverse patient population. Patients vary in their levels of formal education, their cultural and religious backgrounds, their socio-economic circumstances, and their family and community dynamics (27). With such diverse backgrounds, the experiences of caregivers during anaesthesia for their children, may also be a diverse one. It is imperative the anaesthetists understand the nature of these fears, so that they can provide targeted education, counselling and reassurance in the preoperative visit.

The concerns of caregivers of paediatric patients presenting for surgical procedures at CHBAH were not known. Gaining insight into our patients concerns, and what they fear about anaesthesia, allows us to address these concerns in a constructive manner, and thus improve the quality of their experience.

3.2 Aim

The aim of this study was to describe the concerns of caregivers whose children were undergoing anaesthesia at CHBAH, and to explore the factors that contributed to these concerns.

3.3 Objectives

The objectives of this study were to:

- describe the concerns of caregivers related to their child's anaesthesia
- explore factors that contribute to these concerns.

3.4 Ethical considerations

Approval to conduct this study was obtained from the Postgraduate Committee (Appendix 1), and the Human Research Ethics Committee (Medical) (Appendix 2) of the University of the Witwatersrand. Permission was also obtained from the Medical Advisory Committee of CHBAH (Appendix 3), and the Head of the Department of Paediatric Surgery at CHBAH (Appendix 4). Nursing management in theatre was informed of the study.

Identified caregivers were invited to participate in the study, and the aim and methodology that was used was explained to them. In addition to a verbal explanation, potential participants were given an information letter (Appendix 5), with the researcher's contact details in the event that they had any further queries.

Upon agreeing to be involved in the study, participants were given an informed consent form (Appendix 6) to sign, acknowledging that they had understood that their participation in the study was voluntary, anonymous, not subject to remuneration, and would not affect their, or their child's, future treatment in the hospital in any way. An additional consent was obtained for audio-recording of the interview (Appendix 6).

All transcribed data collected was kept private, and will be stored securely for a minimum period of six years, after which it will be destroyed. The audio recorded data will be stored for a period of six years after completion of the study. Only I had access to identifying information of the participants, and confidentiality was maintained throughout the process of data handling and transcription. The data was reported anonymously.

Participants who appeared particularly anxious during the interview, were supported by myself. Their particular concerns were identified and addressed, in order to allay their fears. It was not necessary to refer any participant for professional emotional counselling.

The study was conducted in adherence to good clinical research practices as outlined in the South African Good Practice Guidelines (29), and the Declaration of Helsinki (30).

The format of the interviews was amended slightly after the first 15 interviews. After analysing and engaging with the data, it was felt that the quality of the data would be further enriched by the unobtrusive presence of the researcher at induction of anaesthesia, where the interactions of the caregivers with the children and staff was observed. Once the

caregiver was escorted out of theatre, after induction of anaesthesia, the researcher introduced themselves to the caregiver. Informed consent was obtained from the participants, after objectives of the study was explained them. Caregivers were informed that their participation in the study would not in any way affect the treatment and care which their child would receive.

3.5 Research methodology

3.5.1 Study design

This study utilised a qualitative, explorative research approach, in the form of in-depth interviews with caregivers.

A qualitative approach was selected for this study because this allowed detailed exploration into participants' concerns, and allowed insight into the factors which contributed to these concerns. As explained by Pope and Mays (46) in the British Medical Journal, "The goal of qualitative research is the development of concepts which helps us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all the participants" (46).

3.5.2 Study population

The study population comprised caregivers accompanying paediatric patients, who were classified as an ASA stage I or 2, for surgery at CHBAH.

3.5.3 Study sample

Sample size

An appropriate sample size for a qualitative study is one which adequately answers the research questions (47). Sampling in qualitative research is based on the richness of the data, and not the number of interviews performed (48). Interviews continue until data saturation has occurred, which is when the collection of new data does not provide any further information regarding the issue being investigated (49).

Interviews in this study were conducted until data saturation occurred, which resulted in a sample size of twenty participants. Data saturation was determined to have occurred when further interviews failed to reveal any new or different themes or ideas. Thematic analysis of data was carried out concurrently with the interviews, in order to determine when this had occurred. Regular meetings with and review of the data and data analysis together with

the supervisors was also used as a method to determine if this point was reasonable and acceptable.

Sampling method
A purposive sampling method was employed for this study.

Purposive sampling is the most commonly used method of sampling in applied research. It is a non-probability sampling technique that relies on the judgement of the researcher to select participants with particular characteristics of the populations to facilitate achieving an answer to the research question (50, 51).

Inclusion and Exclusion Criteria
The following inclusion criteria were used:

- Caregivers of children:
    - between the ages of 6 months – 13 years
    - who presented for surgery at CHBAH
    - classified as ASA 1 or 2
- Caregivers who could communicate in English

The exclusion criteria in this study were caregivers who were not adults (under 18 years of age), and those who refused consent.

Caregivers of children below the age of 6 months were excluded from this study as surgery below this age is usually indicated only for emergencies, and not elective procedures. The emergency nature of the procedure itself, as well as the associated complications may contribute to the anxiety experienced by caregivers, which may confound the findings in the interviews.

3.5.4 Data collection
Interviews were conducted at CHBAH, in a private room in the theatre complex, whilst the child was undergoing surgery. A Canadian study conducted by Ogilvie used a similar format, where parents were interviewed during their child's surgery (15). All but one of the participants in this study found it a useful distraction to conduct the interview during the surgery.

3.5.4.1 Selection of participants

Appropriate patients for the study were identified, based on the specified inclusion and exclusion criteria.

I approached caregivers of the identified patients and explained the study, offering them the opportunity to participate if they wished to do so. Informed consent was obtained from the participants, for both the interview, and for permission to audio record the interview.

3.5.4.2 Semi structured, in-depth interviews

In-depth, semi structured interviews were selected as the method of data collection, in order to gain some insight into participants' concerns, when compared to multiple choice questionnaires. Brief or vague responses were explored further by the use of probing questions, which allowed a deeper understanding of each participant's thoughts. Although numerous tools designed to assess anxiety in the perioperative period were identified in various studies in the literature review, there is no clear gold standard tool, and as such, comparison of findings in the different studies, is difficult. In addition, interview based qualitative studies that were reviewed in the literature (15, 17), yielded a great deal of insight into fears and concerns experienced by caregivers. Questionnaire based surveys may limit the responses from participants, whereas the in-depth interviews allowed participants to verbalise and explore their own concerns.

The semi-structured interview guide (Appendix 7) contained both open- and close-ended questions, and whilst I asked some specific questions, additional prompting questions were asked that encouraged elaboration around areas of interest (52).

Conduct of interviews

Interviews were conducted with caregivers who agreed to participate in the study, in a private room within the theatre complex, in order to minimise interruptions from other patients, and noise from the theatre activities.

The interviews consisted of a number of questions designed to gain some insight into participants' concerns regarding the child's anaesthetic, and possible reasons for this.

In spite of a large proportion of patients at CHBAH identifying Xhosa and Zulu as their first languages (53), I conducted the interviews in English, as I was not fluent in either of these languages. Whilst the use of an interpreter may seem to provide a solution to this problem,

studies have shown that untrained interpreters frequently commit errors that results in distortions of meanings (53, 54). Five common mistakes that interpreters make are omission, addition, condensation, substitution and role exchange, where the interpreter replaces the interviewers questions with their own (54). Other issues associated with the use of interpreters is that of maintaining patient confidentiality (55), and the cost to this study of hiring trained interpreters.

Having decided not to utilise an interpreter for this study, various strategies were implemented in an attempt to overcome potential language barriers. All of the participants who were enrolled in the study were informed that the interviews would be conducted in English, and they were asked if they felt comfortable communicating in this medium. In addition to this, if there was any doubt as to the participants understanding of questions, these were rephrased, with an effort made to use more simple terminology. Participants were encouraged to explain their responses repeatedly and in more detail, if any doubt arose as to the meaning of their statements. I was also relatively confident conversing in Afrikaans, and one particular participant, who listed Afrikaans as her home language, was encouraged to speak in Afrikaans when she seemed to struggle to express herself. She declined, however, and the interview continued in English.

I conducted interviews from April to June 2015, based on opportunities available to be relieved from clinical duties in the department. These opportunities were granted as full, or half day sessions.

All the caregivers of paediatric patients, who met the inclusion criteria of the study, and who were presenting for surgery on that particular day were invited to participate in the study.

Following the first five interviews, a period of reflection and analysis was conducted, which showed that the data collected thus far was quite superficial, and lacked depth. Responses to questions were brief, and were often single word answers which provided very little insight into participants' actual thought and concerns. This period of reflection and analysis allowed me an opportunity to identify problems with, and improve their interview technique. These early interviews followed a more rigid interview structure, with many questions that required specific answers, including many yes or no answers. I found it

difficult to engage the participants, and was unable to get them to elaborate on and discuss their responses further.

After discussion with my supervisors, the interview technique was amended to include more open ended questions, which allowed a more insightful discussion to take place. The participants' specific responses were allowed to direct the flow of the interview, and further lines of questioning.

Following another period of reflection and analysis after 15 interviews, it was decided to further amend the interview technique for the last five interviews. On consultation with my supervisors, it was decided that I would accompany the patients and their caregivers into theatre at induction. The caregivers were observed without alerting them to my presence, nor were they informed about the study. I noted their interactions with the child and the theatre staff, as well as their behaviours, facial expressions and body language, which provided objective clues regarding their levels of anxiety in this period. Following induction of anaesthesia, the care givers were escorted out of theatre, and at this point, I introduced myself to the caregivers, informed them about the study, and requested their consent to participate in the study.

This format was adopted because the data did not offer sufficient depth of insight to the experiences of the participants. Observing the caregivers during the induction of anaesthesia would allow the researcher to develop a rapport with the participant, and would also deepen the engagement during the interview.

This format was found to yield more rich data for a number of possible reasons. Firstly, I found it easier to establish a rapport with the participants, having experienced the induction with them. Secondly, I was able to refer to specific examples of behaviours/comments noted at induction, which allowed more extensive discussions with the participants than would be possible without that knowledge.

As Braun and Clarke (31) point out, "analysis is not a linear process of simply moving from one phase to the next. Instead, it is more a recursive process, where movement is back and forth as needed, throughout the phases." This thinking, guided the frequent reflections and analysis of data, resulting in adaptations to the interview format throughout the study.

The interviews lasted between and 10 and 30 minutes. Due to the nature of the study, the interviewees were allowed to continue until I was satisfied that the subject had been thoroughly explored with the participant, and no new information would be forthcoming.

Engaging the participant and preparation for the interview

An important role of the interviewer is to place participants at ease, so that they will feel comfortable volunteering their opinions and experiences (56). In order to facilitate co-operation, I was conscious of appearing unbiased, and of accepting all the participant's responses as natural. I was also conscious not to express surprise, disapproval, or even approval, at any of the participant's comments (56).

Whilst the patient was made aware that I was a doctor in the information letter, I did not emphasis this in the introduction, as a Sri Lankan study showed that in their community, trust and respect for doctors is inbuilt in the local culture, and therefore patients tend to avoid questioning doctors (35). As a result of this perceived social barrier, patients may not feel comfortable discussing their fears with doctors, and inadvertently conceal their fears and anxiety.

I prepared the participant for the interview by attempting to place them at ease, and establishing a rapport with them. This was done by sharing relevant and important information about the study with the participant, such as confidentiality and the potential benefits of the study for both patients and doctors.

Non-verbal communication is very important in engaging with the participant, and is vital to convey interest in the participants responses (56), thus encouraging them to continue. I was mindful of this, and adopted a posture that was open (i.e. did not fold arms, cross legs etc.), and used facial expressions and gestures such as nodding to encourage the participant and to facilitate the conversation.

Flow of the interview

The initial stages of the interview contained ice-breakers and small talk, in order to overcome nervousness in the initial stages and to help both the participant and myself settle into the interview.

The early stages also contained concrete questions, such as demographic information, which also gave the participant some time settle into the interview, before the questions designed to elicit "richer" information on the subject at hand were asked.

I strived for positive closure to interviews, and the last question was open ended in order to allow the participant to mention anything else they feel was relevant (56). Examples of such questions were, "Is there anything else you would like to tell me?", or "Do you think I've left anything out?"

When concluding the interview, I requested the participants permission to contact them, in the event that interpretations of the data needed to be verified (56). I provided an opportunity for the participant to ask any questions, relating to the study, or to particular concerns that may have arisen during the course of the interview. I also educated and reassured the participant about specific perioperative concerns that were raised during the interview.

3.5.4.3 Field notes

Field notes were kept by myself for each interview, and were recorded during and after each interview. These notes contained a narrative account of happenings in the interview, and contributed to the data that was analysed. The field notes included descriptions of the observed events and conversations, but also included a reflective element, which recorded my experiences, reflections and progress in the field (56).

The field notes were compiled immediately after the interviews, in order to avoid periods during the interview where the participant may have feel that they did not have my full attention. However, phrases or sentences were jotted down unobtrusively, which later served as a reminder of the impression, observation or event (56).

The field notes were reviewed at regular intervals along with the interviews, and this reflective process resulted in the modifications that were made to the interview techniques.

3.5.4.4 Audio recording

The interview was audio recorded, so that I could concentrate on the discussion, and not be distracted by trying to take notes. The recordings were transcribed, verbatim, at a later

stage. The interviews were recorded by an in-built voice recorder, on a Samsung S5 smartphone device.

3.5.5 Data management

Data collection and analysis occurred concurrently, in order to determine when data saturation had occurred.

I compiled field notes immediately after the interviews. Participant's names were not used for identification purposes, instead the interviews were numbered in the order in which they occurred.

The audio recordings of the interviews were transcribed verbatim by an external party, after which I confirmed the accuracy of the transcription by listening to the original audio recording, and comparing it to the transcription. The interviews were identified by numbers, allocated in chronological order.

The field notes were attached to the corresponding interview transcription, and these were analysed together. These will be kept for a period of six years, after which they will be destroyed.

3.5.6 Data analysis

This study utilised thematic analysis to analyse the data. Thematic analysis is a qualitative analytical method for "identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail, However, frequently it goes further than this, and interprets various aspects of the research topic." (31)

Analysis was done in accordance with the six phases of thematic analysis, as stipulated by Braun and Clarke (31), and as documented below:

Phase 1	Familiarising yourself with the data Transcribing data, reading and re-reading the data, noting down initial ideas
Phase 2	Generating initial codes Coding interesting features of the data in a systematic fashion across the entire data set, collecting data relevant to each code
Phase 3	Searching for themes

	Collating codes into potential themes, gathering data relevant to each potential theme
Phase 4	Reviewing themes Checking if the themes work in relation to the coded extract (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
Phase 5	Defining and naming themes Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
Phase 6	Producing the report This is the final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back the analysis to the research question and literature, producing a scholarly report of the analysis

This entire process was informed by Braun and Clarke's philosophy that the analysis of qualitative data is a recursive process (31), and this entailed various intertwined phases of analysis, with a lot of back-and-forth movement between the different interviews, in order to facilitate a clearer understanding of dominant themes, as they emerged.

Data analysis was facilitated by a computer based program, MAXQDA 11 ©. This software allowed multi-level grouping of the information transcribed from the interviews. Initial categories were created with common ideas, which were then grouped together to form broader themes. Trustworthiness was ensured by co-coding the data, which was done independently by a supervisor.

3.6 Trustworthiness

Guba (32) proposed four criteria that correspond to well recognised and accepted criteria in quantitative research, in order to ensure trustworthiness:

- Credibility (internal validity)
- Transferability (external validity/generalisability)
- Dependability (reliability)
- Confirmability (objectivity)

Building on these criteria, Shenton (57), suggested numerous provisions for each criterion which could be utilised by the qualitative researcher to ensure trustworthiness of the study. This study applied a number of Shenton's provisions to ensure trustworthiness, adapting them to suit the structure and needs of the study.

The few randomly selected interviews were also co-coded (analysed) by the supervisors, ensuring external validity and generalisability.

3.6.1 Credibility

To ensure the phenomena under investigation have been accurately reported, the following was ensured (57):

- The methodology used in this study, namely in-depth interviews, was similar to processes followed in prior qualitative studies on this subject.
- A wide range of participants were enrolled in the study, so that the views and experiences expressed could be verified against each other. This allowed the construction of an information-rich picture of the different fears and concerns of the population, based on the contributions from a range of people
- Caregivers were encouraged to be frank and honest from the onset to ensure credibility when contributing their data. Another method to ensure honesty include providing repeated opportunities for the participant to withdraw from the study at any stage, so that only participants who offered data freely were included in the study. My independence was also emphasised, with the patient being reassured that I would not be the doctor administering the anaesthetic.
- Another strategy to ensure honesty in the data was the use of iterative questioning, where I reverted to issues discussed previously in the interview, and elicited further information by rephrasing questions in order to confirm expressions as true reflections of participants' perceptions. Discrepancies in the data were identified in the final report, and possible explanations identified.

- Frequent debriefing sessions were held between my supervisors and myself, so that problems in the process could be identified, and alternative approaches sought. These meetings also helped me to recognise my own biases and preconceptions, and these were addressed.
- Examination of the work by colleagues, as these offered a fresh perspective, and assisted in refining/adapting methods, and identifying potential biases and limitations.
- Available literature on this subject had been extensively reviewed, and findings were compared to those of this study, to determine whether the findings were in keeping with published data.

3.6.2 Transferability

In qualitative research, validity relates to how well the results obtained can be applied to a wider population. It is very difficult to extrapolate qualitative finding to a larger population, as the information gathered is specific to a particular environment, or group of individuals. In order for readers to determine whether the findings of this study are transferable to their own particular populations, adequate background information was provided on the environment and population studied, as well as the phenomenon under investigation (57). Information provided included:

- information regarding CHBAH, with respect to its structure, location and workings
- any restrictions in the type of people who contributed data
- number of researchers involved in field work
- data collection methods employed
- number and length of data collection sessions
- time period over which the data was collected.

3.6.3 Dependability

Similar to reliability, this aims to show that if the study was repeated (with the same participants, methods and in the same context), similar results would be obtained (57).

Dependability issues will be addressed in this study by detailed descriptions of the processes employed, thereby allowing the research to be repeated in the future, even if not necessarily to gain the same results. These processes described will include:

- research design and implementation
- data collection
- retrospective evaluation of the project, assessing the effectiveness of the process, and suggesting possible improvements for future studies (57).

3.6.4 Confirmability

To ensure confirmability (related to the concept of objectivity in qualitative work), the following measures were taken to ensure that the findings were a representation of the data obtained, and did not reflect my own potential biases or preconceptions:

- shortfalls and limitations in the study were identified and discussed with respect to their possible contributions to outcomes
- detailed descriptions of the methodology were provided, allowing the processes to be scrutinised
- my own beliefs and perceptions, if any, were identified
- an 'audit trail' was provided , which allows the reader to follow the course of the research in a detailed and comprehensive manner (57).

3.7 Summary

This chapter has discussed the design and methodologies employed in this study. Theoretical concepts regarding thematic data analysis and trustworthiness in qualitative studies have been expanded upon, and adapted to suit the structure and needs of this study.

Chapter 4: Results and discussion

This chapter presents the findings of this study, and these will be compared with previous findings in the literature. In addition, I offer my own personal reflections as part of the research process.

Where relevant, references will be made to specific interviews, and these will be identified numerically (E.g. Interview 1). Words or short phrases used by the participants will be presented in italics in the body of the paragraphs, whilst longer sentences will be separated from the body of the paragraph.

4.1 Demographic information

The following table provides demographic information for the participants in the study, and provides a context for the individual interviews.

Table 4.1: Participant demographics

PATIENT (CHILD'S) DETAILS				PARTICIPANT DETAILS				
Interview	**Age**	**Gender**	**Procedure**	**Caregiver**	**Age**	**Occupation**	**HLOE**	**Language**
1	9	male	buried penis repair	mother	39	security guard	secondary	Xhosa
2	12	male	penis surgery	mother	38	shop assistant	secondary (not completed)	Zulu
3	13	male	sphincter injection	sister	25	security guard	secondary (not completed)	Tsonga
4	3	male	sphincter injection	father	34	engineer	tertiary	English
5	3	female	separation of fingers	mother	46	security guard	secondary	Venda
6	10	female	excision of lump on hand	aunty	25	nil	secondary	Tsonga
7	3	female	vaginaplasty	mother	32	nil	secondary	Tswana
8	13	male	banding	mother	33	shop assistant	post school	Seswati
9	14	male	repair of undescended testis	grandmother	73	cleaner	primary	Zulu
10	7	male	scar release	mother	40	cleaner	secondary (not completed)	Zulu
11	2	female	wrist surgery	aunt	60	secretary	secondary	English/Afrikaans
12	4	female	nephrectomy (congenital)	father	51	temp jobs	secondary (not completed)	Sotho
13	9	male	leg biopsy	mother	21	nil	post school	Zulu
14	6	female	hernia repair	mother	43	packer	secondary	Zulu
16	8	female	tonsillectomy	mother	31	nil	secondary	Xhosa
17	4	female	cochlear implant	mother	29	consultant	secondary	Afrikaans
18	4	male	hernia/undescended testis	father	39	electrician	secondary	
19	6	female	tonsillectomy	mother	40	printing	secondary (not completed)	Afrikaans
20	3	female	keloid excision	mother	30	nil	secondary (not completed)	Xhosa
21	3	female	tonsillectomy	mother	35	nil	secondary (not completed)	Afrikaans

***HLOE -Highest Level of education**

(Primary – Grade 0 to Grade 7, Secondary – Grade 8 to Grade 12, Tertiary – Formal tertiary education eg. university, technical college, etc. Post School – short courses)
Interview 15 was conducted, but a technical error occurred which resulted in an incomplete and inadequate voice recording. As such, it was not analysed, nor included further in the study.

4.2 Results and discussion

Table 4.2 Outline of themes and sub-themes

Theme	Sub-theme	Supporting data
Anaesthesia – A spectrum of life and death		"*induces a sleep*" "*they take their breath away*" "*half dead*"
An emotional roller-coaster ride		"*scared*", "*overwhelming*", "*Am I making the right choice?*"
Why are our caregivers anxious?	Fear of death	"*not waking up*"
	Fear of the unknown	"*I think it's just the fear factor that's in everybody…there is always a chance that something might happen*"
	Community Influences	*"they say they were lucky to come back, no-one comes back*"
	Personal experiences	her fear increased more and more with each surgery
	Perceived risks	"*It's not a 50/50*"
	Media	Grey's Anatomy
	Fear of the theatre environment	*"The scissors and knives"*
	Fear of potential complications	*"what if he bleeds inside?"*
	Fear of pain	"*will he have pain?"*
	Fear related to the admission process	"*I don't want to come back again and again"*
	Anxious children	"*Mom, are they going to kill me?*"
	Relevant topical issues in society	*"load shedding"*
	Overnight hospitalisation	*"She cried the whole night"*
Induction of anaesthesia		*"It might be the last time I see him"*
Adequacy of preoperative information		"*I don't need to know anything because I know that they make him to sleep and not feel pain*"
Coping mechanisms		"*I know she'll be in God's hands*"

Anaesthesia – A spectrum of life and death

The concept of anaesthesia was understood differently by the various participants in the study. A few of the participants had some understanding as to what the concept entailed, using terms like "*deep sleep*", "*put me under*" and "*induces a sleep*". Some of the participants also specifically mentioned the use of an injection or medication to put the children to sleep.

This range of responses seems to reflect the diversity within the participants, with respect to age, level of education and previous individual experiences with surgery and anaesthesia. It can be expected that those participants who had previous exposure to surgery and anaesthesia with either themselves or their children, would have some degree of understanding of the processes involved, whilst those without any prior experience, would be less likely to have an understanding of the concept of anaesthesia.

A number of participants (Interview 1, 2, 3, 6, 7) did not seem to understand the concept of anaesthesia as distinct from the surgery itself. However, on further prompting, it became evident that although most of the participants in this category did not recognise the term "anaesthesia", they had some understanding of the concept. One participant in the group (Interview 14), when asked how she thought her child was going to lie still and allow the surgeons to cut out the hernia, responded that the child would be given medication to make her sleep. Another participant (Interview 10), had been present at induction of anaesthesia at a previous surgery for her child, and was able to identify the mask and oxygen as the tools which made her child sleep, but responded in the negative when asked if she understood what anaesthesia was. This implies that although there may be a general lack of understanding of the role of anaesthesia and anaesthetists, some people may understand the concept of anaesthesia, even though they do not recognize the specific words, especially in English. These particular participants listed their home language as Zulu, Xhosa and Tsonga.

Another interesting interpretation that emerged on questioning, was that of being "killed" for the surgery. This was first raised by a participant who had presented years earlier for a surgical procedure for herself. Her understanding of this experience was that she had been

"*killed*" for the surgery, and then woken up again. She went on to say that she was not afraid at the time, because she was so sick and desperate to get better, that she did not even think about what was going to happen.

"I *saw that thing (mask), coming to my face, and then I was gone".'* (Interview 9)

Another participant (Interview 18) explained that he believed his son was "*half-dead*" during the surgery. His understanding was that if one was able to feel what is happening inside their body, then they were "*very alive*", whereas if one was unable to feel what was happening to their body, then they were "*half dead*". He went on to explain that a surgery could not be done with a person being alive, and once gas was administered to a patient, they became unconscious. This is when he would call the person "*half dead*". For this participant, anaesthesia seems to exist at one point on a continuum of life and death, and his understanding was that a person undergoing anaesthesia was no longer completely alive.

One of the participants had experienced a surgery herself, a caesarean section. She said, "*I just saw the light, and then, nothing"* (Interview 2). She believed that she had been put to sleep by looking into the theatre light. Another participant who had no previous personal experience of anaesthesia, mentioned that oxygen was given to her child so that he would fall asleep. Interestingly, this participant went onto say that she felt that this method was better than the one that existed previously, where patients were asked to count numbers until they fell asleep. She explained that this current method was preferred, as it was felt that patients might not wake up with the previous method of counting numbers (Interview 5).

Both of these participants understood that patients are put to sleep for their operations, but they did not understand the mechanism of the induction. Looking at the lights and counting numbers was their explanation for the process of induction of unconsciousness, which was what they had either personally experienced or been told. However, they were not aware of the intravenous injection of medication, which was what had actually induced the unconsciousness. This may imply a lack of counselling or pre-operative education by the anaesthetists conducting the anaesthesia.

One of the participants, did not appear to understand the term anaesthesia during initial questioning. I then explained that patients were either given a gas to breathe, or medicine in their drip, which made them fall into a very deep sleep. However, at a later stage in the interview, the participant explained that she was worried about the fact that patients are given medication to sleep deeply, and "*they take their breath away*" (Interview 6). She wanted to know what was given to patients to wake them up. This concept of "*taking the patient's breath away*", was not actually explained to the participant, so she obviously had some understanding as to the process, even though she denied any personal experience with surgery or anaesthesia.

An emotional roller-coaster ride

All of the participants in the study expressed anxiety in varying degrees, using words like "*afraid*", "*scared*", "*nervous*", "*overwhelming"*, and "*emotional*" to describe their feelings. These emotionally descriptive words are very similar to those used by participants enrolled in a Canadian study, which explored a parent's experience of their child's dental surgery. Most of the eleven parents who participated in that study described emotions such as fear, worry and concern (25).

Two participants in my study used the phrases "*feel bad"* and "*feel hurt*", in the context of feeling fearful and anxious. These participants were not fluent in English, and it is likely that they struggled to find the appropriate words to express their emotions.

These findings of a high prevalence of anxiety amongst caregivers whose children were presenting for surgery, reflect findings in similar, international studies (11-13). An interesting comparison is a Sri Lankan study, which found the prevalence of anxiety in their population to be 76.7%. The authors suggested that these high levels of anxiety may be related to the fact that Sri Lanka is considered a developing country, and government hospitals provide care to the poorer members of society. They also went on to explain that trust and respect for surgeons is inbuilt in the local culture, and as a result, patients tend to avoid questioning doctors. As a consequence of this perceived social barrier, patients may not feel comfortable discussing or sharing their fears with doctors (35). This would then prevent an opportunity for the doctors to address their concerns, and allay their fears through education and counselling.

An interesting comment was made by one of the participants in my study which may have hinted at this complex, and previously authoritarian aspect of the doctor-patient relationship.

> "*What makes me feel relaxed about doctors is that they give you hope… because they know what they are doing, and they make you believe that what they are doing is going to proceed like…it's going to be successful*". (Interview 13)

Whilst it is encouraging that she has so much trust and faith in the doctors looking after her brother, the statement, "*they know what they are doing"*, may imply that she does not feel that she is in a position to question any of the decisions made by the doctors regarding her brother's care, or even discuss any of her own concerns with them.

A parent whose son had presented for a cochlear implant described emotions ranging from fear to excitement. She explained that on the one hand, she was excited because her son was going to receive some hearing, and that was a big step for them both, whilst on the other, she was scared and anxious about the surgery (Interview 21).

Another mother (Interview 17) whose daughter was also having a cochlear implant, had also gone through an extensive work-up process and counselling to prepare for the implant. She had frequent appointments with speech therapists and psychologists, and even resigned from her job so that she could attend all the appointments with her daughter. This was clearly a high stake surgery for those involved, as the potential for her daughters hearing to be restored lay in the balance. She explained that she became so stressed about the procedure, that she actually started to experience anxiety attacks, for which she was placed on medication by her general practitioner. She described experiencing palpitations and anxiety that was so severe, she thought she may have a heart attack. Two similar studies conducted in Hong Kong and Scotland, both found that a significant number of parents enrolled in the studies had measured levels of anxiety that could be regarded as being in keeping with an illness state (11, 12). This particular participant clearly expressed levels of anxiety that were psychologically and physically debilitating, regarding her daughters impending surgery.

In the study by Ogilvie (15), it was noted that parents described feelings of guilt, and questioned whether they had made the right decision in allowing their child to have the surgery. Participants in my study were not asked specifically if they experienced any guilt or doubt about subjecting their child to surgery and anaesthesia. This mother, was the only participant who spontaneously volunteered that it had taken her a long time to decide to proceed with the surgery for her daughter.

> "*Am I making the right choice?"* (Interview 17)

The doctors had explained to her that headaches were a common side effect after a cochlear transplant, and she was worried about subjecting her daughter to these side effects. As discussed, she had undergone extensive education and counselling regarding the procedure. Many of the other surgical procedures that children underwent in this study can be considered to be small surgeries, including hernias, tonsils and biopsies. These care-givers are thus unlikely to have received the same degree of counselling and education regarding the procedure and side effects, and this may be why they did not raise the concern of whether they were making the right decision in the interviews.

Why are our caregivers anxious?

Various factors were identified which caused participants to be fearful and anxious for their child's surgery. The most commonly described fear amongst patients was that of death. This also appears to be the most commonly experienced fear or concern in the literature (4-8, 10). Interestingly, this was most often described by the participants as "*not waking up*" after the operation, or "*not coming back"*, another similarity to international literature. Other concerns raised include fears of the theatre environment, that the children may feel pain after the procedure, surgical and anaesthetic complications, and intra-operative awareness. Certain factors which were found to cause significant anxiety in patients and parents in other studies, such as the risk of brain damage and memory loss (5, 10) and post-operative nausea and vomiting (5, 7), were not identified by participants in this study.

- **"Will he wake up after the operation?" – Fear of death**

Almost every participant in the study referred to a fear of death, with the basis for this fear appearing to be multi-factorial. Underlying factors that contributed to this concern included

a fear of the unknown, the experiences of the community at large, personal experiences, perceived risk of surgery, media influences and a general fear of the theatre environment.

- **Fear of the unknown – The "*human*" factor**

A number of participants alluded to the fear of the unknown, as a reason for worrying about death. This was a common perception amongst participants who had had no prior exposure to surgery, for either themselves or their children. One of the participants mentioned that whenever anyone speaks of theatre, she becomes nervous. Her simple explanation for this was, "*we are human beings*', and fear of the unknown is a normal human emotion. Another participant (Interview 11), who had been exposed to multiple surgery's herself after a diagnosis of breast cancer, and who felt she was well informed as she had family members who worked in the health care field, explained it by saying, "*I think it's just the fear factor that's in everybody…there is always a chance that something might happen*". The mother who had brought her four year old daughter in for a cochlear implant, admitted that despite the extensive counselling that she had had regarding the procedure, she was still very anxious about the possibility of her daughter not waking up after the surgery.

> "*I think because I'm human, that stuff goes through my head*". (Interview 17)

A number of participants found it difficult to explain the basis of their fear of death. This may be attributed to language barriers, or that the participants genuinely could not express the root of their emotions, coming back to the fact that fear of the unknown is experienced as a normal human emotion.

- **Community influences – "They were lucky to come back, no-one comes back"**

Many of the participants explained that a general perception existed in their community that if you go to the hospital for an operation, you may not come back alive. This was quite a common theme, and appeared in the majority of the interviews.

> "*Some of the neighbours say that she/he went to theatre and they didn't come back"* (Interview 14).

One of the participants (interview 16) had heard of a case of a child who went in for teeth extraction, and did not survive the procedure.

In order to establish whether these stories were true personal experiences or here-say, some of the participants where asked if any of the people who had been saying this in the community had ever actually had surgery themselves. One participants replied, "*They have, but they say they were lucky to come back, no-one comes back*" (Interview 1). Further, this same participant's mother had also had a surgical procedure, and after the procedure, had told her, "*there is a lot of lights and everything, then they kill you…if you come back you are lucky*". She went on to say that her uncle was also supposed to have surgery to his arm, but he ran away from the hospital and went back home, because he thought he would die if he went to theatre. To this day he still has a deformed arm. These incidents may well have contributed to the anxiety levels experienced by this participant, who has clearly been exposed to a number of perceived negative experiences regarding surgery and anaesthesia.

- **Personal experiences**

An individual's own past experiences may also contribute to the fear and anxiety surrounding the current procedure, but this seems variable, and may also be dependent on other factors. One mother who had brought her child in three times previously for surgery to the hands and feet, explained that her fear increased more and more with each surgery, although she couldn't explain why (Interview 5). On the other hand, another mother who had brought her son in for the second time, found that she felt less anxious than the first time, because they were now more familiar with the process (Interview 8).

- **Perceived risk of surgery – "*It's not a 50:50*"**

The degree of concern experienced by the caregivers is also related to the perceived risk of the surgery. One of the participants (Interview 1) mentioned that in the community, surgery to the upper body was considered high risk, and "*they think you are not going to make it*". A father accompanying his son for an injection to improve sphincter tone, admitted that he wasn't too worried, because his son's procedure was not very invasive (Interview 4). Another mother, whose daughter was having her tonsils removed, phrased this in an interesting manner: "*It's not a 50/50*" (Interview 19). When prompted, she went on to say that this was not a case where there was a fifty percent chance of life, and a fifty percent chance of death. The doctors had explained to them that this was not a major procedure with major complications, and this contributed significantly in alleviating her stress. This

reflects the findings from a study conducted in Hong Kong, that parents experienced higher anxiety levels if their children underwent major surgery (12).

Another parent explained that the young age of her child (three years old), contributed to her fear and anxiety (Interview 21).

- **Media – "Grey's Anatomy"**

Media, in the form of newspapers, television, movies etc. also seems to play a role in the participants' perceptions of surgery and anaesthesia. One of the participants had seen a baby go to theatre on a television program, who never came back. She admitted that this had contributed to her fear (Interview 2). Interestingly, another participant who admitted to watching a lot of television and specifically, Grey's Anatomy (a medical drama series currently popular in South Africa), felt that this media influence had actually helped to calm him down, because the show had prepared him for theatre in some way. He explained there were "*no surprises"*, and he had an idea what to expect (Interview 4). Another participant had got the impression from the media that sometimes doctors could be careless, especially with caesarean sections. She explained that sometimes doctors loose tools inside the patient's womb, although she denied that this contributed to her own anxiety (Interview 8).

- **The light, scissors and knives – Fear of the theatre environment**

Another factor that participants attributed their anxiety to, was a general fear of the theatre environment. Three of the participants mentioned that they found all the machines inside the theatre very intimidating. Interestingly, one of the participants who found the theatre equipment frightening, had actually accompanied her child to theatre three or four times previously. Thus, despite being relatively familiar with the theatre environment, she still found it frightening. When prompted as to what frightened her about theatre, another participant explained that she was afraid of the scissors and knives in the theatre (Interview 2). The study by Ogilvie also found that parents identified hospital equipment as a source of anxiety, although in that study, it was intravenous equipment that was mentioned most frequently in that study (15).

- **"What if he bleeds inside?" – Fear of potential complications**

The potential for both surgical and anaesthetic complications was also found to contribute to participant's fear and anxiety levels.

One participant who had brought her son in for a previous procedure, admitted that she had been much more worried for the first procedure, which was a liver biopsy. "*They will cut a piece, and what if he bleeds inside?"* (Interview 8). She went on to say that she had a friend whose daughter's surgery was complicated by a bleed, and a subsequent surgery was required to drain the blood from her stomach. She admitted on further questioning that this past experience with her friend had contributed to her fear and anxiety for her own son's operation.

Another participant had experienced an anaesthetic complication with her own mother. She explained that her mother presented for an eye operation, and too much medication was given to her to relax, and her throat closed up. Although her mother was fine after this complication, she admitted that it was at the back of her mind, and contributing to her own anxiety (Interview 11).

The potential for complications, like the possible overdose described above, seemed be to a significant anxiety provoking factor. One of the participants (Interview 14) reported that she had a neighbour who had had instruments left behind in his abdomen after surgery. A number of other participants in the study (Interviews 18, 21) also admitted to hearing stories in the community of situations where doctors had made mistakes, and left scissors or needles inside patients. One participant felt particularly strongly that this contributed greatly to his anxiety when bringing his own child to theatre (interview 18).

Only one participant mentioned specifically that she was worried about surgical damage – "*damaged vein"* (Interview 21), by which she likely meant bleeding. However, this may have been considered by other participants and mentioned in the broad category of surgical concern.

There is evidence that surgical risk was also a common trigger for anxiety (4, 11, 15). A study conducted in India found that 30% of the patients recruited for that study were more afraid of the anaesthesia, than the surgery (9). However, as discussed previously, some of the

participants in my study were not all able to distinguish between anaesthesia and surgery, and their anxiety was more a reflection of the entire peri-operative process.

The mother whose daughter had the cochlear implant admitted that the anaesthetic her daughter was to receive was a significant source of concern for her. She elaborated that her daughter had had multiple scans (CT, MRI etc.), for which she had received general anaesthetics. She was worried that the number of anaesthetics that her daughter had experienced may lead to complications.

> "*I'm not sure whether the anaesthetic is…you know, too much of a good thing can be a bad thing*". (Interview 17)

In addition, this particular participant's mother had previously had knee surgery, and the anaesthetist apparently struggled to wake her up after the operation. She admitted herself that her mother's experience may well be a contributing factor to her own stress. The idea of an overdose of drugs that will result in one sleeping forever and not waking up, was also raised by another participant (Interview 21).

- **Is my child going to feel pain?**

Another common concern experienced by the participants was that their children may experience pain. This was also a common finding in the literature (4, 5, 7, 8, 10, 11, 15).

Almost all of the participants who raised this concern were worried about pain in the post-operative period. Even when asked specifically if they had any concern about the children experiencing pain intra-operatively, they denied this, saying that the child would not be able to experience pain during the surgery as he/she was under an anaesthetic. It seems that these participants do not consider the possibility of intra-operative awareness, and have implicit trust in the ability of the anaesthetic to render them completely unconscious. One participant actually became quite anxious and agitated during the interview when asked if she was worried about her child being awake during the operation. She responded by exclaiming, "*Iyhoo*, do you think he is going to wake up*?" (Interview 14).

(*Iyhoo is an exclamation to denote shock or surprise, in Xhosa)

She was then quickly reassured that this was a highly unlikely scenario and that the doctors had means of establishing depth of anaesthesia. She responded after that explanation that this was honestly not something she had considered.

Only one participant spontaneously expressed her concern that her child would wake up during the operation, and experience intra-operative pain (Interview 16). Another participant admitted after some prompting, that she was worried about her child waking up early and feeling aware. She went on to say that she was aware that the dosage of medicines administered to children was calculated based on their weight, and she was worried that if too little medication was given to the child, this would result in earlier emergence (Interview 17).

This relatively low incidence of anxiety regarding peri-operative awareness, is in contrast to findings in other studies. International studies have found that intra-operative awareness was a common and significant concern amongst both surgical patients, and parents of children presenting for surgery (5, 7-10). Interestingly, both a Sri Lankan (35) and a Nigerian (10) study found intra-operative awareness to be a significant concern amongst patients, with intra-operative awareness being the most common fear identified amongst patients in the former study . Both of these countries, like South Africa, are considered developing countries, with at least comparable socio-economic conditions. It is therefore surprising that only two patients in this study admitted to concerns regarding intra-operative awareness. This may be due to a difference in general medical knowledge and awareness between the respective populations, which in turn may be influenced by education, community exposure and access to information.

Personal experiences again seemed to affect the degree of concern the participants had regarding their children experiencing post-operative pain. One lady (Interview 2) had a caesarean section previously and complained that she still experienced pain from the procedure, although she was unable to distinguish whether it originated from the surgery, or the anaesthetic (spinal anaesthesia). A quantitative study done in New York in 1991 found that neither past anaesthetic experiences nor the type of anaesthetic received previously was related to patients concerns (8). Not many of the participants in my study

had been exposed to anaesthesia previously, so it is not possible to draw any conclusions in this regard.

- **"I don't want to come back again and again" – Anxiety related to the admission process**

The interaction with the surgical team and the process up to the point of surgery also triggered anxiety in the caregivers at the various stages of the process.

One parent explained that his child had been cancelled for surgery (hernia repair) four times previously, and he found this process to be very stressful. He explained that he was very worried when he saw the hernia growing, especially when it became painful for his son. His son also had an undescended testicle, which was to be repaired during the same procedure. The doctors had warned him of potential complications of undescended testicles, including testicular cancer and infertility. Being aware of these possible complications, he became extremely anxious each time the surgery was cancelled (Interview 18).

Another parent used the word "*suspicious*" to describe her feelings. She explained that the surgeons had told her that they were going to use a laser to remove her daughter's tonsils. However, when she arrived for the surgery and found that her daughter would be asleep for the procedure, she said, "*now that they are putting her to sleep, I'm thinking maybe they are going to use scissors, something like that"* (Interview 16). She had understood the use of a laser as a less invasive procedure, which would not require an anaesthetic. However, the need for a general anaesthetic now implied that it was a much more invasive procedure, in her understanding. This misunderstanding may stem from inadequate counselling by the surgical team, including the failure to explain the need for a general anaesthetic with either of the methods. When asked if she felt like she would have benefited from more information pre-operatively, she responded that she would have liked more detailed information. "*I guess the part, where like, how they're removing the tonsils, they must be specific about it*".

The success of the surgical procedure was also an important factor causing anxiety for the caregivers. "*I don't want to come back again and again, the child is growing up*" (Interview 2), said a mother whose child was having surgery for a buried penis. One participant (Interview 3), the sister of a 13 year old boy who was presenting for repeat injections to

improve sphincter tone, admitted she was very worried about whether the surgery would work. Their mother had passed away and she was now looking after her brother, and this was now the ninth or tenth procedure since his birth. The doctors had counselled her that this procedure was not guaranteed to work, so she was very anxious about this. Another participant (Interview 10) admitted that she had felt "*bad*" from when her son was booked for surgery the previous day. He was booked for a scar release, and this was his fourth operation, so she was hoping it would be his last one.

Following on from the success of the procedure, patients are also anxious about long term complications related to the procedure. A father who accompanied his child for a nephrectomy due to a congenital pathology, was worried about how his daughter was going to cope without a kidney. He wondered whether she would have a normal life, or if there were going to be some changes. He went on to say that he would be okay if there were no changes (complications). He later admitted that he was worried about whether his daughter would be able to have children after her kidney had been removed (Interview 12). This likely implies inadequate surgical counselling, and the father may also have felt too intimidated to pose this question to the surgical team.

Participants also had practical concerns regarding the care of their children after the surgery, which seemed to cause some concern. A participant whose son was having a hernia repaired, was asked whether she wanted any further information from the doctors before the procedure. Surprisingly, her only concern was the type of trousers her son could wear after the operation (Interview 14). Whilst this may seem like a minor and relatively insignificant concern, this was obviously something that had been bothering this mother. She mentioned that her son loved to play, and she was worried about him feeling pain after the operation. These concerns may possibly indicate that she was anxious about caring for her son at home post-operatively. A hernia repair is considered a relatively minor procedure, and children are often discharged on the same day, into the care of their caregivers. A Swiss study looking at parents whose children underwent day case surgery found that factors that precipitated stress included a feeling of insufficient preparedness, and worry about post-operative complications like fever, problems with feeding and pain (25). Whilst this study did not examine the 'preparedness' of parents to look after their children at home following day surgery, the experiences from my study may suggest a

deficiency in this regard, which may be contributing to anxiety experienced by these caregivers. Adequate education and counselling is required to prepare these caregivers for this task, and further work needs to be done in this regard in order to establish the best method of achieving this in our patient population.

- **"Mom, are they going to kill me?"**

Anxiety amongst caregivers also seems to be affected by the degree of anxiety and fear experienced by their children. One participant's nine year old son had asked her, "*Mom, are they going to kill me?*" (Interview 1). She then explained to him that the doctors would not kill him, but would do the surgery for him and he would come back safely after the operation. This settled her son and he was no longer stressed, which she claimed also reduced her own stress levels.

- **Relevant topical issues in society**

It seems that relevant topical issues at a particular time, also have an impact on anxiety experienced by caregivers. One example of this, is the national electricity crisis that South Africa is currently experiencing, with the national electricity provider being unable to provide adequate electricity to meet the requirements of the country. This has led to wide spread, sweeping blackouts, resulting in long periods without access to electricity. Two different participants spontaneously discussed the issue of electrical power failures, without any prompting. They were both concerned about the plan in the theatre, in the event of a power failure. One mother had observed that most of the equipment in theatre was run on electricity. Whilst the participants were re-assured that the hospital had back-up generators which would function in the event of a power failure, this had been a significant concern for them both, showing that different topical issues also play a role in anxiety experienced by caregivers.

- **"She cried the whole night" - Overnight hospitalisation**

Another factor provoking anxiety in caregivers, was having to leave their children alone in the hospital overnight. Hospitalisation was found to be a trigger for anxiety in two international studies (8, 11), although the specific issues regarding this were not discussed in further detail.

Many of the participants in my study mentioned that this was the first time they had ever spent a night away from their children. They found it very stressful to leave the child alone in the hospital ward overnight, under the care of people they did not know. A mother who accompanied her eight year old daughter for a tonsillectomy, described the thought of leaving her daughter alone in hospital as "*unbearable*" (Interview 16). She had to leave her daughter alone in the hospital on the night before the surgery, and was very upset as her daughter was crying a lot. She admitted that she hardly slept at all that night, and came into the hospital very early that morning to see her daughter. She went on to say that she would have been less anxious, if she had been able to spend the night with her daughter. The mother of a child receiving a cochlear implant also noted that one of the major stresses she experienced was the thought of leaving her child alone in the hospital. Her daughter had been admitted previously for radiological studies which required overnight admission in hospital, and she explains how she found her daughter in bed one morning, wet and crying. She was very worried that her daughter would start to perceive the hospital as a "*bad place*", and the cochlear implant procedure as a "*bad thing being done to her*" (Interview 17). A further complication in this particular scenario was that the child was hearing impaired, and could only communicate in sign language. This caused further anxiety, as her daughter would not be able to communicate with anyone in the ward. This particular parent eventually managed to spend the night before the cochlear implant with her daughter in the ward, after making a special arrangement with the nursing staff.

A father who had found it quite stressful to leave his son alone in the hospital overnight, was relieved that he was able to accompany his son into theatre at induction, as he felt his son would have been very upset if he had to leave him alone again (Interview 4).

This issue, which contributes to peri-operative anxiety, is one that could be relatively easily addressed by simply placing a chair at the child's bedside in the ward, in order to allow one person to stay overnight in the ward with the child. CHBAH is a very large hospital, and manages a huge number of patients within a very resource-constrained environment. This results in crowded wards, with very little free space. However, considering the significant positive effects that accommodating these caregivers overnight before surgery may result in, it is definitely an avenue worth looking into.

Presence at induction of anaesthesia

The presence at induction seemed to have a favourable response amongst most of the participants. A father accompanying his son for an inguinal hernia repair (Interview 4) felt that being present at induction helped him to put his mind at ease about the impending surgery. One of the mothers who explained the negative attitude towards surgery and anaesthesia in the community because of a fear of death, said she would now be able to explain to other people what happened in the theatre, so that people might not get so nervous (Interview 5). Another participant also felt that being present at induction was a beneficial experience, although she admitted that she only became scared after going into the theatre. When prompted further, she responded that she became scared when her daughter started crying after the mask was put on her face, and after a little while, her daughter became "*lame*" (limp) (Interview 7). This was re-iterated by a mother who admitted she started feeling more anxious when her daughter starting fighting as the mask was put on her face. She said that she felt as if something was going wrong, and was only re-assured when the anaesthetist explained to her that this was a normal reaction (Interview 16). Another perspective was introduced by a mother who felt that it was important for her to be present at induction of anaesthesia, as it might be the last time she saw her son (Interview 10).

Adequacy of pre-operative information

Pre-operative information was found to influence the peri-operative anaesthetic experience, and alleviate anxiety in a study by Mitchell (6). A Swedish study in 2006, found that parents felt that they needed sufficient information in order to help them cope with the process. Interestingly, the participants wanted more information specifically regarding the anaesthetic process itself (17).

The authors of a Sri Lankan study noted that "trust and respect for surgeons is inbuilt in the local culture", and therefore patients tend to avoid questioning doctors. As a result of this perceived social barrier, patients may not feel comfortable discussing their fears with doctors, and inadvertently conceal their fears and anxiety (35). This may well be a relevant issue in the South African community, with patients possibly concealing their fears because of cultural restrictions which prevent them from questioning, or discussing perioperative

concerns with doctors. The authors also note that there are limited support structures available in Sri Lanka for patients to discuss fears and concerns.

Most of the participants enrolled in my study felt that they had been provided with adequate information in the preoperative visit, and there was no further information or counselling required that could help them prepare for theatre, or that would relieve their anxiety. One mother did not seem to have received detailed information from the doctor, and was only given instructions regarding feeding times prior to surgery. Interestingly however, she did not feel like she required any further information. "*I don't need to know anything because I know that they make him to sleep and not feel pain*" (Interview 10). Another participant explained that she felt relaxed after seeing the doctors and she felt that they made her believe that the operation would be successful. She did however go on to say that the doctors ignored her question regarding when the patient was going to wake up. Her explanation for this was, "*maybe they think you'll be stressed or you'll end up crying*" (Interview 3). When asked how she felt about this, she replied that it was better that way!

Another participant explained how the doctors told her they were going to "*make her baby sleep*" (Interview 21), and she assumed this would be done with drugs such as Valium or something to drink. However, her child was induced with oxygen and volatile agents, and she felt like she would have preferred to have been told this in advance. Interestingly, this mother had brought her child in for a cochlear implant, and had done an exhaustive amount of research on her own regarding the condition and management options, so even when she was counselled for the surgery, she already had an idea of what to expect. This supports the idea that the education and counselling done by the anaesthetist in the pre-operative visit should be tailored to meet the requirements and expectations of the care givers. Some people want detailed information and risks, whilst others seem to have implicit trust in the anaesthetist, and require very little additional information.

Coping mechanisms

Developing coping skills and support structures seems to be a key element in combating the anxiety experienced by the caregivers interviewed.

One of the participant's believed that she was able to cope with the stress of the process, by maintain a positive outlook, and taking each day as it came. She gave an analogy of a coin,

where like in life, there are two sides. She explained that there was always a positive and negative side to everything, and she chooses to look at the positive side, and how it will benefit her.

This participant, along with others, also attributed her ability to cope with the stress to support that she had received from her family, community and church. A number of the participants in the study relied on religion and faith to provide them with support during these stressful times.

> "*I know she'll be in God's hands*". (Interview 19)
>
> "*Whatever the outcome is, that's God's will*". (Interview 21)
>
> "*Oh God, please help my son*". (Interview 2)
>
> "*I just put my trust in God*". (Interview 8)
>
> "I'm praying God helps me". (Interview 5)

One of the participant's explained that she depended on her family for support, whilst another had family members who worked in the health care sector, and she felt this provided invaluable support.

4.3 Personal reflections

This entire process was an incredibly eye-opening experience for me, both as a researcher, and as an anaesthetist.

Anaesthesia is often viewed as a clinical speciality that is firmly grounded in science, and anaesthetists are expected to have an extensive knowledge of principles of physiology, pharmacology, physics, biochemistry, and numerous other basic sciences. This science, allows us to manipulate various aspects of a patient's consciousness and homeostasis, in order to allow the otherwise unimaginably invasive process of surgery, and the consequences thereof. Indeed, this science is what drew me to the speciality in the first place.

However, I think that as an anaesthetist, I sometimes forget about the individual person who exists beyond the tag of patient.

When I started this journey I was confident that I was offering the best care possible to my patients, from the first time I met them in the pre-operative visit, right through to when I recovered them after the surgery. I realise now that this may have been an incorrect, and maybe even somewhat arrogant, assumption. Whilst I do everything possible to prepare for their procedure, and equip myself with the skills and knowledge to deliver the best possible medical service, I appreciate now that I have been neglecting the very important emotional aspect behind these surgeries.

I was intrigued to find that many participants in the study still believed in the various myths and misconceptions about anaesthesia. I was also very surprised to find that most of the participants in the study experienced significant levels of anxiety, surrounding their child's surgery. I had assumed that our pre-operative visits provided sufficient education, information and support for our patients, but clearly, this does not always appear to be the case.

Sitting with the caregivers outside the theatre, whilst the surgery was underway, also gave me a very different perspective on the operative period. I usually forget about the caregivers as soon as they leave the theatre after induction, and this process gave me some insight into the stress and anxiety they experience whilst waiting for the surgery to be done.

I think ultimately, the most valuable lesson I have learnt during this process, is that of having empathy for our patients. Through the interviews and time spent with the participants, I have experienced the other side of paediatric anaesthesia, and this has provided me with invaluable insight, and the determination to use this to be a better, more holistic doctor.

Another area of personal growth for me, was my experience with qualitative research. This was a very foreign concept to me initially, coming from a very scientific background.

Having reviewed the available literature on this topic, I expected to find similar concerns experienced by our population at CHBAH. This, on reflection, is quite evident by the way I conducted the initial interviews. I asked very direct, close-ended questions, which might subconsciously have been done to reproduce these findings. I became anxious when the interview started moving in a different direction to what I had expected, or when

participant's had unexpected responses. I was essentially conducting a qualitative study, in a quantitative manner.

However, through a process of constant reflection and analysis, aided greatly by my supervisors, I was able to work through these issues and adapt my interview style accordingly. I learned to accept differing or unexpected viewpoints, and to recognise that these individuals' personal experiences was what was important, and not any pre-conceived notion that I may have had.

From my experiences during the course of this study, I have come to appreciate the need for more qualitative research in medicine, especially with regards to exploring our patients' perceptions and experiences of different situations. This information will allow us, as clinicians, to provide a more well-rounded and holistic quality of care for all our patients.

Chapter 5: Summary, limitations, recommendations and conclusion of the study

This chapter presents a summary of the study, and discusses both limitations of, and recommendations arising from the findings. A conclusion is also presented in this chapter.

5.1 Summary

5.1.1 Aim

The aim of this study was to describe the concerns of caregivers whose children were undergoing anaesthesia at CHBAH, and to explore the factors that contributed to these concerns.

5.1.2 Objectives

The objectives of this study were to:

- describe concerns of caregivers related to their child's anaesthesia
- explore factors that contribute to these concerns.

5.1.3 Methodology

This was a qualitative, explorative study, which utilised in-depth interviews with respondents to collect information. The study was conducted at CHBAH, and the sample population comprised caregivers of paediatric patients presenting for surgery. Twenty semi-structured interviews were conducted, after which audio recordings were transcribed verbatim. Thematic analysis of the data was conducted using the software program, MAXQDA 11©.

5.1.4 Results

The results of this study showed that caregivers of paediatric patients who presented for surgery at CHBAH, experience anxiety during the peri-operative process.

A number of the concerns identified which contribute to this anxiety, are similar to those discovered by similar studies conducted internationally. These include a fear of death, pain and anaesthetic and surgical complications. However, certain findings emerged which may prove to be unique to our population.

The fear of death appears to be a significant concern amongst the participants interviewed in the study. The basis of this fear is multifactorial, and is influenced by various factors

including an individual's own personal past experiences, stories relayed in the community about peoples experiences and perceptions of surgery and anaesthesia, the portrayal of the health care system and its flaws in the media, and the perceived risk of the surgery. Participants also admit that there is an element of fear and anxiety, which I shall refer to as the "human element", which they described as the normal emotions that one experiences when dealing with these situations.

Other concerns experienced by caregivers include that of the child feeling pain after the surgery, fear of the theatre environment, and the potential for surgical and anaesthetic complications.

Intra-operative awareness, post-operative nausea and vomiting, memory loss and brain damage were identified as concerns in the literature, but were not raised as significant issues by our participants. Whilst it may be that these concerns were simply not experienced by the participants, it is more likely that it may imply that participants did not have a good understanding of the process of anaesthesia, and what it entailed, or that this understanding may have been superficial.

The literature shows that the mortality in the peri-operative period is low (42, 43), yet this appears to be the biggest concern for the participants in this study. It is apparent from these results, that there is a great deal of benefit which can be attained by improving the quality of our education and counselling of caregivers before surgery. Caregivers need to be counselled about the risks of the surgery, and this needs to be placed in context by explaining the frequency with which they occur. Caregivers should also be given an opportunity to ask questions, and discuss any concerns they may be experiencing with an anaesthetist.

5.2 Limitations

The interviews in this study were all conducted in English, and it was decided that an interpreter would not be utilised. However, whilst all the participants were able to converse in English, only two of the participants identified English as their home language, and their possible poor command of the language may have affected the quality of the information received. This was evidenced by some of the participants struggling to find words to describe their feelings adequately.

5.3 Recommendations

- Anaesthesia education

The preoperative visit by the anaesthetist provides a crucial opportunity for discussion, education and counselling. The anaesthetist needs to make use of the preoperative visit to explore and discuss caregivers', and indeed all patients', concerns and fears. Patients also need to be educated about the process of anaesthesia, including how it is conducted, and what they may expect to see and happen inside the theatre. This may be aided by visual aids such as pictures (theatre machines, environment, masks etc.), short videos, or educational pamphlets.

The wards in the hospital are often overcrowded, and it is very difficult to find a quiet space in which to have these detailed, private discussions with patients. The anaesthetists are also often very busy, and may struggle to find enough time to allow these discussions. A potential solution for this may be to conduct anaesthesia education in small groups in the paediatric outpatient department, from where the patients are actually booked for theatre. This will also allow caregivers of children who may present as day cases an opportunity to allow receive this education. These can be supplemented by information leaflets, printed in various languages, which caregivers can take home to read at their own leisure. All caregivers must be encouraged to ask questions and discuss any concerns they may have with the anaesthetists.

- Overnight hospitalisation

Another factor causing significant concern, which can be relatively easily addressed, is that of caregivers not being allowed to stay with their children overnight in the hospital wards. Despite the fact that the wards are often full, caregivers should not be refused permission to spend the night with their children, especially prior to surgery. Whilst it may not be financially feasible to build overnight facilities for caregivers, a chair can simply be placed at the child's bedside, and one caregiver can then spend the night with their child.

5.4 Conclusion

The findings of this study have shown that a single event can be experienced, and thus interpreted, differently by different individuals. '*Weltanschauung*' (a German word translated to mean "world view"), is the overall perspective from which an individual sees and interprets the world, and is influenced by numerous variables, a few of which include factors such as their personality, upbringing, past life experiences, and beliefs, ideals, attitudes and behaviours that they have developed. The consequence of these differing experiences and interpretations, is that every patient, or accompanying person, experiencing an anaesthetic, is experiencing it in a unique manner. It is crucial for anaesthetists to understand this, and also that a standard 'one size fits all' approach cannot be utilised to interact with all of our patients. The peri-operative visit needs to be tailored to suits the needs of each particular individual, addressing their specific fears, concerns and questions.

Medicine is defined by an online dictionary as 'the science and art of diagnosing and treating disease or injury, and maintaining health' (58) . Medicine is quite clearly an incredible science, which is constantly evolving with the development of new processes, skills, technologies and drugs. The art of medicine, lies in its distinguished history of caring and comforting, and in holistically understanding the patient as a person. We, as anaesthetists, need to start embracing the art of medicine, in order to truly deliver the highest possible standard of care to our patients.

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Appendices

Appendix 1: Post Graduate Committee of the University of the Witwatersrand approval

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Ms Thokozile Nhlapo
E-mail: thokozile.nhlapo@wits.ac.za

09 January 2015
Person No: 0204006F
PAG

Dr JA Yogeswaran
P O Box 1099
Umtata
5099
South Africa

Dear Dr Yogeswaran

Master of Medicine: Approval of Title

We have pleasure in advising that your proposal entitled *Concerns of caregivers of paediatric patients regarding anaesthesia at an academic hospital in Johannesburg* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Appendix 2: Human Research Ethics Committee (Medical) of the University of the Witwatersrand approval

M140130

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140130

NAME: (Principal Investigator)	Dr Janani Yogeswaran
DEPARTMENT:	Department of Anaesthesiology CM Johannesburg Academic Hospital
PROJECT TITLE:	Concerns of Caregivers of Paediatric Patients Regarding Anaesthesia at an Academic Hospital in Johannesburg (revised title)
DATE CONSIDERED:	31/01/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Mrs Juan Scribante

APPROVED BY: Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 21/05/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 3: Medical Advisory Committee of CHBAH approval

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 16 October 2015

TITLE OF PROJECT: Concerns of caregivers of paediatric patients regarding anaesthesia at an academic hospital in Johannesburg

UNIVERSITY: Witwatersrand

Principal Investigator: J Yogeswaran

Department: Anaesthesiology

Supervisor (If relevant): J Scribante

Permission Head Department (where research conducted): Yes

Date of start of proposed study: October 2015
Date of completion of data collection: December 2016

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Human Research Ethics Committee of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....
Recommended
(On behalf of the MAC)
Date: 16 October 2015

.....
Approved/Not Approved
Hospital Management
Date: 2 / 10 / 15

Appendix 4: Department of Paediatric Surgery at CHBAH approval

Umnyango wezempilo no Kuthuthukiswa Komphakathi
Lefapha la Maphelo le Tshebeletso le Ntshetsopele ya Sechaba
Department of Health and Social Development
Departement van Gesondheid en Maatskaplike Ontwikkeling

Professor Jerome Loveland
Department of Paediatric Surgery
Chris Hani Baragwanath Academic Hospital
Tel. number: +2783 676 0004
Email: loveland@wol.co.za

Date: Wednesday 27th November 2013

Research Project:

"Concerns experienced by caregivers of paediatric patients regarding anaesthesia at an academic hospital in Johannesburg"

To whom it may concern

The above project is being submitted as a topic for a Masters in Medicine by Dr Jonani Yogeswaran, currently a registrar in the Department of Anaesthesia. I am familiar with the proposed study and its defined end points, and fully support Dr Yogeswaran performing it on Parents of patients undergoing elective surgical procedures within the Department of Paediatric Surgery, Chris Hani Baragwanath Academic Hospital.

Please don't hesitate to contact me should you require any further information.

Kind Regards

Jerome Loveland
Associate Professor
School of Clinical Medicine
Head
Department of Paediatric Surgery
Chris Hani Baragwanath Academic Hospital
University of the Witwatersrand

Appendix 5: Information letter

Dear Sir/Madam

Good day. My name is Janani Yogeswaran, and I am training to be a specialist, in anaesthesia. In anaesthesia, we make people sleep for operations, and look after them whilst the surgeon is doing the operation.

I am doing a study as part of my MMed qualification from WITS University. The title of my study is "Concerns experienced by caregivers of paediatric patients regarding anaesthesia at an academic hospital". I want to find out what worries parents and caregivers have when their child undergoes an anaesthetic. I also want to try and understand why they have these worries. The reason I am doing this study is because I believe if we as doctors know what you as caregivers are thinking and feeling, we can deal with these worries better.

I have got permission to do this study from the Human Research Ethics Committee (Medical) (No: M140130), and the Postgraduate Committee of the University of the Witwatersrand.

Taking part in this study is completely voluntary, and you do not have to take part in it if you don't want to. If you decide not to take part in this research project, neither you nor your child will be treated any differently in the ward or in theatre. There are no benefits to you taking part in this study, other than contributing to our knowledge. Participation is also anonymous, meaning that we will not collect nor use your name or personal details in the report. You can also change your mind about being in the study at any time, without giving a reason.

If you do decide to take part in the study, I will talk to you in a private space in theatre while your child is having the operation. I will ask you a few questions, but there are no correct or incorrect answers, as I just want to see what your feelings are. The interviews will be tape-recorded, so that I can make notes later.

If you agree to take part in this study, I will ask you to sign two consent forms. By signing these you will give me permission to include you in the study, and to make a tape recording of what we say.

If you have any further questions, you can contact me on 011 488 4397 or Prof Cleaton-Jones, chairperson of the Ethics Committee, on 011 717 1234.

Thank you very much.

Janani Yogeswaran

Appendix 6: Informed consent

- **Consent for participation in the study**

I ……., consent to participate in the study on understanding fears and concerns experienced by caregivers of children undergoing anaesthesia.

Dr Yogeswaran has fully explained the interview process and its purpose, and I understand and agree that:

- My participation in this study will help anaesthetic doctors gain better insight into fears and concerns experienced by caregivers of paediatric surgery patients
- There is no financial benefit to participation in this study, and participation is completely voluntary

I am also aware that I can withdraw my participation from this study at any time.

…….. (Signature of participant)

- **Consent for audio-recorded during the interview**

I ……., consent to my interview done for the study titled "Concerns of caregivers of paediatric patients regarding anaesthesia at an academic hospital" being audio recorded.

I understand that the interview will be transcribed at a later stage, so that the information from all the interviews can be analysed. I also understand that I will remain anonymous, and only the researcher will be able to identify me. I have also been informed that the recording must be stored securely for a period of 6 years, after which they will be destroyed.

…… (Signature of participant)

Appendix 7: Interview Guide

Ice – breakers and small – talk

- "It's been very hot/cold the last few days, hasn't it?"
- "Is this the first time you've ever come to Bara?"
- "I'm sure you can't wait for the operation to be over"

General

Age of child:

Gender:

Nature of operation:

Relationship of participant to child:

Age of participant:

Education level of participant:

Occupation:

Home language:

Outline of Interview

Have you, or any one you know, had any experiences with anaesthesia?

How did you or they find that experience?

What do you think happens when your child goes under anaesthesia?

What words can you use to describe the feelings/emotions you have, when you think about your child undergoing anaesthesia?

Can you tell me more?

Do you have any fears or concerns?

Tell me about these?

Why is …….. a concern for you?

Exploring possible contributing factors of concerns:

Family and community beliefs

Cultural influence

Media (television/newspapers)

Your, or someone else's past experiences