Caregivers' concerns and experiences with their childs' peri-operative care when undergoing cardiac surgery

Patrick Kielty

A research report submitted to the Faculty of Health Sciences,

University of the Witwatersrand, Johannesburg,

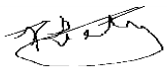
in the partial fulfilment of the requirements for the degree of

Master of Medicine in the branch of Anaesthesiology

Johannesburg, 2022

Declaration

I, Patrick Kielty, herewith declare that this research report is my own, unaided work. It is being submitted for the degree of Master of Medicine at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



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Signed

On this 25th day of April 2022

Abstract

Objective:

To identify and explore experiences and concerns of caregivers whose children underwent anaesthesia for cardiac surgery.

Design:

A descriptive, exploratory, qualitative study was undertaken.

Setting:

The study was conducted at Nelson Mandela Children's Hospital, Johannesburg South Africa.

Subjects:

A total of 13 caregivers of children who were undergoing cardiac surgery were interviewed between June 2020 and September 2020. The sample size required by this type of study was determined by the scope, depth, and nature of the information that was required to gain insight into the experiences of the participants

Interventions:

None.

Measurements and main results:

Semi-structured, open-ended interviews were conducted with the aid of an interview guide. Caregivers were interviewed in either English or isiZulu. Field notes and audio recordings were collected. Data were coded and thematically analysed. The caregivers reported their experiences to be complex. Their common experiences and concerns included being fully informed, and feeling disempowered and excluded which led to feelings of anxiety, fear, and guilt. However, caregivers reported feeling hope and perceived that they were welcomed and valued by supportive staff. Caregivers reported having good relations with, as well as having a good understanding of the role of the treating anaesthetist.

Conclusion:

Numerous complex, interacting factors were identified that influenced the perceptions and experience of the caregivers. Education of the caregiver prior to surgery, employing a family-centred multidisciplinary approach, should be implemented by the healthcare workers. This could help create confidence in the anaesthetist and may improve the overall experience of families of children undergoing cardiac surgery.

Keywords:

Paediatric; cardiac surgery; anaesthetists; role; peri-operative concerns; experiences; caregivers.

Acknowledgements

- I would like to thank my wife, Genna Kielty, for inspiring the topic and for her all her support
- Thank you to my supervisors, Dr. Janine Wagner, Prof. Palesa Motshabi and Dr. Julie-Ann Herbst for all their hard work and expertise. Thanks for the hours supporting me through this Masters in medicine.
- To Anele Jiyane for translating and transcribing the interviews.

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ICU: Intensive Care Unit

NMCH: Nelson Mandela Children's Hospital

CEO: Chief Executive Officer

Draft Article: Caregivers' concerns and experiences with their childs' peri-operative care when undergoing cardiac surgery

AUTHORS

*Dr Patrick Kielty, MBBCH, DA(SA)[1]

ORCID ID 0000-0002-3276-0261

Dr Janine Wagner, MBBCH, DA(SA), MMed, FCA(SA), PhD [1]

ORCID ID 0000-0002-8726-9218

Dr Julie-Ann Herbst, MBBCH, DA(SA), FCA(SA) [1]

ORCID ID 0000-0002-3530-9644

Dr Palesa Motshabi, BSc, MBBCH, DA(SA), FCA(SA), PhD[1]

ORCID ID 0000-0001-9990-6336

1. Department of Anaesthesiology, School of Clinical Medicine, Faculty of Health Sciences, University of the Witwatersrand

***Corresponding author**

Charlotte Maxeke Johannesburg Academic Hospital, Department of Anaesthesiology

7 York Road, Parktown, 2193

Contact number: 0826839906

Email: drpatrickkielty@gmail.com

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Introduction

When children present for surgery it can result in a large amount of anxiety and emotional stress for caregivers, as well as for the children themselves. According to Wisselo et al. (1) caregivers' concerns often centred around induction and emergence of anaesthesia, as well as post-operative pain and nausea. In addition, Gulur et al. (2) have found that female caregivers tend to be concerned about risks and side effects, whereas male caregivers tend to be more concerned about death of the child intra-operatively (2).

The concerns and experiences of caregivers, when their children undergo anaesthesia for cardiac surgery, are not always fully understood due to the complexity of the illness. Many of these concerns are inadequately addressed during the pre-operative visit by the anaesthetist (1). Very little research has been conducted in the South African context to gain insight into these concerns.

Children presenting to the operating room for cardiac surgery pose many challenges for both the child and the caregiver due to the nature of the illness (2). Congenital heart disease is fairly prevalent in South Africa affecting 0.6 to 0.8 children out of every 1000 live births, which equates to approximately 11 000 children annually (3). If the appropriate treatment is provided then the survival to adulthood is around 85 % (3).

There is a paucity of data concerning South African caregivers' perioperative experiences. The aim of this study is to identify and describe the experiences and concerns of caregivers when their children undergo anaesthesia for cardiac surgery. This research seeks to identifying caregivers' experiences and concerns which will enable anaesthetists to gain better insight into what caregivers would prefer to know when their children undergo anaesthesia for paediatric cardiac surgery in order to alleviate caregivers' anxiety. By gaining this insight, anaesthetists will be able to have more goal directed, multi-faceted discussions with caregivers which could include multidisciplinary teams. This may result in a better overall experience and satisfaction for families and children undergo cardiac surgery (4).

Methods

Design

The study was designed as a descriptive, exploratory qualitative study. A phenomenological perspective was used to understand and describe the caregivers' experiences and give them meaning (5).

Setting and participants

The population group studied were caregivers of children undergoing cardiac surgery at Nelson Mandela Childrens' Hospital. This hospital operates as a referral facility specialising in tertiary care paediatric surgery.

A purposive sampling method was used to select participants within the post-operative cardiac ward (6).

Inclusion criteria consisted of caregivers of children that underwent cardiac surgery that had consented to participate in the study as well as to an audio recording of the interview. Exclusion criteria consisted of participants who withdrew from the interview, as well as caregivers unable to converse in English or isiZulu. A total of thirteen caregivers were interviewed, consisting of ten mothers, one father, and two grandmothers.

Data collection

Data collection took place between 1st June 2020 and 30th September 2020. Semi-structured, in-depth interviews were conducted in the form of a conversation guided by, but not limited to, specific open-ended questions according to an interview guide (Appendix 9). Two pilot interviews were conducted before data collection to refine the interview guide. The interviews lasted from 13 minutes to 95 minutes and were conducted by the first author of this article, who is an anaesthetist, who was accompanied by a translator. As not all caregivers spoke English as their first language, they were given the choice of conducting the interview in English or isiZulu, or a combination of both languages. The interviews were audio recorded and then transcribed into English by the translator.

Each of the participants was given a study number to ensure that all data was kept anonymous, and any other identifying factors were removed from the transcripts.

Interviews were conducted until the researcher perceived that the data were “rich”, “thick”, and saturated. This equated a sample size of 13 participants (7).

Data analysis

The transcripts were checked using the audio recordings to ensure the accuracy of transcription. The data were analysed using thematic analysis and were coded using MAXQDA® version 20 after which common themes and further sub-themes were identified (8, 9). The coding strategy used is presented in Table 1. To maintain consistency of the data, Braun and Clarke’s six-phase approach was used (8). Trustworthiness of the data was maintained using the aspects described by Guba and Lincoln namely credibility, transferability, dependability, and confirmability (10).

Ethical considerations

Ethical clearance to conduct the study was granted by the University of Witwatersrand Human Research Ethics Committee (Medical) (Appendix 2). Permission was also obtained from the CEO of Nelson Mandela Childrens’ Hospital (Appendix 7).

The caregivers were approached and invited to take part in the study. Those who agreed were given an information letter (Appendix 10) further explaining the study. They were asked to sign two consent forms, one for participation (Appendix 11) and a second consent form for permission to audio record the interview (Appendix 12). Caregivers were told they could withdraw from the study at any time. If the support of a clinical psychologist was required, the referral process was provided in the patient information letter.

All information gathered from the interviews was treated with the strictest confidentiality. The participants’ real names were replaced by a study number therefore ensuring their anonymity. The study was conducted according to the principles of the Declaration of Helsinki (11) and the South African Guidelines for Good Clinical Practice (12). The coding strategy employed is presented in Table 1.

Table 1. Coding strategy

Theme	Subtheme	Quotation
Being fully informed	Caregivers' knowledge of role of anaesthesia	"It's something that helps the child during the operation so that he will not feel the pain and be non- responsive"
	Perception of being well informed	"They come and explain that they going to put him to sleep and the whole process of how it's going to happen"
Disempowerment and exclusion	Lack of involvement	"They do greet me but do not ask me anything when they find me next to the bed"
	Weak and powerless	"I was like asking myself a lot of questions that I didn't know how to answer them"
Welcomed and valued	Good rapport with caregivers	"All the sisters and the nurses are friendly; they greet you all the time"
	Mutual respect	"Everything was good they have treated me as a person, and they value people"
	Reassured	"Ah, I feel confident here, just from the gate"
Anxiety and fear	Trauma and pain	"I just wish that when they were doing all these tests, they would come with a conclusive report instead of saying, today we found this, now we're dealing with that… today we found this. It feels like it's a never-ending trauma"
	Agitated and worried	"I was so worried, scared, you know thinking about losing a child, it's a difficult thing"
	Insecure	"I was so scared, like what's going to happen, I'm going to lose my baby"
	Depressed and crazy	"Before the operation I almost got crazy, looking at the situation my child was in"
Guilt	Blaming others	"You know when you want someone to blame. Then I said to myself let me not blame someone let me accept the situation"
	Responsibility and self-condemnation	"You need to sign the consent form, some people will say you are signing in for your child's life, it's not easy it's a very difficult time I will not lie to you"
Hope and support	Drawing from religious faith for support	"The only hope I had was through prayer, I prayed day in and day out"
	Community support: family, friends, staff, other caregivers	"The whole time I was counting the hours. I was busy chatting on WhatsApp with people"
Relief	Thankful	"I am short of words, but the treatment was good on him, so I do not have anything to worry about"
	Joy and excited	"Happy. Happy, happy, happy. And that day I sleep nicely"

Results

The caregivers reported their experiences of their child's peri-operative cardiac surgery, and the results showed their encounters to be complex. The seven interrelated themes and subthemes identified are presented in Figure 1 below.

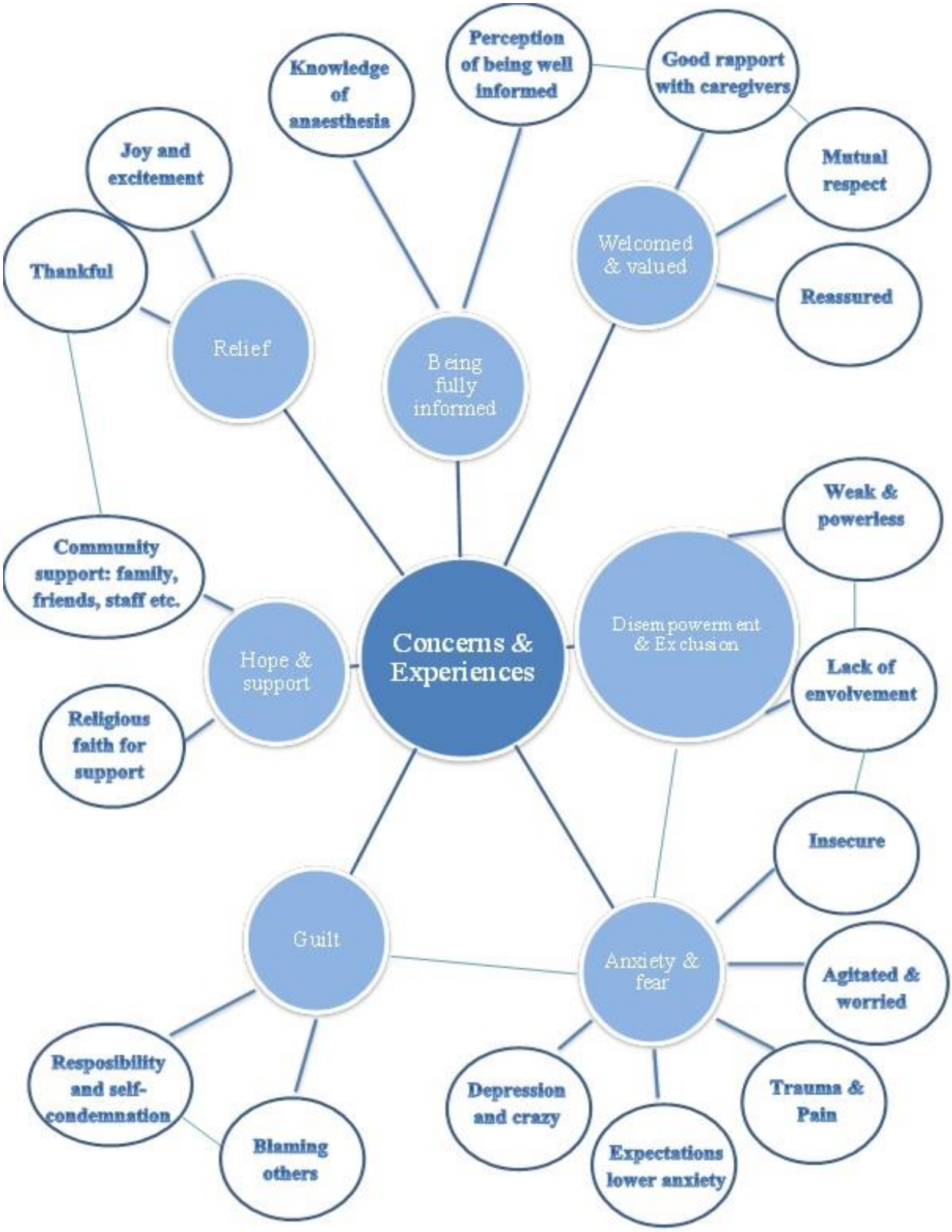

Figure 1. Interrelated themes and sub-themes

Being fully informed

Caregivers' understanding of the definition and role of an anaesthetist differed drastically. There were those who showed a good understanding and were able to describe certain responsibilities performed by the anaesthetist while others had little to no understanding at all. Many of the caregivers whose children underwent cardiac surgery also had little knowledge or understanding of congenital cardiac disease or cardiac surgery. This lack of knowledge led to some caregivers wanting to acquire more information, sometimes by using the internet and in other cases by asking the doctors questions on ward rounds. However, some caregivers felt that the information given to them by doctors, as well as what they had researched themselves resulted in them feeling overwhelmed: *"I don't want to ask many questions because you get overworked. I end up Googling and doing all sorts of stuff"* (P1). For some caregivers, perceptions after their discussions with the anaesthetist pre-operatively, was that they felt better informed about the procedure and felt that they had gained knowledge about the surgery that was to be performed. This was shown by one caregiver, who even wished to share her newfound knowledge with others: *"I have learned a lot and I can't lie. It's true that if you teach a woman, you teach the whole world because now that I have learned all these things it will be easy for me to share with other people"* (P9).

Disempowerment and exclusion

Many healthcare workers consulted with both the mother and the child every day, resulting in some caregivers having to explain their child's history numerous times. This often led to them reliving their traumatic experiences repeatedly and feeling as though they were not always being heard or empowered by the doctors, as one caregiver said: *"It feels like you're going for an interview all over again. That was just working my nerves"* (P1). Although it seemed as though the doctors took the time to involve the caregivers, it was not always the type of involvement that the caregivers required. Caregivers sometimes perceived that the conversation only revolved around the patient and that the caregivers were overlooked and excluded. One caregiver said: *"They only care about the kid, but the mother is also here. I wouldn't have signed those consent forms if I had no feelings for my kid. So, I also have feelings. I think in future they should also involve us"* (P2).

Some caregivers had the perception of feeling powerless to influence the outcome of their child's condition: *"I didn't know the outcomes of tomorrow because he is in ICU, you know anything can happen at any time"* (P2). For one particular caregiver the entire experience became too overwhelming, and they did not feel strong enough emotionally to deal with the stress of their child's peri-operative care and chose to exclude themselves from the entire process: *"I couldn't even come to the hospital to be honest. Only my husband came. It was just too much for me"* (P1).

Welcomed and valued

Caregivers described feeling a sense of confidence and trust within the hospital environment created by many positive interactions between caregivers and staff members of the hospital. One caregiver said:" The *hospital is new I understand but the way people are showing humanity here it's amazing"* (P9), whilst another expressed: *"It's like everyone who is employed here they get a mandate on how to treat people at work, the way I see it"* (P9). Staff attitude was important to result in a pleasant experience for families. This view was supported by a caregiver who said: *"All the sisters and the nurses are friendly; they greet you all the time"* (P8).

The many positive interactions that took place between healthcare workers and caregivers demonstrated a sense of mutual respect and teamwork. This acknowledgement of respect was shown by a caregiver that said: *"Like I just see as a trend here, it's a doctor, nurse, and me you see we are helping each other"* (P9). It was through these interactions that many caregivers felt valued and appreciated. These interactions also created a sense of reassurance among caregivers. This was evident by one caregiver stating: "*I felt okay because they told me that Nelson Mandela is a good one and they will do everything to make us feel happy and also the kids to be good"* (P6).

Anxiety and fear

Caregivers experienced a wide range of emotions throughout their hospital stay and sometimes found it difficult to regulate their emotions. Every caregiver admitted to feeling anxious and insecure at some point peri-operatively. The overwhelming cause of this being fear of death, or fear of the child not waking up after surgery. One caregiver became tearful when explaining: *"I was so worried, scared, you know thinking about losing a child, it's a difficult thing"* (P2).

Another caregiver explained: *"I was so scared, like what's going to happen, I'm going to lose my baby* (P3). The perception of the life-threatening nature of the procedure increased many caregivers' levels of anxiety. This was evident when one caregiver said: *"I was so scared. I was shaking when I come from theatre"* (P11), whilst another also displayed feelings of worry in saying: *"What if at night there are other problems. That night I didn't sleep peacefully"* (P13).

Some caregivers felt extremely overwhelmed and struggled to deal with the stressful situation they found themselves in. After the surgery a caregiver revealed: *"I was so scared on Friday, I just felt like I could walk away from the hospital and never do that again"* (P3). Other caregivers felt equally overwhelmed due the amount of information given to them daily, which resulted in frequent traumatic experiences: *"I just wish that when they were doing all these tests, they would come with a conclusive report instead of saying, today we found this, now we're dealing with that… today we found this. It feels like it's a never-ending trauma"* (P1). These frequent experiences also resulted in some caregivers experiencing periods of depressed mood: *"It just raises your heart rate. You get depressed all over again. So, it's just been a rollercoaster"* (P1).

Guilt

Times of stress sometimes led to caregivers feeling guilty resulting in them trying to blame others, often those closest to them. This was frequently the case when they were given bad news by doctors: *"I was thinking maybe it is the mistake of the mother, you know when you want someone to blame. Then I said to myself let me not blame someone let me accept the situation"* (P5).

Some caregivers expressed that should they experience the loss of their child, or a serious complication occur it would result in them feeling guilty. This was particularly evident when consent for surgery needed to be signed, with caregivers expressing feeling the weight of this responsibility by saying: *"Yoh! I think that was the hardest day of my life because I had to sign those forms before they put the child to sleep, I said to myself I am signing my child's life or risking my child's life"* (P5). Another caregiver shared a similar experience and stated: *"You need to sign the consent form, some people will say you are signing in for your child's life, it's not easy it's a very difficult time I will not lie to you"* (P5).

Hope and support

During periods of high emotional stress many caregivers felt better if they had the support of others, particularly family members, friends, and healthcare workers. One caregiver stated how she frequently spoke to her family: *"The whole time I was counting the hours. I was busy chatting on WhatsApp with people"* (P9). Another caregiver perceived that support of the healthcare workers had helped them cope: *"I will thank the sisters and the Drs for supporting me"* (P8). Some caregivers described that comfort and support that was obtained by other caregivers sharing stories and personal experiences. A sense of agency was created, and they shared their acquired knowledge with each other: *"There were other people there, so we were talking. Then all of us were waiting for our kids from the theatre, so sometimes we will talk"* (P13).

Nearly all the caregivers mentioned religion, God, or prayer at some point during their interview although not every caregiver admitted that they had strong religious beliefs or backgrounds. Prayer and belief in God were used to help caregivers through times of emotional stress, as one of the caregivers described: *"Then I just told myself, let me get done with this whole process, whatever happens, happens, it was God's will"* (P3), whilst another caregiver stated: *"If God wanted my child to live God will make it happen"* (P5). Prayer did not only help some caregivers emotionally, but it was also used to idle away time. This was evident particularly when the child was in theatre and ICU: *"Most of the time what kept me was prayer, we will pray with other mothers at night, we will pray for our kids and the doctors to ask god to lead them into a successful operation"* (P13).

Relief

For some caregivers the rollercoaster of emotions experienced resulted in a negative experience, however there were others that expressed feelings of hope and positivity. On completion of the surgery, despite caregivers feeling exhausted, there was an overwhelming sense of relief resulting in significant excitement and joy. One caregiver expressed her happiness by saying: *"Ooooh! I am feeling great and excited"* (P9), while another shared her relief post-operatively by saying: *"I am very different, and I have joy in my heart"* (P5).

Although for most children the recovery process still had a long way to go, caregivers within that moment were relieved that they were another step closer to their child being able to live a normal life, however some caregivers still expressed disbelief: *"I still ask myself if this is the miracles, even now"* (P8).

Most of the caregivers were extremely thankful to everyone involved in caring for their child peri-operatively. They showed their appreciation of healthcare workers by saying: *"I just want to thank them for the job they did. I do really appreciate it and if it wasn't for them, I don't know what could have happened"* (P3) and: *"I am so grateful to all the people who have assisted me. I will buy them something nice or leave money for them to buy whatever they want"* (P8). One specific caregiver even described a memorable moment when they met with staff in the ward to thank them: *"I even played a song to the doctors and the staff just to say thank you for contributing to my child's life and helping her"* (P5).

Discussion

Caregivers did not always believe that they were fully informed about the procedures and risks for their child's surgery. They reported their experiences and concerns to be complex and some participants reported feeling fearful about asking questions. Caregivers often described a rollercoaster of emotions, from fear, anxiety and guilt to hope and relief.

The definition and role of an anaesthetist can be broad (13, 14, 15, 16). Often this role is misunderstood resulting in misconceptions. It is important to identify the caregivers' knowledge of anaesthesia to determine their expectation of the anaesthetist to improve user experiences and ensure service satisfaction (1). The results of this study showed that although many of the caregivers had a good knowledge of the role of the anaesthetist, there were some that had little to no knowledge at all. The lack of knowledge and many misconceptions displayed by caregivers may have resulted from their differing levels of education. In a study by Mathur et al. (15) it was shown that higher levels of education resulted in better and more informed understanding of all the roles that an anaesthetist may perform peri-operatively.

Caregivers dealt with this lack of knowledge differently, ranging from “information seekers” or “monitors”, to “blunters” that chose to ignore any details that may be overwhelming to them (1). In most cases, a good relationship between caregivers and healthcare workers set a solid platform where this information could be sought in a relaxed yet professional environment.

This was also identified by Lopez et al. (4) who described how family perspectives become important for healthcare workers with regards to decision making and these perspectives may even influence the clinical outcomes. To bridge this gap in knowledge the anaesthetist should provide the caregiver with adequate information pre-operatively (17). According to Wisselo et al. (1) this could be done best by creating a video, containing the necessary information, which can be given to caregivers to watch at home before the surgery.

Similar to studies conducted by Wei et al. (18) and Harvey et al. (19), caregivers experience a wide range of emotions when their children undergo cardiac surgery. As found in these studies, anxiety was one of the most common emotions experienced peri-operatively (20, 21, 22). This study showed findings similar to Burkle et al. (23), where fear of death, or not waking up after surgery was the most overwhelming cause of anxiety. Other common causes of anxiety were a fear of the unknown, including unknown outcome, as well as fear of an unknown or foreign environment (19, 21). The medical equipment and monitors within theatre and ICU can be intimidating for many people who have never encountered that environment before (22). This study showed similarities to the study by Wei et al. (18) where a much more confident approach was taken by caregivers who had been to theatre before and had their own previous experiences to relate to. Caregivers also expressed that a “loss of control” was a common source of anxiety. It is essential for anaesthetists to maintain good communication with caregivers to allay their anxiety. Good communication, and a family-centred approach towards support, will assist the caregiver with creating confidence and trust in their anaesthetist (4, 24, 25, 26).

The emotional rollercoaster that caregivers experienced together with the feeling of loss of control often resulted in feelings of guilt (18, 27, 28). Similar to a study by Amin et al. (29) some caregivers felt guilty for their child’s condition and resorted to blaming themselves or others.

The use of a multidisciplinary approach by the healthcare workers may be useful peri-operatively to help caregivers express and deal with their emotions. Healthcare workers should provide reassurance to caregivers to alleviate any guilt they may feel and express that it is not the fault of the caregiver for their child's condition (18, 28).

At the time of discharge, most caregivers felt relieved that their long medical journey was reaching a conclusion (24, 30). Caregivers with a strong family support structure felt empowered to go home and care for their child. For those caregivers without a strong support system or those that had some anxiety about being discharged, health workers may need to take care of the needs of the caregivers as well. Caregivers' experience must remain important when implementing a multidisciplinary program of care (31).

Although it was outlined in the study information letter, this study may be limited in that there may have been a misconception that the interviewer was part of the healthcare team or would report back to the healthcare team. This may have affected the quality of the data as participants may have been hesitant to provide negative descriptions of their experiences due to fears of it impacting on their child's hospital care.

The study represented the views of caregivers whose children were undergoing cardiac surgery at Nelson Mandela Children's Hospital. This is a specialist hospital that serves state patients. The results of this study therefore cannot be generalised to other population groups with different socioeconomic backgrounds, as may be the case in other provinces or countries.

Throughout the peri-operative process, caregivers experienced a wide range of emotions. Depending on the time of the data collection in relation to the current condition of the child, caregivers may describe different experiences and give different responses. This may explain why similar studies done elsewhere may have varying results. Because of this, the results of this study cannot always be generalised in other contexts. Due to the fact that interviews were conducted in the ward post-operatively caregivers may have had time to process their experiences as well as the surgical outcome of their child. This may have resulted in changing some caregiver's perceptions and even may have resulted in a change in their recall of events.

The involvement of a multidisciplinary team peri-operatively may result in an improvement in the overall experience of families of children when undergoing cardiac surgery, as well as experience of the children themselves. Further interventional studies assessing the effect of implementing a multidisciplinary team approach are recommended.

Conclusion

Caregivers' concerns that affect their perceptions and overall experience may differ from what doctors believe the caregiver should be concerned about. Good communication and a family-centred approach towards support, may assist the caregiver with creating confidence and trust in their anaesthetist. Anaesthestist should take more time to explain and answer questions, acknowledging the feelings of the caregivers, and try to be more reassuring. The involvement of a multidisciplinary team peri-operatively may result in an improvement in the overall experience of families of children when undergoing cardiac surgery, as well as experience of the children themselves.

Financial disclosure and conflicts of interest

The authors have disclosed that they do not have any conflicts of interest to declare. The study was financially supported by the Department of Anaesthesiology, University of the Witwatersrand.

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APPENDICES

Appendix 1: Proposal

Caregivers' concerns and experiences with their childs' peri-operative care when undergoing cardiac surgery

Patrick Kielty

0702269N

Supervisor: Dr Janine Wagner

Department of Anaesthesiology

Co-supervisors: Dr Julie-Ann Herbst

Department of Anaesthesiology

Dr Palesa Motshabi

Department of Anaesthesiology

1. Introduction

Multiple definitions for anaesthesia exist. According to the Oxford Dictionary, anaesthesia is defined as " insensitivity to pain, especially as artificially induced by the administration of gases or the injection of drugs before surgical operations" (1). The Royal College of Anaesthetists defines anaesthesia as "loss of sensation" (2). Many people have little understanding of anaesthesiology and what the role of an anaesthetist is during the peri-operative period (3, 4). This widespread ignorance results in myths and misconceptions about anaesthesiology. This knowledge gap often becomes evident when caregivers bring their children for surgical procedures that require an anaesthetic.

Children presenting to the operating room for surgery pose many challenges for both the child and the caregiver (5). When these children present for cardiac surgery these challenges are likely to become even greater due to the nature of the illness. Congenital heart disease is fairly prevalent in South Africa affecting 0.6 to 0.8 children out of every 1000 live births, which equates to approximately 11 000 children annually (6). If the appropriate treatment is provided then the survival to adulthood is around 85 % (6). Approximately 4500 of the 11 000 children with congenital heart disease will require surgical intervention annually (6).

Anxiety is one of the most common emotions experienced by caregivers peri-operatively (7). This is brought about by different factors which may include fear of death of a child, pain experienced by a child and fear of the unknown. When children present for surgery the caregivers often experience a wide range of emotions. Wei et al. (8) conducted a study that examined parents' experiences of having a child undergo heart surgery, and reported that at times parents were "sad and despairing"; and at other times, they were "happy and hopeful". Harvey et al. (9) also described in a study they conducted that mothers displayed a "roller coaster of feelings", ranging from "shock and fear" to feeling "truly blessed" and "joyous relief".

When a child undergoes cardiac surgery there are many risks involved, one of which is death. The caregiver will be made aware of this prior to surgery through acquiring informed consent. This will result in the caregiver experiencing some degree of anxiety. When looking at patient fears of anaesthetic complications, it was found that, "Fear of death was the greatest concern as compared to the other risk factors independent of the severity of the surgery" (10).

The caregivers' fear of death of their child is brought about by the fact that the outcome of the surgery is unknown (9). According to a Spanish national survey regarding patients' fears prior to a surgical procedure, the fear of the unknown was one of the most common causes of peri-operative anxiety (11). The feeling of not knowing what to expect is linked to the lack of familiarity with the situation. When caregivers bring their child for surgery for the first time, it may feel more difficult as opposed to a caregiver who has experienced this before (12). It is important for the caregivers to be made aware of the procedures in order to improve their knowledge of what to expect, and therefore help them to overcome their fears (12).

When adult patients come for surgery under general anaesthetic, one of the most common concerns is the possibility of experiencing post-operative pain (11, 13). This is likely to result in the caregiver expressing the same degree of concern for their child. The difficulty that caregivers face is that although they are not experiencing the pain themselves, they will have little control over the effect that the surgery may have on their child. The feeling of losing control is related to the stressful environment in which the caregivers find themselves. Critical times include when parents received their child's diagnosis, when their child is handed over to the surgical team, and when they visit their child in the paediatric intensive care unit after surgery (8). Handing the child over to the surgical team may be challenging because the caregivers could feel as though the child is no longer theirs and what happens to their child is no longer within their control. When caregivers experience a loss of control it may result in them feeling a certain degree of guilt (14).

In a study of parents' experience of their child's general anaesthesia for dental surgery, it was evident that some parents felt guilty for their child's condition whilst others felt blameless (15).

A similarity may exist with regards to caregivers of children undergoing cardiac surgery, as they may see themselves as the cause of their child's condition, especially in children with congenital heart disease (16). Wei et al. (8) support this belief and reports that in their study, "After the initial shock of hearing about their child's heart defect, all parents started to blame themselves. They thought it was their fault that their child was born with a heart defect".

A sense of loss of control is also experienced when caregivers find themselves in the unfamiliar technological environment of the paediatric cardiac intensive care unit (9). This feeling of unfamiliarity is a result of them engaging with healthcare professionals unknown to them as well as hearing people speak using medical jargon that they may not understand (9).

The numerous monitors and medical equipment used within the setting of an intensive care unit are likely to be intimidating for many people who have never encountered this environment before. This may reflect a gap in knowledge.

Caregivers' knowledge about anaesthesia may be limited. It is the responsibility of the anaesthetist to adequately educate and counsel patients and their family members during the pre-operative visit (17). This process of educating the family should be based on the needs of the individuals. When looking at providing caregivers with information prior to surgery, the coping style of the individual may be considered (18). The two coping styles have been defined as "monitors" and "blunters" (18). "Monitors" are individuals who require large amounts of information in order to feel secure whereas "blunters" avoid receiving too much information as it may lead to distress (18).

Even though we may be able to determine an individual's coping style, Wisselo et al. (18) found that understanding the specific coping style of the caregiver may not determine what information they require pre-operatively.

The role of the anaesthetist is to discuss the concerns of the caregiver, explain the procedure, and attempt to allay any fears or misconceptions around their child's surgery and anaesthesia (17). Wisselo et al. (18) found that many anaesthetists often discuss what they themselves deem to be important and relevant information. Very often this information is not necessarily what the caregivers would have liked to have known prior to the surgery (18, 19).

It is important for the anaesthetist to be made aware of the caregivers' preferences with regard to decision making as this often differs from healthcare providers views (20). This emphasizes the importance of good communication between the anaesthetist and the caregiver during the pre-operative visit (20). Lopez et al. (20) have described how, "listening to the family's perspectives is important to improve clinical decision making and patient outcomes".

Good communication forms part of the foundation on which a "family-centred" relationship is built (21). From the literature, six aspects have been identified around family-centred care namely: "respect, information and education, coordination of care, physical support, emotional support, and involvement of parents" (22). Improving the relationship between the anaesthetist and the caregiver will assist in creating confidence and trust in the healthcare system (20).

It is essential that the caregiver has a good relationship with the anaesthetist as it has been shown that, “Healthcare providers play an irreplaceable role in alleviating parents’ emotional toll when their child undergoes cardiac surgery” (23). According to a study on “Healthcare providers caring”, caregivers felt as though the healthcare providers assisted them the most when they supported them with the following: understanding their experience; providing emotional support; assisting them with tasks; encouraging them during difficult times; and empowering them to maintain belief (23). This support is essential at the time of discharge.

Although at the time of discharge the caregiver may feel a sense of relief, it may also be followed by a feeling of isolation (24). After the child has been discharged and sent home, the caregiver often becomes the “surrogate nurse” as they will be responsible for the child’s care at home (21). Difficulty arises particularly soon after discharge when caregivers feel that their lack of knowledge about their child’s condition results in increased levels of stress and helplessness (24). As a result of their child’s increased health needs, physical and social isolation is a common occurrence (24). This may impact negatively on the caregivers’ ability to cope with caring for their child at home.

Through identifying caregivers’ concerns, anaesthetists will be able to gain better insight into what caregivers experience and what they would prefer to know when their children undergo anaesthesia for paediatric cardiac surgery. By gaining this insight, as well as understanding some of the emotional aspects related to paediatric anaesthesia, anaesthetists will be able to have more goal directed discussions with caregivers. This would possibly result in a better overall experience for families when children undergo cardiac surgery.

2. Problem statement

The concerns of caregivers, when their children undergo anaesthesia for cardiac surgery, are not always fully understood. Many of these concerns are not adequately addressed during the pre-operative visit by the anaesthetist (18). Very little research has been conducted in the South African context to gain insight into these concerns. Gaining further insight into what caregivers fear when their child comes for cardiac surgery, may contribute towards improving their overall experience (20).

3. Aims

The aims of this study are to identify and describe the experiences and concerns of caregivers when their children undergo anaesthesia for cardiac surgery.

4. Objectives

The objectives of the study are to:

- identify and explore experiences and concerns of caregivers when their child undergoes anaesthesia for cardiac surgery
- understand the causes of these concerns.

5. Research assumptions and definitions

The following definitions will be used in the study.

Child: is a person younger than 18 years old.

Caregiver: is a person who provides care and is primarily responsible for a child who needs supervision. It may include but is not limited to a parent or legal guardian.

Anaesthetist: is a qualified doctor working in the Department of Anaesthesiology including interns, medical officers, registrars and consultants.

6. Demarcation of study field

The study will take place at Charlotte Maxeke Johannesburg Academic Hospital (CMJAH), a 1200-bed central hospital, as well as Nelson Mandela Children's Hospital (NMCH). The Cardiac unit within each hospital has a paediatric population who are undergoing cardiac surgery. Caregivers of children in the paediatric cardiac unit will be interviewed for the study.

These interviews will take place in a private room in the ward so that caregivers can remain in close proximity to their children, whilst also allowing the interview to remain confidential.

7. Ethical considerations

Ethical clearance will be applied for from the University of Witwatersrand Human Research Ethics Committee (Medical). Permission to conduct the study will be obtained from the CEO of CMJAH and NMCH (Appendix A, B, C, D).

The caregivers will be approached and invited to take part in the study. The study will be explained by the researcher. Those who agree to take part will be given an information letter (Appendix E) further explaining the study and will be asked to sign a consent form (Appendix F). The caregiver will then be asked to sign a second consent form requesting permission to audio record the interview (Appendix G).

All information gathered from the interviews will be treated with the strictest confidentiality. It is not possible to ensure complete anonymity due to the nature of the study, but only the researcher and the translator (if required) will need to be aware of the identity of each caregiver in order to link the data together and draw conclusions. The participants' real names will be replaced by a study number therefore ensuring their anonymity. A separate list will be kept with the name of the participants, their child's name and hospital number, and the participants' study number. In order to maintain confidentiality this list will be password protected and only the researcher and supervisors will have access to it. Data will be stored securely for six years after completion of the study on a password protected database, after which it will be destroyed.

As a precautionary measure, a pilot study involving 8 participants will be performed to determine the feasibility of the interview guide as there might be a high rate of attrition, and distress amongst study participants due to the sensitive nature of the questions. Any questions that are found to result in participant distress will be removed from the interview guide.

During the interviews, if it is evident that any of the caregivers are unable to cope they will be allowed to withdraw from the study at any time.

Any caregiver that requires support emotionally or socially will be referred to a clinical psychologist at CMJAH and the details of such will be provided in the patient information letter.

The study will be conducted according to the principles of the Declaration of Helsinki (25) and the South African Guidelines for Good Clinical Practice (26).

8. Data collection

Research design

The study will use a qualitative research design, and semi-structured interviews will be conducted.

Study population

Caregivers of children undergoing cardiac surgery at CMJAH and NMCH will be the focus of the study.

8.3 Study sample

8.3.1 Sample method

In this study, a purposive sampling method will be used. Purposive sampling is when personal judgement is used by the researcher in order to choose cases that will help to achieve the research objectives (27). Data collection will take place through semi-structured, in-depth interviews. The interviews will be conducted post-operatively, in a private room within the ward. The interviews will be audio recorded and transcribed. Once transcribed, coding will take place whereby common themes will be found.

8.3.2 Sample size

The study will be conducted until the data is thick and rich, and the researcher perceives that a point of data saturation has been reached. Therefore, the researcher is unable to calculate a sample size but anticipates that between 10-20 interviews will need to be conducted (28).

8.3.3 Inclusion and exclusion criteria

Inclusion criteria:

- Caregivers of children undergoing cardiac surgery at CMJAH and NMCH.
- Caregivers that consent to participation in the study as well as audio recording.

Exclusion criteria:

- Interviews that are not completed, or where participants decide to withdraw will be excluded from analysis.
- Caregivers who are unable to converse in English or isiZulu.

8.4 Collection of data

Data collection will take place through semi-structured, in-depth interviews. Participants will be given the option of being interviewed in either English or in isiZulu. It was decided that the interviews would be conducted in these languages as these are the predominant languages spoken by most patients who attend CMJAH and NMCH. If the participant opts to be interviewed in English, then the researcher will conduct the interview himself. If the participant choses to be interviewed in isiZulu, then the interview will be conducted using a translator by the name of Anele Jiyane. Anele is a qualitative researcher and therefore a skilled and experienced interviewer.

These semi-structured interviews will take place in the form of a conversation guided by, but not limited to specific questions. This allows the interviewer to ask additional questions based on the participants' previous answers. The interviews will be conducted post-operatively, in a private room within the ward. The interviews will be audio recorded and transcribed. The interviews that are conducted in English will be transcribed by the researcher, whereas those conducted in isiZulu will be transcribed by the translator. The isiZulu transcripts will then be translated into English by the translator.

9. Data analysis

Data that is transcribed will be checked using the audio recordings to ensure accuracy of transcription. The data will then be coded and common themes will be determined. Once information is grouped into themes, similarities and differences among participants will be elaborated on and together with the literature, conclusions will be drawn (29).

10. Significance of the study

Anaesthetists encounter many caregivers whose children come for surgery. Most of these caregivers come to theatre with many concerns. In the majority of these cases, the anaesthetist has spoken to the caregivers during a pre-anaesthetic consult prior to them coming to the operating room.

During this pre-anaesthetic consult, they often discuss with the caregivers what they deem to be important and what they think they should know about their child's anaesthetic. Caregivers' concerns that affect their perceptions and overall experience may often differ from what doctors believe the parent should be concerned about. This study may assist anaesthetists working at CMJAH, as well as other South African anaesthetists, with their pre-operative discussions by identifying the concerns of caregivers of children undergoing cardiac anaesthesia. This may result in an improvement in the overall experience of families of children when undergoing cardiac surgery, as well as experience of the children themselves.

11. Trustworthiness

Trustworthiness of the data will be found using the four aspects as described by Guba and Lincoln (30).

Credibility: how confident the researcher is in the truth of the findings (30, 31).

Transferability: how applicable the findings are to other contexts (30, 31).

Confirmability: the degree of neutrality in the findings (30, 31).

Dependability: the extent that the study could be repeated in order to find consistent results (30, 31).

12. Potential limitations of the study

Findings from the study cannot be generalised to a larger population due to both the small sample size in the study as well as the specific sample population that will be used.

Although assumptions will be made about parents answering honestly and reliably, this cannot be guaranteed as answers to questions will be subjective in some way.

The research quality will depend largely on the interviewing skill of the researcher, which could result in the data being influenced by the researchers' personal bias.

Although the participants will be given the option of being interviewed in either English or isiZulu, neither of these may necessarily be their home language. This may affect the quality of the data that is collected.

13. Project outline

Activity	Aug '19	Sept '19	Oct '19	Nov '19	Dec '19	Jan '20	Feb '20	Mar '20	Apr '20	May '20	June '20
Proposal											
Proposal submission											
Ethics approval											
Postgraduate approval											
Data collection											
Data analysis											
Draft article											
Submission											

14. Financial plan

The Department of Anaesthesiology will bear the cost of printing and paper for the postgraduate approval. Stationery and transport costs will be funded by the researcher.

The researcher will use his own mobile device, Samsung Galaxy S10, for audio recording of the interviews on a free mobile application. An Apple I-Pad, belonging to the researcher, will be used as a back-up device for audio recordings. The researcher's own laptop will be used to transcribe the data and to write up the research report.

A translator will be used in this study to conduct some of the interviews where participants have opted to be interviewed in isiZulu. The translator will be required to transcribe these interviews and to translate them into English transcriptions. Funding will be required for the use of a translator. Part of the cost will be borne by the Department of Anaesthesia, but the researcher will also apply to the Jan Pretorius Research Fund, which is administered by the South African Society of Anaesthetists (SASA).

Budget:

Item	**Price per page**	**Number of pages**	**Copies**	**Total**
Proposal	R 1	19	2	R 38
Ethics	R 1	10	2	R 20
Postgraduate form	R 1	2	2	R 4
Complete report	R 1	70	2	R 140
Information letter	R 1	1	20	R 20
Consent form	R 1	1	20	R 20
Consent audio recording form	R 1	1	20	R 20
Translator				R 7500
Grand Total (Estimate)				R 7762

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Appendix 2: Human research ethics committee clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Dr P Kielty

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M1911153

NAME: (Principal Investigator)	Dr P Kielty
DEPARTMENT:	School of Clinical Medicine Department of Anaesthesiology Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Caregivers' concerns and experiences with their child's peri-operative care when undergoing cardiac surgery
DATE CONSIDERED:	2019/11/29
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Drs J Wagner, J-A Herbst and P Motshabi
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2020/03/20

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 Research Office Secretary on the 3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
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 research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **November** and will therefore reports and re-certification will be due early in the month of **November** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE CLEARANCE CERTIFICATE NUMBER IN ALL ENQUIRIES

Appendix 3: Graduate studies committee approval

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

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

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

03 January 2020
Person No: 0702269N
PAG

Dr P Kielty
5 Vegan Villa
11 Glendower Avenue
1609
South Africa

Dear Dr Patrick Kielty

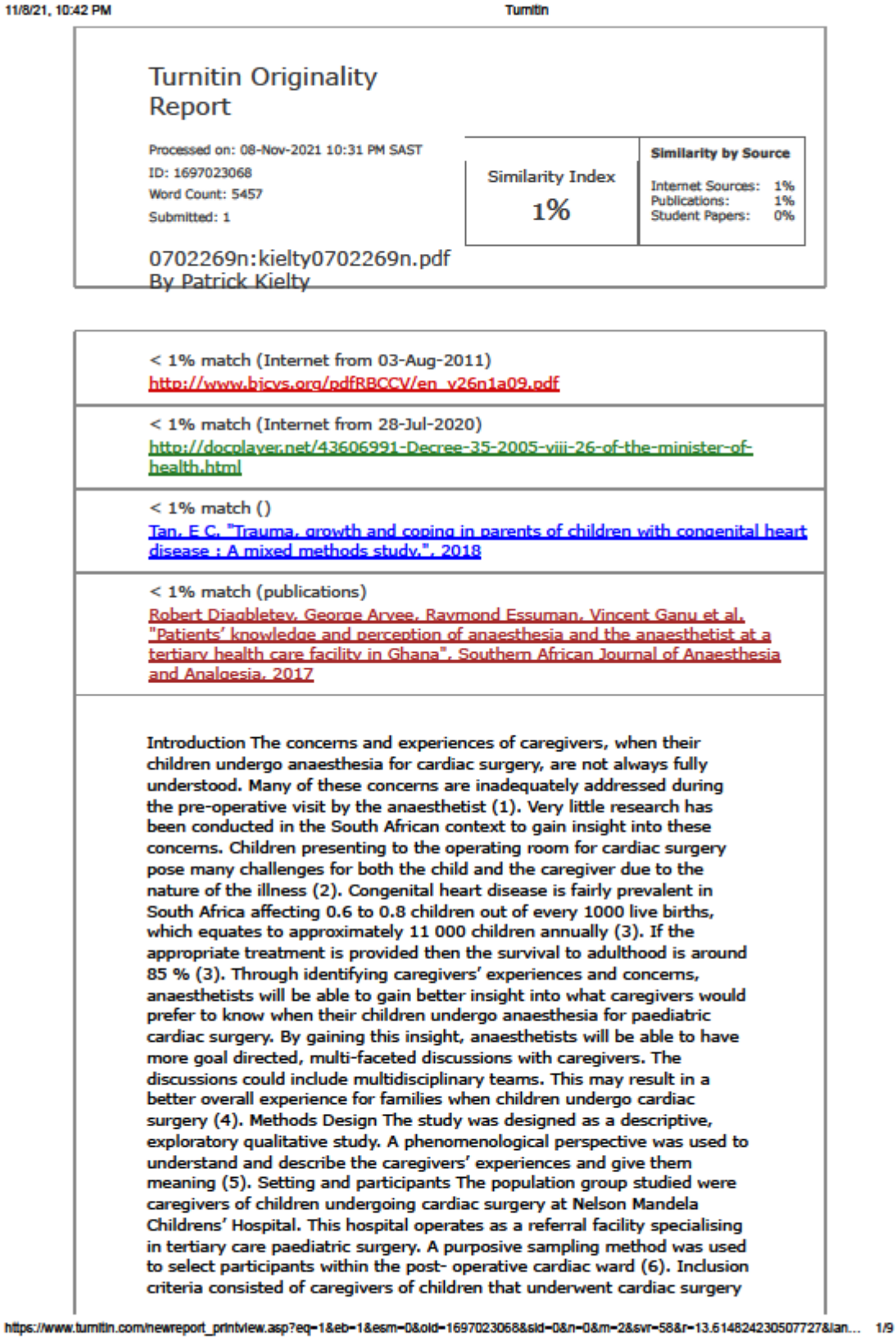
Master of Medicine in Anaesthesia: Approval of Title

We have pleasure in advising that your proposal entitled *Caregivers' concerns and experiences with their childs' peri-operative care when undergoing cardiac surgery* 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 4: Plagiarism/ turnitin report cover page



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Word Count: 5457
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0702269n:kielty0702269n.pdf
By Patrick Kielty

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Robert Diagbletey, George Aryee, Raymond Essuman, Vincent Ganu et al. "Patients' knowledge and perception of anaesthesia and the anaesthetist at a tertiary health care facility in Ghana", Southern African Journal of Anaesthesia and Analgesia, 2017

Introduction The concerns and experiences of caregivers, when their children undergo anaesthesia for cardiac surgery, are not always fully understood. Many of these concerns are inadequately addressed during the pre-operative visit by the anaesthetist (1). Very little research has been conducted in the South African context to gain insight into these concerns. Children presenting to the operating room for cardiac surgery pose many challenges for both the child and the caregiver due to the nature of the illness (2). Congenital heart disease is fairly prevalent in South Africa affecting 0.6 to 0.8 children out of every 1000 live births, which equates to approximately 11 000 children annually (3). If the appropriate treatment is provided then the survival to adulthood is around 85 % (3). Through identifying caregivers' experiences and concerns, anaesthetists will be able to gain better insight into what caregivers would prefer to know when their children undergo anaesthesia for paediatric cardiac surgery. By gaining this insight, anaesthetists will be able to have more goal directed, multi-faceted discussions with caregivers. The discussions could include multidisciplinary teams. This may result in a better overall experience for families when children undergo cardiac surgery (4). Methods Design The study was designed as a descriptive, exploratory qualitative study. A phenomenological perspective was used to understand and describe the caregivers' experiences and give them meaning (5). Setting and participants The population group studied were caregivers of children undergoing cardiac surgery at Nelson Mandela Childrens' Hospital. This hospital operates as a referral facility specialising in tertiary care paediatric surgery. A purposive sampling method was used to select participants within the post- operative cardiac ward (6). Inclusion criteria consisted of caregivers of children that underwent cardiac surgery

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Appendix 5: Journal guidelines to authors

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Conflicts of Interest and Source of Funding: "Author A" has received honoraria from "Company 1." "Author B" is currently receiving a grant (#12345) from "Organization Y," and is on the speaker's bureau for "Organization X" — the CME organizers for Company 1. For the remaining authors none were declared.

Human and Animal Subjects. All studies of human subjects must contain a statement within the Materials and Methods section indicating approval of the study by the Institutional Review Board (or institutional review body) that subjects have signed written informed consent, or that the Institutional Review Board waived the need for informed consent. ***Before* your submission can be sent out for peer review, it is necessary that you address this issue of institutional review approval.** This is in accordance with the International Committee of Journal Editors uniform requirements for manuscripts submitted to biomedical journals. Please see http://www.icmje.org for more details. All animal studies must contain a statement within the Materials and Methods section confirming approval by the Institutional Animal Care and Use Committee and that the care and handling of the animals were in accord with National Institutes of Health guidelines or other internationally recognized guideline for ethical animal treatment.

Statistical Review. Any study containing quantitative data and statistical inference should be reviewed by a consultant with formal statistical training and experience.

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MANUSCRIPT CONTENT

Title Page. The title page should contain 1) the title; 2) first name, middle initial, and last name of each author; 3) highest academic degrees, fellowship designations, and institutional affiliation for each author; 4) name of the institution(s) where the work was performed; 5) the address for reprints and a statement regarding whether reprints will be ordered; and 6) financial support used for the study, including any institutional departmental funds. The authors should also provide six key words for indexing, using terms from the Medical Subject Headings list of Index Medican. Structured abstracts are required for all manuscripts (except editorials, letters, and book reviews) submitted to *Pediatric Critical Care Medicine.*

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Text Material. The text should be organized into the following sections: Introduction, Materials and Methods, Results, Discussion, and Conclusions followed by Acknowledgments, References, Figure Legends, and Tables. Secretarial and editorial assistance are not acknowledged. Results may be presented in the text, in the figures, or in the tables. The Discussion section should interpret the results without unnecessary repetition. References to related studies should be included in the text section.

In addition, the following should be observed:

- The full term for which an abbreviation stands should be used at its first occurrence in the text unless it is a standard unit of measure. The abbreviation should appear in parentheses after the full term. Abbreviations should not be in the title, figure legends or table titles.
- For standard American units, do not use values that are more significant than your analysis is capable of accurately measuring (e.g., $Paco_2$ 84 torr [11.2 kPa], not 83.7 torr).
- Hemodynamic measurements for pressure (e.g., MAP) should appear in mm Hg and gas tension measurements (e.g., Po_2) should appear in torr with SI units in parentheses. The units of vascular resistance are dyne. sec/cm^5.
- Please provide r^2 values for parametric data.

References. All references should be cited in sequential order in the text and typed on a separate sheet of paper. References should be identified in text, tables, and legends by full-size Arabic numerals on the line and in parentheses. Do not use wordprocessing footnote, endnote, or paragraph numbering functions to make a list of references. Titles of journals should be set in italics and abbreviated according to the style used in *Index Medicus.* If journal titles are not listed in *Index Medicus* they should be spelled out. Unpublished data or personal communications should be noted parenthetically within the text but not in the References section. Inclusive page numbers (e.g., p. 1-10) should be used for all references. Listed below are samples of standard references; however, a complete listing of references can be found on the International Committee of Medical Journal Editors Web site, www.icmje.org.

Standard Journal Article: Bone RC, Fisher CJ, Cemmer TP, et al: Sepsis syndrome: A valid clinical entity. *Crit Care Med* 1989; 17:389-393

Standard Book with Authors: Civetta JM, Taylor RW, Kirby RR. Critical Care. Third Edition. Philadelphia, Lippincott, Williams & Wilkins, 1996

Standard Book with Editors: Norman IJ, Refern SJ (Eds): Mental Health Care for Elderly People. New York, Churchill Livingstone, 1996

Standard Chapter in a Book: Phillips SJ, Whis-nant JP: Hypertension and stroke. *In:* Hypertension: Pathophysiology, Diagnosis and Management. Laragh JH, Brenner BM (Eds). Second Edition. New York, Raven Press, 1995, pp 465-478

Standard Web Site/Electronic Format: Marion DW, Domeier R, Dunham CM, et al: Practice management guidelines for identifying cervical spine injuries following trauma. Available at: http://www.east.org. Accessed July 1, 2000

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2. Create, scan, and save your artwork and compare your final figure to the Digital Artwork Guideline Checklist (below).
3. Upload each figure to Editorial Manager® in conjunction with your manuscript text and tables.

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- Crop out any white or black space surrounding the image.

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- Photographs, radiographs, and other halftone images must be saved at a resolution of at least 300 dpi.
- Photographs and radiographs with text must be saved as postscript or at a resolution of at least 600 dpi.
- Each figure must be saved and submitted as a separate file. Figures should not be embedded in the manuscript text file.

Remember:
- Cite figures consecutively in your manuscript.
- Number figures in the figure legend in the order in which they are discussed.
- Upload figures consecutively to the Editorial Manager® Web site and number figures consecutively in the Description box during upload.

For captions and variables within a figure, use Helvetica (or Arial) font, if possible, in upper and lower case letters. Radiographic prints must have arrows (if applicable) for clarity. Color photographs will occasionally be published in the journal if use of color is vital to making the point; authors will be charged the cost of color reproduction. Figures that do not conform to these specifications will be sent back to the corresponding author for correction.

Figure legends should contain enough information for the reader to understand the illustration without referring to the text, but should be concise and should not repeat information already stated in the text. Figure legends should be typed on a separate page. Figures must be referenced sequentially in the text. Authors must assume charges for changes made to figures after manuscripts are accepted.

Units of Measure. Authors should provide units of measurement in SI units. Authors should refer to the *American Medical Association Manual of Style*, Tenth Edition (p. 787) for details regarding SI units for laboratory data.

Manufacturer. Provide in parentheses the model number, name of manufacturer, their city, and state or country, for all equipment described in the paper.

Drug Names. Only generic drug names should be used. Trademark or brand names should not be used except in specific cases where the brand name is essential to reproduce or interpret the study. These exceptions should be noted in accompanying correspondence. The manufacturer with the city, state, and country must be provided for any brand name drugs.

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Laboratory Investigations. These include laboratory and animal research. This category of manuscript has a word limit of 2000 to 4000 words (8-16typed double-spaced pages) which includes an abstract of no more than 300 words; the Discussion section of the manuscript should be limited to no more that 1500 words; a maximum of 40 references; and no more than 7 Figures and/ or Tables.

Review Articles. These consist of critical assessment of literature and data pertaining to clinical topics.In review articles, emphasis should be placed on cause, diagnosis, therapy, prognosis, and prevention. Information concerning the type of study or analysis, population, intervention, and outcome should be included for all data used. The selection process used for all data should be described. Meta-analyses will be considered as review papers. The recommended length of review articles is 2000 to 3000 words (8-12 typed double-spaced pages) which includes an abstract of no more than 300 words; a maximum of 100 references; and no more than 10 Figures and/or Tables.

Brief Reports. These should be short reports of original studies or evaluations. The recommended length of brief reports is no more than 1500 words (6 typed double-spaced pages) which includes an abstract of no more than 300 words; a maximum of 25 references; and no more than 2 Figures and/or Tables.

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Evidence-Based Journal Club. These articles provide an evidence-based critique of a recent important paper in the field of pediatric critical care medicine. The recommended length is no more than 1500 words (6 typed double-spaced pages) which includes an abstract of no more than 300 words; a maximum of 25 references; and no more than 4 Figures and/ or Tables.

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Correspondence can also be sent to:
Patrick M. Kochanek, MD, MCCM
Editor, *Pediatric Critical Care Medicine*
Society of Critical Care Medicine
500 Midway Drive
Mt. Prospect, IL 60056

Appendix 6: Charlotte Maxeke Johannesburg Academic Hospital CEO Approval

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. X Dhlamini
Office of the Clinical Director
Email: Xolisane.Dhlamini@gauteng.gov.za
Tell: (011): 488-3710
05 November 2019

Dear Dr. P Kielty

STUDY TITLE: Caregivers' Concerns and Experiences with Their Childs' Peri-Operative Care When Undergoing Cardiac Surgery

Permission to conduct the above-mentioned study is provisional approved. Your study can only commence once Ethics approval is obtained. Please forward a copy of your Ethics Clearance Certificate as soon as the study is approved by the Ethics Committee for the CEO's office to give you the final approval to conduct the study.

Supported / ~~not supported~~

Dr. M.I. Mofokeng
Clinical Director
DATE: 8/11/2019

Approved / not approved

Ms. G. Bogoshi
Chief Executive Officer
DATE: 11.11.2019

Appendix 7: Permission letter from CEO of Nelson Mandela Children's Hospital

Nelson Mandela Children's Hospital
A family dedicated to care

Date: 4th March 2020

Title of Research Project	**: Caregivers' Concerns and Experiences with their Childs' Peri-Operative Care when Undergoing Cardiac Surgery**	
Department or Programme	**: Anaesthesiology**	
Supervisor	**: Dr Janine Wagner**	**Co-Supervisor: Dr Julie-Ann Herbst Dr Palesa Motshabi**
Primary Investigator	**: Dr Patrick Kielty**	

Dear Dr Patrick Kielty

You have been given permission to conduct research at Nelson Mandela Children's Hospital. Please note that the following conditions should be met:

You have been given permission to conduct research at Nelson Mandela Children's Hospital. Please note that the following conditions should be met:

1. Ethical Approval should be sort from a Human Ethics Research Committee of any recognised institution. Once such approval is granted, it must be submitted to the Hospital Research and Ethics Committee for record-keeping.
2. There will be no cost to the hospital associated with conducting this research.
3. Once the research is completed, the Hospital will be notified, and a report of the results provided.
4. The hospital will be acknowledged in any publications and presentations that will be given in relation to this research.

Documents submitted and required:

Title of document	Required documents
Approval from Ethics Committee	
Ethics Clearance Certificate	
Research Protocol	
Report of the results	

All the best with your research

Recommended/Not Recommended

Prof. Hopewell Ntsinjana / ~~Dr Andrew Grieve~~
Academic Committee Chairperson / ~~Deputy Chairperson~~
Date: 05/03/2020

NPC Registration No: 2011/009134/08
Web address: http://www.nelsonmandelachildrenshospital.org
P.O. Box 797, Highlands North, 2037. 6 Jubilee Road, Parktown 2193. Tel: (+27 10) 133-0600

Appendix 8: Permission letter by the Anaesthesiology Head of Department

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

WITS UNIVERSITY

Department of Anaesthesia – University of the Witwatersrand

7 York Road, Parktown, 2193 South Africa • Telegrams "Witsmed" • Telephone (011) 488-4344 • Fax (011) 488-4343

Department of Anaesthesia
Area 361
Charlotte Maxeke Johannesburg Academic Hospital

Tel: 011 488-4344

18th September 2019

Subject: **Permission to conduct survey from Department of Anaesthesiology**

To whom it may concern,

This letter stands to affirm that I, Dr PMV Motshabi, grant permission to Dr Patrick Kielty HPCSA number MP 0766747, to conduct survey in Department of Anaesthesiology at University of Witwatersrand for his study "Caregivers' concerns and experiences with their childs' peri-operative care when undergoing cardiac surgery".

The approximate period will be, but not limited to, the months of January 2020 to June 2020, until his sample size is obtained. The information obtained from the data will be used for Dr Kielty research study for his Masters in Medicine only, and will include information and data relevant to his study.

Yours sincerely,

WITS UNIVERSITY

Dr Palesa Motshabi
Academic Head: Department of Anaesthesia
Head of Clinical Unit: Cardiac Anaesthesia

Tel: +27 (0)11 488 4344
Cell: 083 432 1594
Email: palesa.motshabi@wits.ac.za
Website: www.wits.ac.za

WITS SCHOOL OF CLINICAL MEDICINE

FACULTY OF HEALTH SCIENCES

Charlotte Maxeke Johannesburg Academic Hospital, 6th Floor, Area 361/16, Jubilee Road, Parktown, Johannesburg

Appendix 9: Interview Guide

1. When did you first find out that your child was sick?
2. How did it make you feel? (Probe depending on answer given)
3. When you were told that you child required surgery, what were your thoughts and feelings about this?
4. On the day of your child's surgery, how were you feeling that morning?
5. Explain what you think an anaesthetist is in your own words.
6. Did the anaesthetist for your child's surgery speak to you before the operation? If so, what did he/she say to you?
7. Did you ask him/her any questions? If so, what did you ask and why?
8. After speaking to the anaesthetist, how did you feel?
9. If you could have a chance to speak to the anaesthetist again, is there anything else you would have liked to have known before the surgery? If so, why?
10. When you walked into the theatre with your child how did you feel?
11. Explain in your own words what you think it means to be put under anaesthetic.
12. How did you feel about your child receiving anaesthetic and why?
13. Were you present when they put your child to sleep? If so, can you explain to me in your own words what happened? What were you thinking? How did you feel? If you were not present, why not?
14. When your child was in theatre and you were in the ward, what did you do to keep yourself busy?
15. What were you expecting when the surgery was over?
16. When you first saw your child after the surgery, how did you feel?
17. Now that the surgery is over, how do you feel now? Are you feelings different from before the surgery and how so?
18. How do you think you have handled your feelings before, during and after your child's operation? Is there anything that has helped you cope?
19. When you are allowed to go home with your child, how do you think you will feel?

Summarising questions:

1. How would you describe your overall experience? Why?
2. What do you think the doctors and nurses could do differently to improve the experience?
3. Is there anything else you would like to tell me that we haven't already discussed?

Thank participants and end the interview.

Appendix 10:Patient Information Letter

Study Title: Caregivers' concerns and experiences with their childs' peri-operative care when undergoing cardiac surgery

Hello

My name is Patrick Kielty. I am a doctor who is studying to specialise as an anaesthesiologist at the University of the Witwatersrand. An anaesthesiologist is a doctor that gives patients medicine in order to make them sleep for their operation.

For my degree I am doing a research study and I would like to invite you to take part.

I am conducting the study in order to try to find out what caregivers, like you, experience when their child is coming for cardiac surgery. The reason for the study being done is that doctors can use this information in the future to try to improve the experience of other caregivers.

If you agree, I will sit with you and ask you questions about how you feel. This should not take longer than 30 minutes. We will be doing the interview in a private room in the ward. With your consent, the interview will be audio recorded to keep a record of the questions and answers given.

After you have answered the questions, we can discuss the things that you were asked and I will explain anything that you do not understand. You are free to ask any questions that you have about the study and I will explain further. If you have any questions that you only think of after the interview, you can contact me later.

Being part of this study will not affect the treatment of your child in any way.

If at any point during the interview you feel that you do not want to answer, you do not have to and you can withdraw from the study at any time. If you wish to withdraw from the study, neither you nor your child will be disadvantaged in any way.

If you feel at any point that you are distressed or are not able to cope emotionally then you may wish to book an appointment with a clinical psychologist at Charlotte Maxeke Academic Hospital. Please feel free to contact Maleney Naidoo, a senior clinical psychologist, on 076 156 0236, in order to set up an appointment. She will be able to provide counselling, at no extra cost to you, and will help you to find ways to cope with your emotions.

If you chose to be involved in the study, you may decide whether you want the interview to be done in English or isiZulu. If you chose to be interviewed in isiZulu, the questions will be asked in isiZulu by a translator, Anele Jiyane.

The only people who will look at the answers to the questions will be my supervisors and I, and the translator (if interviewed in isiZulu). I will not be using people's names as part of the study and we will be assigning numbers to all the people who are interviewed. No-one will know that you have been interviewed except for my supervisors and me.

The study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand. The function of this committee is to protect the rights and dignity of all people who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study was done, please contact the Chairperson of this Committee, Professor Clement Penny, who may be contacted on 011 717 2301, or by e-mail on clement.penny@wits.ac.za. The telephone numbers for the Committee secretary are 011 717 2700/1234 and the e-mail addresses are zanele.ndlovu@wits.ac.za and rhulani.mukansi@wits.ac.za.

For more information you may contact me on 083 683 9906 or e-mail me at patrick.kielty@ymail.com.

You will be given a copy of this form to keep and will be asked to sign consent forms to confirm that you agree to be interviewed and that you agree for the interview to be audio recorded.

Thank you very much for your time.

Appendix 11: Consent for participation

Informed consent for interview participants

I, _____ (name of participant), confirm that I have read and understood the written information letter, that was attached above, for the study entitled "Caregivers' concerns and experiences with their childs' peri-operative care when undergoing cardiac surgery".

- I have asked any questions that I had and am satisfied with the answers.
- I am aware that the researcher will keep all information confidential throughout the study through the use of a study number.
- I am aware that the results of this study may be presented in the form of a written report, an academic presentation, and/or a publication.
- I understand that I do not have to answer questions I am not comfortable with, and that I may withdraw from the study at any time without any disadvantage being held against me.

Participant:

I give my consent to take part in this study.

Participant name: _____

Participant signature: _____

Date: _____

Researcher:

I _____ (name of researcher) hereby confirm that the above participant has been fully informed about the nature, conduct, risks, and benefits of the above study.

Researcher signature: _____

Date: _____

Appendix 12: Consent for audio recording interview

Informed consent for audio-recording from interview participants

I, _____ (name of participant), confirm that I have read and understood the written information letter, that was attached above, for the study named "Caregivers' concerns and experiences with their childs' peri-operative care when undergoing cardiac surgery".

- I have asked any questions that I had and am satisfied with the answers.
- I am aware that the researcher will audio record the interview on an electronic device and then transcribe the conversation onto a computer.
- I understand that only the researcher and translator (if required) will have access to the electronic files.
- I am aware that the researcher will keep all information confidential throughout the study, and that my data will be unidentifiable as I will be assigned a study number.
- I am aware that all recorded information and transcripts will be destroyed after six years of completing the study.

Participant:

I give my consent for the researcher to audio record the interview for this study.

Participant name: _____

Participant signature: _____

Date: _____

Researcher:

I _____ (name of researcher) hereby confirm that the above participant has been fully informed about the nature, conduct, risks, and benefits of the above study.

Researcher signature: _____

Date: _____