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AN ANALYSIS OF THE IMPACT ON THE QUALITY OF LIFE OF MOTHERS WHO HAVE A CHILD WITH A CLEFT LIP AND PALATE

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements of the degree of Master of Family Medicine

January 30, 2013

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Co-Supervisor: Dr T. H. Smith

Declaration

I, Zaheda Bhabha, declare that this research report is my own work. It is being submitted in partial fulfilment of the degree of Master of Family Medicine at the University of the Witwatersrand, Faculty of Health Sciences. It has not been submitted before for any degree or examination at this or any other university.

Signed: Zaheda Bhabha

Student No. 9701165V

Date:_____

Dedication

I would like to dedicate this work to my parents, Amina and Aboo Baker Bhabha, for their continuous encouragement to better myself, my husband Naseem for his endless patience and help, to my daughter Zuhaira who inspired me to do this research due to her condition and to my son Ahmed who always understood that mom needed to work hard on this project.

Abstract

A descriptive study was undertaken on mothers who have children with non-syndromic cleft lip and palate. It involved 42 mothers from one public and one private hospital in Johannesburg during the period starting January 2009 and finishing in December 2009. A self-administered questionnaire was used to determine the Impact on the Quality of Life exerted by these children on their mother's lives.

The majority of the mothers in the study are African or White, comprising 11 African, 17 White, seven Indian and four Coloured mothers. Thirty-five (35) were married, one was single, and five chose not to respond. Twenty-one (21) of the mothers interviewed had high school education and 19 tertiary education. Thirty-one (31) were employed; seven unemployed and two gave no response.

Sixty-five percent (65%) of the children are male and 35% are female of whom 48.8% were diagnosed prenatally and 51.2% postnatally. Only forty-seven percent (47%) of participants received adequate counselling during prenatal and postnatal care while 53% did not. Seventy-eight percent (78%) of the women in the study said they would attend prenatal care for their subsequent children.

Impact on Family Scale

This study examined the difference in quality of life for the family after the birth of the affected child as compared to before the birth assuming that parents lived a near normal life before the birth of their child. It can be seen that the majority of the women identified the following five items: being overtired and exhausted; managing to cope with the condition; family becoming closer as a result of the illness; partners analysing problems together; and treating the child as normally as possible as affecting their quality of life.

There is no significant difference in most of the items across the four races. That is, African, White, Indian and Coloured mothers assessed the items similarly, except when considering the question of additional income being required to cover medical expenses: here African and Coloured mothers found that more income was required to cover medical expenses while Indian and White mothers disagreed.

When comparing the relationship between the level of education of mothers and the impact on the family there is a similar trend as regards race. There is no significant difference in the items between the two levels of education, except for the need to reduce time spent at work to care for the sick child, and travelling to hospital which both add to the mental and a physical strain. Mothers with a tertiary education found that this was not a problem; however those with a high school education found that it impacted badly on their lives.

Most parents said they would have preferred an antenatal diagnosis and adequate counselling prior to the birth as well as post-delivery, and they will access this service for subsequent children.

The research highlights important factors affecting parents whose children have cleft lip and palate. Among the most important of these are that a prenatal diagnosis is preferred in most cases, also that counselling—both in the prenatal and postnatal period—plays a vital part in managing the sick infant. Other important findings highlighted were that mothers with a tertiary education had lower-impact scores than mothers with a high school education; also that families found themselves drawn together and helping one another manage circumstances better.

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Dr. Anne Wright, my research supervisor, for all her encouragement, support and advice throughout this process. I would also like to thank Dr. T. H. Smith for all her support and for co-supervising this project.

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Professors L. A. Chait and Bruce Sparks for encouraging me to use my daughter's condition as an opportunity to undertake further study to help understand how the situation affects other families.

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LIST OF ABBREVIATIONS

HRQoL	Health Related Quality of Life
OFC	Oro facial clefting
CLP	Cleft lip and palate
HADS	Hospital Anxiety and Depression Scale
CL	Cleft Lip
CP	Cleft Palate

CHAPTER ONE: INTRODUCTION

1.1 Rationale for the study

With increases in congenital malformation and chronic illness in children, and with cleft lip and palate being one such issue with an average incidence of 1:700 live births, the number of families with a chronically ill child has also obviously increased. This increase is combined with a transfer of increasingly complex medical care to the home situation. Furthermore, the demographics of families have changed over the last couple of decades so that families are generally smaller in size, there is a higher ratio of single-parent families and mothers are more often in employment.[1]

These changes to the family structure result in medical personnel needing to have a better understanding of the consequences for families, particularly a mother caring for a chronically ill child. The care-giving demands can be extensive and may lead to adverse psychosocial consequences for parents.

When the researcher was 16 weeks pregnant after undergoing a foetal abnormality scan at the foetal medicine specialist, she and her husband were informed that their child had a cleft lip and palate. They were told at that time that the extent was difficult to ascertain and also that other abnormalities could be associated with a cleft lip, but these were impossible to diagnose. The researcher and her husband went through the next six months in a daze of confusion, carrying out research, reading, meeting other doctors and specialists in this field, and trying to find the best way forward for their child. All of this was only possible because both were medical doctors. Because of this they were able to go out and obtain the relevant information. From their personal experience, from the time of diagnosis to the time of delivery and moving forward, no help was volunteered: the researcher and her husband learned that if any assistance was needed, they had to seek the help themselves. Support groups were few and far between and specialists in this field were hard to find. Resources and reading material were also quite limited and thus finding answers to simple questions presented a challenge. It was as a result of this experience that the topic for this study was conceived.

The researcher wanted to know how having a child with this type of defect impacted on the life of a mother. How do mothers perceive this impact and how does it change their lives? Does

having a child with a cleft lip and palate affect all other parents as it affected the researcher? Do they also feel scared, embarrassed, hurt, let down, anxious, and even ill as a result of the ill-health of their child? How do parents who are unable to access this information before the birth deal with the situation? Do they cope better because they have less time to ponder and more time to act? Would they have preferred a prenatal diagnosis? Would parents who had a prenatal diagnosis prefer to have not had it, and would they have experienced a better pregnancy had they not known?

In a study by Hartzmann et al.[2], parents of chronically ill children were found to be at risk for an impaired Health Related Quality of Life (HRQoL), particularly concerning vitality, sleep, daily activities, social functioning and depressive emotions. Up until now, most studies have explored direct predictors of parental well-being and HRQoL, and positive associations were found with higher socio-economic status, coping style, few child behaviour problems, less care-giving demands, more social support and an older age[3]. To the researcher's knowledge, most of the studies addressed adaptation to illness in diseased populations in children or adults, and only a few studies focussed on parental well-being. More specifically, this study addresses the deficit of information on the quality of life of mothers after the birth of such a child, particularly a child with cleft lip and palate.

In his study the researcher uses the Impact on Family Scale in an interview with mothers who have a child with a cleft lip and palate and attempts to measure the changes in family life. Results obtained from this study will be compared to the study done by Kramer et al.[13] and deductions will be made to see if the impact on families with a baby who has a cleft is comparable to both First and Third World countries.

When dealing with families, the family physician plays an important role in offering support. Both parents and child need help in dealing with the everyday issues that arise; initially the depression of the mother and subsequently assisting parents with feeding and other related issues that may arise. It is here that an understanding and well-informed family physician becomes a valuable resource to the family.

1.2 Aims

To explore the impact on the quality of life of mothers whose children have been born with a cleft lip and palate.

1.3 Objectives

To explore:

1. The demographic features of mothers: age, race, marital status, level of education, employment status of parents, sex of child and parity.
2. The difference in quality of life after the birth of the affected child.
3. The adequacy of postnatal counselling with regard to the condition of the child.
4. Parental preference regarding the prenatal diagnosis.
5. Whether a prenatal diagnosis will be requested in all subsequent pregnancies.

CHAPTER TWO: LITERATURE REVIEW

2.1 Incidence

It is well known that 3% to 4% of all pregnancies result in the birth of an infant with a major birth defect or a genetic problem. Nevertheless, most parents approach pregnancy anticipating the birth of a healthy and structurally normal child. Cleft lip and palate is one of the most common congenital malformations in the head and neck region with an average incidence of about 1:700 live births; non-syndromic orofacial clefts are the most frequent craniofacial embryopathy in humans[4].

The etiology of clefting is still unclear; it is most likely that both exogenous (teratogenic) and endogenous (genetic) factors contribute[5]. In most patients, the diagnosis of an orofacial cleft is made by clinical examination at birth but the number of patients diagnosed before birth by ultrasound examination is increasing. Facial clefts and other craniofacial abnormalities are usually discovered from ultrasounds performed for indications other than the risk of clefts or craniofacial abnormality.

2.2 Prenatal diagnosis

Many studies were under taken to determine the validity of ultrasound examination, an example of such a study was undertaken in Europe to determine the validity of ultrasound examinations of foetuses diagnosed with clefts prenatally: comparing the seven foetuses diagnosed prenatally with the actual finding postnatally, only three of the clefts were accurately diagnosed, three were underestimated and one was overestimated[6]. These results demonstrate the validity of the ultrasound findings made by an experienced sonographer. This study helps the researcher to identify whether an accurate prenatal diagnosis would play a vital part in the management of the child postnatally, and how this prenatal diagnosis would impact on the quality of life of the mother postnatally.

2.3 The need for prenatal ultrasounds

Ultrasound examinations are viewed by the general public as a method of obtaining the first baby picture and at the time, parents are usually not expecting the sonographer to identify a birth

defect. The initial shock caused by the discovery of a cleft is followed rapidly by fear, anger, guilt and sadness as couples grieve for the loss of the anticipated normal child[7], almost in the same manner as when people grieve the loss of a loved one. It is during this period of uncertainty that parents require the most support and counselling. Parents also have to make provision for the increase in medical costs required to bring up a child with this type of abnormality as well as the uncertainty and lack of knowledge about providing for the special needs of their child.

2.4 The South African perspective regarding ultrasounds

In South Africa, a foetal anomaly scan is not routinely offered to all pregnant mothers, only to a select few. It is offered when patients are at a high risk of a congenital abnormality based on family history, and to parents on medical aid who wish to have the scan done, and parents who will have it done after pressure from the gynaecologist. However, because of the increased cost, most opt to omit this scan.

2.5 The foetal abnormality scan

Foetal abnormality screening is a specialized technique carried out at between 11 and 13 weeks of gestation and then again at 20 weeks by an obstetrician who specializes in foetal medicine. In the private healthcare sector, parents may elect to have the abnormality screen or not, and thus the defect may go undetected by the attending physician. It is for this reason that the majority of cleft babies are only discovered at birth.

2.6 International reviews of ultrasounds and prenatal diagnosis

Giving birth to a child with a cleft lip and palate can be emotionally traumatic for parents. The facial appearance awakens negative feelings and reactions in others such as family friends or strangers seeing the child for the first time. Feeding and caring for these children in the neonatal period has been known to be difficult.

In order to understand parent's experiences of having a child born with a cleft lip and palate, a study was undertaken in Sweden, this study also helped the researchers understand how parents perceived the encouragement, social and mental support from professionals, family and friends[8]. The study helped to explain how parents dealt with the situation, in particular, the first meeting

of the parent with the child, the trauma of not having the perfect child for whom they had hoped, the grieving process and finally the slow acceptance and adaptation to the situation. Parents described the importance of a knowledgeable and helpful craniofacial team, but also commented that the lack of knowledge exhibited by other healthcare professionals—especially in the primary care field—made it difficult and expensive to obtain help on a day-to-day basis. Feeding advice, which is particularly crucial to parents at this time, was also poorly meted out. Family and friends commented on the child positively or by being neutral, which was seen as a lack of interest. A visible scar on the face, especially in the case of a girl, was also seen as a problem. Most parents also demonstrated anxiety at the possibility of their child having speech defects. Judging from the comments and findings in this study, it is evident that the child with a visible/conspicuous birth defect, such as a cleft lip, brought with it many functional, emotional, financial and social strains for the family that have never been accurately measured or ameliorated. The aim of this study is to measure that impact and assist healthcare teams to provide the necessary care to the child and parents.

Other studies like the one carried out by the Department of Surgery at Duke University Medical Center, Durham, North Carolina, again demonstrated that parents go through a tremendous amount of stress, anxiety and fear following the discovery that their child has a cleft[9]. This study established that professionals need to be available to assist with the adjustments and transitions that parents of cleft babies will face. This study also indicated the following:

- The parents' needs appear to be greatest at the times of transition: birth, operation and schooling.
- Feelings of loss and grief accompany the birth of a child with a cleft. The greatest loss is that of having an imperfect child and coming to terms with, and loving, this imperfect child.
- Financial issues often burden these parents and they find marked difficulty in dealing with these or even talking about them.
- Different parents have different needs based on their education level, extent of the cleft and familiarity with clefting. These factors tend to determine how well parents deal with the birth of the child with the cleft.

- Cleft palate team members thus have multiple avenues to help parents deal with the cleft baby and offer support.

The birth of the baby is the point at which the availability of a well-structured craniofacial team becomes particularly important. Team members can step in and offer optimism and hope both for the family and the subsequently to the patient. This then becomes the starting point of treatment for family and patient.

It is this information that has the first impact on the quality of life of the mother and family. It is accepted that concern for their children's wellbeing is foremost in most parents' minds from the moment that they are informed of a medical condition.

2.7 The Impact on Family Scale

The Impact on Family Scale[10] was developed as a tool to try to measure the impact that childhood illness has on the family structure. This scale was designed for use with the mother as the respondent in an interview. The assumption was that changes occur in the family because of illness, thus forcing the family to make adjustments in its immediate environment. The focus is on any change in the normal behaviour of the family that is directly attributable to illness. In the development of this scale, particular focus was given to any negative impact on the family, but it is also possible that some unifying function can be gained from the illness, by mobilizing the family to interact around shared negative experiences and by the provision of new roles for members. These negative impacts are thematically arranged in terms of losses, financial burden, restrictions on social life, decreased interaction with significant others, less time for other family members and increased subjective distress and strain[10].

In order to investigate the experience of receiving the diagnosis of clefting in both the prenatal and postnatal period, a study was done in the United States, this time at the University of Pittsburgh, Pennsylvania. The following common views emerged, based on the initial period between the delivery of the diagnosis and preparation for the birth of the child. Of the parents who received the news postnatally, some felt that a prenatal diagnosis would have been more beneficial as that they could have planned for the birth, and parents who had received the diagnosis prenatally validated this comment. Parents were then faced with other issues, namely:

the option to terminate, the extent of disease, as well as seeking and sifting through the information available on the Internet regarding clefts and craniofacial abnormalities[11].

2.8 Other studies using this scale

A study undertaken in Germany by Kramer et al.[12] to determine the impact on a family having a small child with a cleft lip and palate, demonstrated after interviewing the mothers, and using the same Impact on Family Scale, that parents have to compensate both financially and emotionally for the increased strain that the child with an orofacial cleft brings with it. Parents found themselves more burdened socially and economically after the birth of the affected child while the extent of the clefting also played an important part in the burden that parents perceived. An incidental finding from this study was that a prenatal diagnosis did not decrease that impact on the family in any way but the prenatal diagnosis meant that the stress began much sooner.[12]

Keeping with the above study by Kramer et al[19], earlier reports indicated that families might experience a reduced quality of life, particularly during the very early life of the cleft patient[13]: only families having children below two years of age were included in this study. At this age, families are confronted with both the birth of the cleft patient and the reality of the operations required for reconstruction. The instruments applied in this study included the Impact on Family Scale, which allowed a reliable and valid assessment of different types of impacts affecting the quality of life in families. Most of the observed impact on family scores ranged between 1 and 2 in this study. This suggests lower impacts in families having children with OFC when compared to certain other health conditions examined by Impact on Family Scale[14, 15, 16].

A study done by Weigl et al.[17] showed that the well-being of the mother of a CLP child is an important protective factor for the child, since up to now little attention has been paid to this topic. In this study, 50 mothers of CLP children aged from one to ten years were examined using the 36-item Short-Form Health Survey and the Hospital Anxiety and Depression Scale (HADS) to screen for quality of life, anxiety and depression. In cases with a deteriorated quality of life, it was important to pay attention to the mental health and wellbeing of the mother so as to facilitate good care and eventual emotional stability and improved self-esteem for the child.

2.9 Adaptability of the study to South Africa

It has already been ascertained that a cleft child places significant strain postnatally on the family structure financially, emotionally and psychologically, but no study has been carried out in South Africa to measure the impact of this strain on the family. South Africa is vastly different from Germany where the comparative study was done. South African families are on average poorer and have less access to tertiary medical care. In South Africa there is no social medical insurance to assist in easing the parental burden of caring for a child with special needs.

In his study the researcher uses the Impact on Family Scale in an interview with mothers who have a child with a cleft lip and palate and attempts to measure the changes in family life. Results obtained from this study will be compared to the study done by Kramer et al.[13] and deductions will be made to see if the impact on families with a baby who has a cleft is comparable to both First and Third World countries.

When dealing with families, the family physician plays an important role in offering support. Both parents and child need help in dealing with the everyday issues that arise; initially the depression of the mother and subsequently assisting parents with feeding and other related issues that may arise. It is here that an understanding and well-informed family physician becomes a valuable resource to the family.

CHAPTER THREE: METHODOLOGY

3.1 Study Design

This is a descriptive study on all mothers who have children with cleft lip and palate.

3.2 Site of the Study

Hospitals identified were all hospitals in Johannesburg where cleft lip and palate surgery is performed, namely:

- Charlotte Maxeke Johannesburg Academic Hospital is a university hospital where the majority of cleft surgery is conducted in the public sector. The international Smile for Life Foundation also subsidizes Smile Week at this hospital, making it an ideal access point. The departments participating in this study were the Department of Obstetrics and Gynaecology, the Department of Plastic Surgery, as well as the Wits Dental Hospital and the School of Oral Health Sciences.
- Park Lane Clinic is a private clinic where a large amount of private cleft lip and palate surgery is conducted. Vodacom, a private cellular phone company, subsidizes the Smile Train where patients unable to afford private surgery are also operated on, on a *pro-bono* basis. In addition, the Vodacom Smile Train runs a support group for all parents of children with clefts at the Donald Gordon Medical Centre, Parktown, Johannesburg, on the first Wednesday of every month. Patients attending this clinic who fit the profile for the sample population were also requested to assist with this study. Plastic surgeons operating at this hospital were requested to assist with patient identification.

3.3 Study population

The sample population included the mothers of all children diagnosed with orofacial clefting who fulfilled all inclusion and exclusion criteria and were attending the clinics at the selected hospitals.

3.4 Sampling: Sample Size

The sample size necessary to carry out non-parametric studies, as calculated by the statistician, worked out at approximately 50 with a loss to follow-up of 15%. Thus, the researcher anticipated collecting a sample of more than 35 patients. Because the population group is small, non-parametric studies are the best way to interpret data. The sample size for a non-parametric study is derived by calculating the sample size required for a reliable *t-test* and then adding 15%.

The formula $n = \frac{4s^2}{d^2}$ is used to calculate a sample size for a t test.

The sample size calculation used, to obtain a margin of error of 5 for a variable with a standard deviation of 15, was:

$$n = \frac{(4)(15^2)^1}{5^2}$$

=36

The sample size is therefore 36 + 15% = 41.4

The sample size collected involved 42 patients, in keeping with the number required to fulfil the criteria for non-parametric tests.

The majority of the study population came from the cleft lip and palate clinic at the Charlotte Maxeke Johannesburg Academic Hospital. The cleft lip and palate clinic at the Dental School sees patients from the greater Johannesburg area as far afield as Pretoria and Springs, and is the only clinic of its kind in this area. It is here that newborn children are brought immediately after birth to be fitted with an obturator in order to improve feeding. Patients involved with the Smile for Life Foundation as well as the Vodacom Smile Train are also seen at this clinic.

The clinic sees an average of between two and three newborn children per week both from the public and private sectors. The clinic is run by Professor Gerald Gavron who had agreed to allow the researcher to conduct the research there. Babies are seen weekly after being fitted with an obturator until the second operation is concluded at around age one year.

Professor L. A. Chait is a plastic surgeon in private practice who conducts both private as well as pro-bono surgery at Park Lane Clinic. He agreed to allow the researcher access to patients attending both his rooms and the Vodacom Clinic.

Dr. T. H. Smith, who is in the Obstetrics and Gynaecology Department at the Charlotte Maxeke Johannesburg Academic Hospital, had also agreed to request the Department of Obstetrics and Gynaecology to keep a record of all babies born with a cleft during the first six months of 2009 and inform the researcher so that they could be included in the study.

The sample population was collected over the first eight months of 2009 and a total of 42 parents were interviewed.

3.5 Data collection methods

Questionnaire: All data was collected and recorded on a questionnaire that was applied to all participating mothers by the researcher on a one-on-one basis. The data was collected, based on the questionnaires where mothers answered according to the Likert Scale, and recorded on the forms.

Consent: After first obtaining verbal consent from participating mothers, written consent was obtained and mothers were asked to sign a consent form. These forms were checked and validated before any questionnaire was filled out.

Interviews: The approximate duration of the interviews was 30-40 minutes. Mothers were interviewed at any time from the birth of their child up to its reaching 18 months. Interviews were conducted on all mothers at their first, as well as at their subsequent, Wednesday visits to the Cleft Palate Clinic at the Charlotte Maxeke Johannesburg Academic Hospital, which runs the dental school.

Mothers from the Smile Train Foundation were contacted first telephonically and then interviewed when they attended the support group run by the Vodacom Smile Train Foundation on the first Wednesday of every month at the Donald Gordon Medical Centre. Mothers were informed telephonically about the study that was being conducted, after which their clinic dates were noted by the researcher and follow-up interviews conducted as per appointment with the mother on their respective dates.

3.6 Measuring instruments

The measuring instrument used during the course of the study is the Impact on Family Scale. The Impact on Family Scale is a 24-item questionnaire measuring four dimensions of impact.

- *Financial burden* refers to economic consequences for the family.
- *Familial/social impact* concerns the disruption of social interaction.
- *Personal strain* assesses the psychological burden experienced by the primary caretaker.
- *Mastery* refers to the coping strategies employed by the family[18].

The instrument was used to detect a subjectively perceived quality of life in affected families. This was developed in the Anglo-American literature as a self-report instrument to measure the effects of chronic conditions and disability in childhood on family[19]. The same scale was used in the study carried out on cleft children in Germany by Kramer et al.[20], with favourable results. The questionnaire was administered and the questions answered and scored according to the Likert Scale. A total impact score was calculated by averaging all of the scores.

The scores are calculated by adding the score from 1 to 4 and dividing it by the number of questions. A high score will indicate a strong relationship whereas a low score indicates a weak relationship.

3.7 Inclusion Criteria

- Mothers of children with unilateral complete cleft lip and palate;
- Mothers of children with bilateral complete cleft lip and palate; and
- All mothers of children with clefts and aged under 18 months who are not affected by any syndromes.

3.8 Exclusion Criteria

- Mothers of children with cleft lips and palate associated with other syndromes
- Mothers of children with clefts and aged over 18 months.

- All mothers who did not give written consent

3.9 Analysis

The questionnaire was scored and scores were recorded in a database and analysed statistically using SPPS (Statistical Packages for Social Sciences) version 13. Owing to the size of the sample obtained as well as the structure of the data, comparative analysis was undertaken using the non-parametric Kruskal-Wallis, Mann-Whitney U and Friedman Tests.

In order to identify the interactions of several investigated parameters, a multivariate correlation analysis was performed.

All tests were performed at a significance level of 5% ($P<0.05$).

Impact on Family Scale: in this section, the researcher examined the perceived difference in the quality of life of the family after the birth of the affected child as compared to before the birth. First, the reliability (consistency) of the questionnaire was analysed with Cronbach's Alpha coefficient.

The frequency distribution and descriptive statistics are presented graphically or in table format.

When analysing the results of this study, the reliability (consistency) of the questionnaire with Cronbach's Alpha Coefficient was first analysed. The most common measure of internal consistency of a questionnaire is Cronbach's Alpha Coefficient. The range of the alpha is from 0 to 1. As a rule of thumb the alpha of a scale equals to 0 .70 or greater is acceptable for items to be considered reliable. Results of the reliability analysis are presented in Appendix A. Table 1 demonstrates the reliability of the Impact on Family Scale.

3.10 Bias

No real bias existed in selecting patients since patients attending the cleft clinic included both affluent and poor. The reason for this is that it is the only clinic of its kind in Johannesburg. No private dentists in Johannesburg offer this service to cleft babies.

The patients obtained through the Smile Train Foundation were not financially able to afford private medical care and were not on medical aid.

The researcher found herself particularly sensitive to the answers given by parents and sought to understand their opinions without interjecting due to her having a child with a cleft lip and palate.

3.11 Timing

The study was conducted over a one-year period. It commenced in January 2009 and was concluded in December 2009. Data was collected during the first eight months of the study, after which the analysis was carried out.

3.12 Ethics

The protocol was submitted to the Human Research Ethics Committee and approval was obtained. Clearance number M090309 was obtained on 27/03/09 (Appendix C).

Written consent was obtained from Professor W. G. Evans (acting Head of Orthodontics at the School of Oral Health Sciences, Wits Dental Hospital); Professor L. A. Chait (in his capacity as a professor involved in the Vodacom Smile Train Foundation); and Dr T. H. Smith (in his capacity as a Principal Specialist and Senior Lecturer in the Department of Obstetrics and Gynaecology at the University of the Witwatersrand). This was necessary in order to conduct the research at the specific hospitals as well as to have access to patient files so that patients could be contacted regarding their willingness to participate in the study (Appendices D, E and F).

All parents were issued with a consent form and an information form prior to conducting the interview. Consent was obtained from the mothers before the questionnaire and the interview. (Appendix B).

Mothers were informed of the study by the researcher on their initial visit to the clinic. The study was described and mothers were requested to allow the researcher to interview them. After written consent was obtained they were interviewed immediately; if not, their details were noted by the researcher and then given the information letter. They were then contacted a week later, prior to their visit to the clinic, to see if they had changed their minds. Parents were allowed to exclude themselves from the research at any point should they so wish, and no compulsion was placed on them to write their names or children's names on any of the questionnaires so that patient confidentiality could be maintained at all times.

3.13 Limitations

It is important to point out the specific challenges that were encountered during the research process as this may have a major impact on the data and the results. The researcher was only available periodically to interview patients and may have missed periods where there were different groups of patients that would have met this patient profile. Also, patients from specific socio-economic groups that either had their own transport or were able to access public transport formed the bulk of the patients interviewed. Parents in the lower socio-economic groups were thus automatically excluded from this study as the researcher had no access to them.

3.14 Funding

All of the costs of the research were borne by the researcher.

CHAPTER FOUR: RESULTS

4.1: Introduction

Two hospitals involved in treating children with cleft lip and palate were identified, one in the public sector and one in the private sector. In the two hospitals, three specialist departments were approached in order to help identify the suitable study population. A total of 41 mothers were identified who fulfilled all the inclusion criteria. Information and consent forms were handed out. The next step was an interview involving a questionnaire which included demographic information as well as the Impact on Family Scale: this was completed by the participating mothers as shown in Appendices A, B, G and H.

A total of 41 parents were interviewed and the results obtained are presented below.

4.2 Demographic Aspects

Table 1: The distribution of race across the study sample

White	**41.4%**
African	**26.8%**
Indian	**17%**
Coloured	**0.97%**

Table 2: The marital status of mothers in the study sample

Married	83%
Single	0.2%
No Reply	12%

Table 3: The level of education of the mothers included in the study

High School	52%
Tertiary	47%

Table 4: The employment status of parents

	Employed	Unemployed
Employment status of mother	82%	18%
Employment status of spouse	95%	5%

Table 5: The distribution of child's gender within the sample

Male	63.4%
Female	34.1%

The demographic aspects showed that this was not a fairly evenly balanced sample in the context of South African families: the race distribution was fairly skewed with the majority of the parents being White, and 85% were married, 52,5% had finished high school level of education and 82% of the parents were employed. The frequency of distribution of the gender of the child was in line with the general statistics as 65% of the children affected with cleft lip were boys.

4.2 Diagnostic aspects

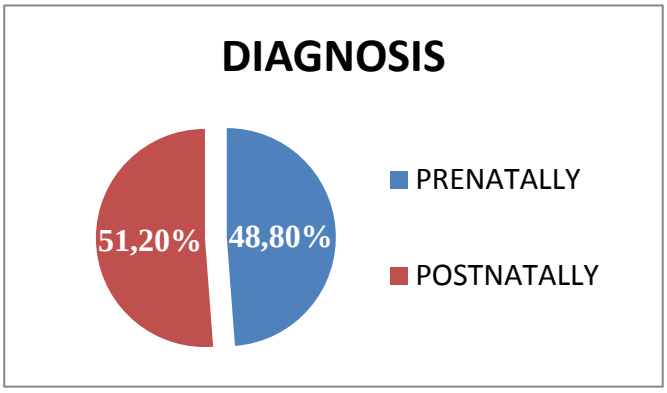


Figure 1: Frequency distribution of prenatal and postnatal diagnoses of cleft lip and palate

The numbers of women whose child's cleft lip and palate was diagnosed during prenatal or postnatal care were almost equal, with 48.8% (20 out of 41) of the cases being detected during prenatal care and 51.2% during postnatal care.

4.2.1 Counselling given to parents

Table 6: Adequate counselling received prenatally and postnatal

YES	47%
NO	53%

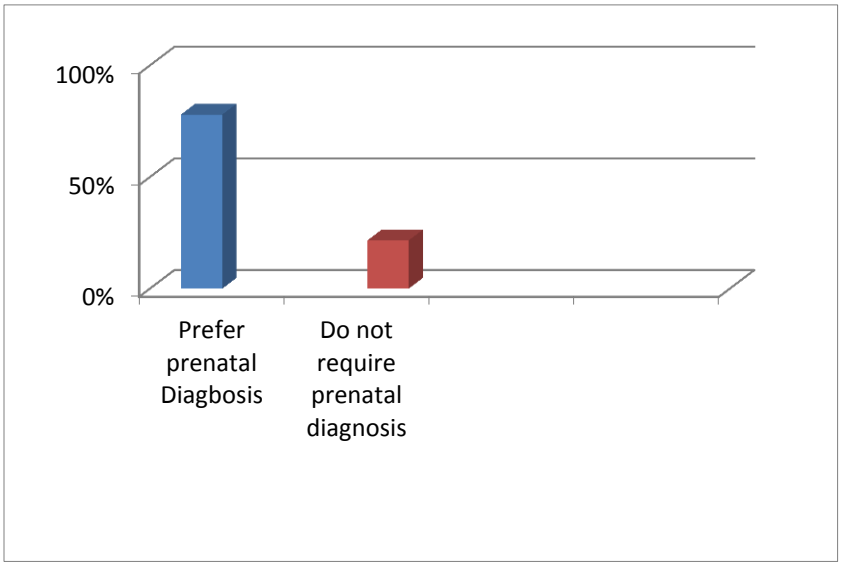


Figure 2: Women who desire to attend prenatal diagnosis for their subsequent children

Figure 1 and Figure 2 demonstrate that although the majority (51.2%) of the diagnosis are made postnatally, majority of the parents (80%) prefer to have a prenatal diagnosis.

4.3 Impact on Family Scale

This section examined the difference in the quality of life of the family after the birth of the affected child as compared to before the birth. First, the reliability (consistency) of the questionnaire was analysed using Cronbach's Alpha Coefficient. The most common measure of internal consistency of a questionnaire is Cronbach's Alpha Coefficient. The range of the alpha is from 0 to 1. As a rule of thumb, the alpha of a scale equal to 0.70 or greater is acceptable for items to be considered reliable. Results of the reliability analysis are presented in Appendix A.

Table 7: Reliability analysis of questions related to the Impact on Family Scale

Cronbach's Alpha	Items (n)
0.723	24

The Cronbach's Alpha Coefficient of 72%, in Table 4.9.1, is a clear indication that the 24 questions correctly assess the concept of impact of the cleft lip and palate on family scale, though there are some questions that could be removed to increase the value of the Cronbach's Alpha Coefficient.

The significantly correlated questions based on the Cronbach's Alpha Coefficient were questions 1, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 17, 19, 20, 21, 22, 23 and 24.

Questions 2, 3, 4, 5, 15 and 18 had non-significant Cronbach's Alpha values and were thus omitted from further data analysis.

Table 8: Frequency distribution of the Impact on Family Scale assessment (n=41, represented as a percentage)

	Absolutely true	True in most of aspects	Not true in most aspects	Not true at all
1. An additional income is required to cover medical expenses	9.8%	24.3%	17.1%	48.8%
2. The illness causes financial problems in my family	7.3%	4.9%	22%	65.8%
3. I have to reduce time at work to care for the sick child	19.5%	22%	17.1%	41.4%
4. Medical management results in reduced time at work	19.5%	17.1%	9.8%	53.6%
5. My family gives up things often due to uncertainty in the health of the child	0	4.9%	9.8%	85.3%
6. Neighbours treat us differently because of the illness of our child	2.4%	2.4%	7.3%	87.8%
7. We see family and friends less due to the abnormal baby	0	0	7.3%	92.7%
8. There is not much time left for family due to increased time looking after the baby	4.9%	4.9%	2.4%	87.8%
9. I have little desire to go out because of the child	0	2.4%	12.3%	85.3%
10. We are not able to travel out of the city due to uncertainty of child's health	0	0	2.4%	97.6%
11. We often have to change plans going out at short notice	2.4%	4.9%	2.4%	90.3%
12. We often wonder about special treatment of the child. Should I treat my child differently	2.4%	14.6%	12.3%	70.7%

13. I have no desire to have more children due to fear of this condition being repeated	0	9.8%	22%	68.2%
14. Nobody understands the burden that you have to cope with	0	32.5%	15%	52.5%
15. Travelling to hospital is a strain on me both mentally and physically	4.9%	39%	17.1%	39%
16. It is like we live on a rollercoaster, happy when the child is well and sad when it is ill	2.4%	4.9%	9.8%	82.9%
17. It is often hard to find someone to take care of our child due to them not understanding the special needs of the child	0	0	12.3%	87.8%
18. We live from day to day and do not plan for the future	7.4%	2.4%	2.4%	87.8%
19. Due to the illness/special needs of my child I am often overtired and exhausted	9.8%	65.8%	0	24.4%
20. Managing to cope with the condition of my child helped me to manage myself	53.8%	38.5%	7.7%	0
21. Due to our special experiences we have become closer as a family	77.5%	20%	2.5%	0
22. My partner and I often analyse problems together	74.4%	17.9%	7.7%	0
23. We have decided to treat our child as normal as possible	97.6%	2.4%	0	0
24. Our relatives are not very understanding and helpful and think that they know better than me what is best for my child	7.3%	0	0	92.7%

Table 8, above, shows the frequency distribution of all the items of assessment in regard to the impact of cleft lip and palate on families. It can be seen that in most of the items, that the majority of the women assessed them as “not true” except for five where they answered “true”. The five items are owing to the condition, women being overtired and exhausted; managing to

cope with the condition; family becoming closer because of the condition; partners analysing problems together and treating the child as normally as possible.

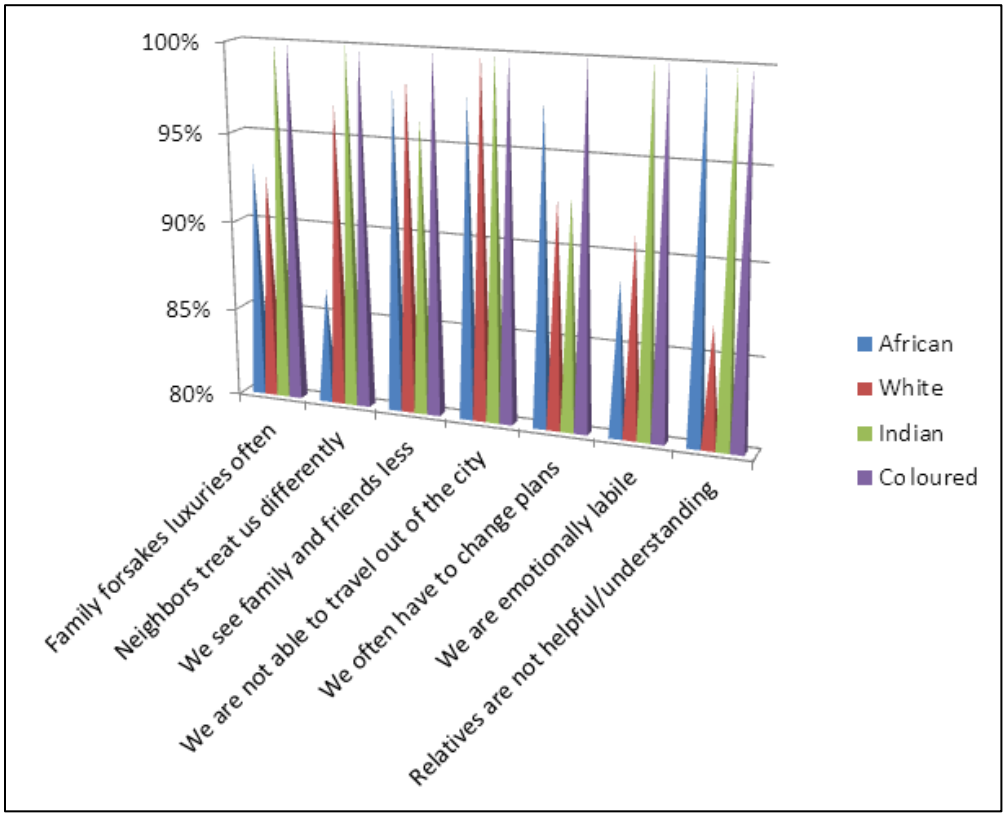


Figure 3: The relationship between the Impact on Family Scale and race

Figure 3 shows the relationship between the Impact on Family Scale and the race of the participants. There is no significant difference in most of the items across the four races. That is, African, White, Indian and Coloured participants assessed the items in almost the same manner.

Table 9: The relationship between the level of education of women and the Impact on Family Scale

		Level of education mother %	
		Tertiary	High school
Financial	1. An additional income is required to cover medical expenses	21.1	47.6
	2. The illness causes financial problems in my family	21.1	4.8
	3. I have to reduce time at work to care for the sick child	21.1	57.1
	4. Medical management results in reduced time at work	21.1	47.6
	5. My family gives up things often due to uncertainty in the health of the child	10.5	0
Familial and social	6. Neighbours treat us differently because of the illness of our child	5.4	3.8
	7. We see family and friends less due to the abnormal baby	94.6	96.2
	8. There is not much time left for family due to increased time looking after the baby	0	0
	9. I have little desire to go out because of the child	100	100
	10. We are not able to travel out of the city due to uncertainty of child's health	10.5	9.5
	11. We often have to change plans going out at short notice	5.3	0
Personal Psychological strain	12. We often wonder about special treatment of the child. Should I treat my child differently	0	0
	13. I have no desire to have more children due to fear of this condition being repeated	10.5	3.8
	14. Nobody understands the burden that you have to cope with	15.8	19
	15. Travelling to hospital is a strain on me both mentally and physically	15.8	3.8
	16. It is like we live on a rollercoaster, happy when the child is well and sad when it is ill	21.1	42.9
	17. It is often hard to find someone to take care of our child due to them not understanding the special needs of the child	31.6	52.4
	18. We live from day to day and do not plan for the future	15.8	0
	19. Due to the illness/special needs of my child I am often overtired and exhausted	0	0
Mastery/Coping strategies	20. Managing to cope with the condition of my child helped me to manage myself	15.8	3.8
	21. Due to our special experiences we have become closer as a family	68.4	81
	22. My partner and I often analyse problems together	89.5	85.7
	23. We have decided to treat our child as normal as possible	89.5	100
	24. Our relatives are not very understanding and helpful and think that they know better than me what is best for my child	84.7	89.5

The relationship between the level of women's education and the Impact on Family Scale items follows a similar trend when it comes to race. There is no significant difference in the items between the two levels of education, except for reducing time at work to care for the sick child and travelling to hospital being a strain on the mother both mentally and physically: for women with tertiary education these are not true and for those with only high school education they are considered to be true statements.

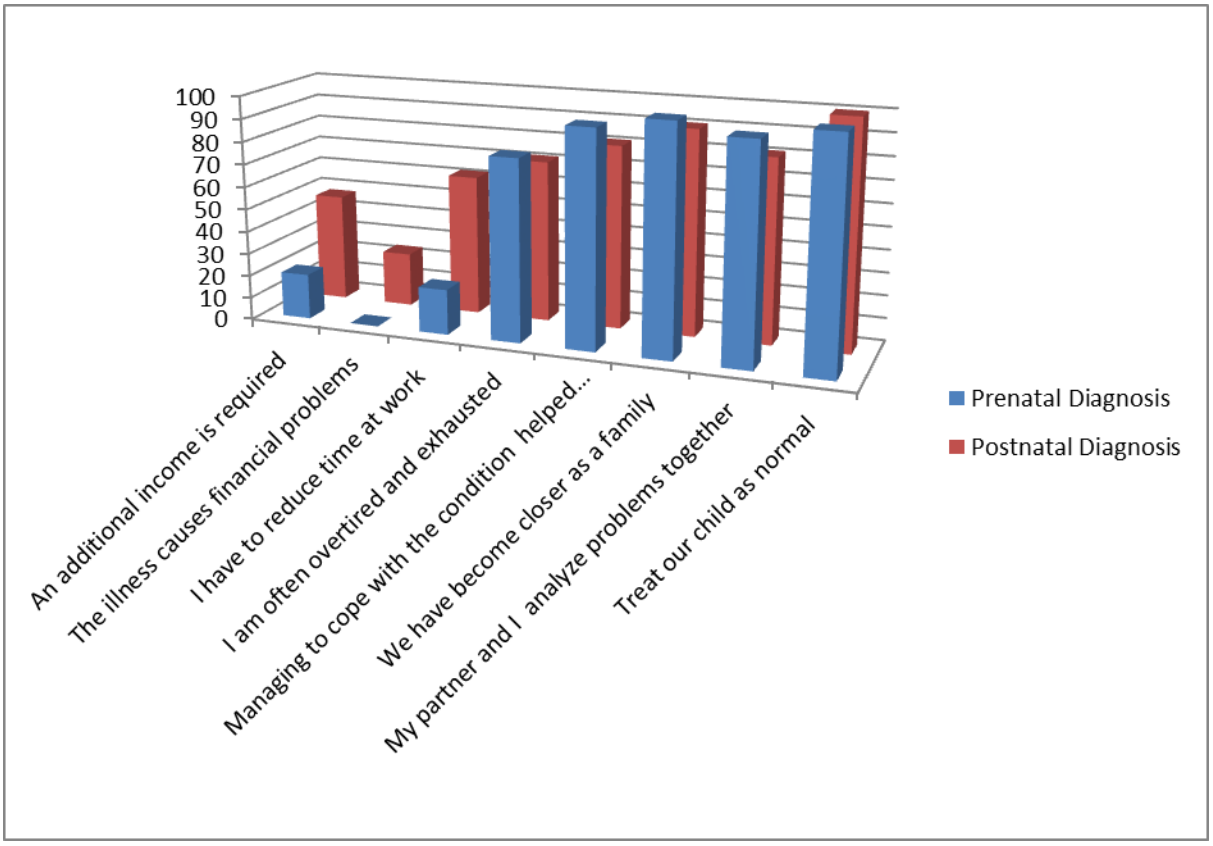


Figure 4: Relationship between Impact on Family Scale and diagnosis made prenatally or postnatally

Important aspects in the relationship between the Impact on Family Scale items and the fact that the diagnosis of cleft lip and palate of children was made during prenatal or postnatal care is shown in Figure 4 above. Travelling to hospital being a strain on the mother both mentally and physically is shown here as a major factor.

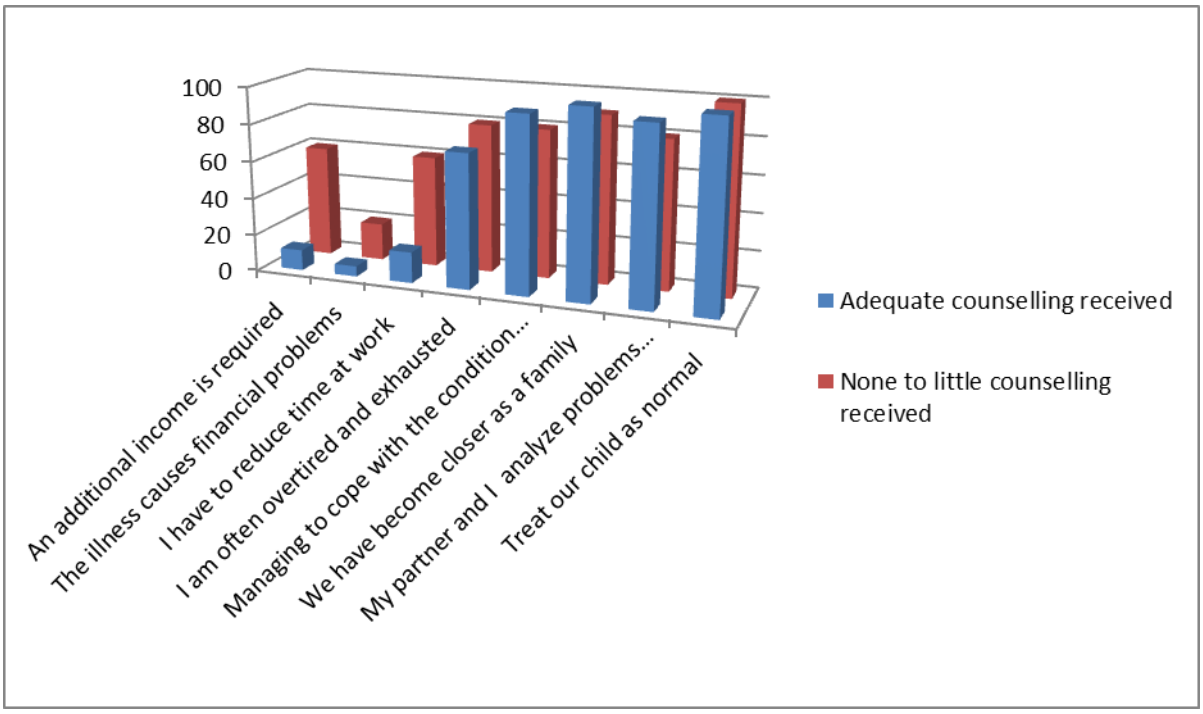


Figure 5: Relationship between Impact on Family Scale and adequate prenatal and postnatal diagnosis received

Figure 5 indicates the relationship between adequate counselling received during prenatal and postnatal care and the Impact on Family Scale items. A similar pattern can still be noticed when compared with the previous figure. The difference is seen in the additional income that is required to cover medical expenses and reduction of time at work to care for the sick child where those who received counselling found that they did not have to reduce time at work and those that did not have counselling found that they did have to reduce time at work.[1]

[1] Note: significance testing was done for all parameters but only important ones that showed real changes have been presented.

CHAPTER FIVE: DISCUSSION

It has been shown in many studies that non-syndromic orofacial clefting affects family functioning and reduces the quality of life of both school-aged children and their parents. A study undertaken by Kramer et al.[21] in Germany showed that non-syndromic orofacial clefts might affect family functioning and probably reduce the quality of life in school-age children and their parents. Family functioning was found to be superior in families where children had cleft lip to those families where children had cleft palate only or a cleft lip and palate. Results in the above mentioned study compare well to this study, however in this study, the patient population was limited to children with non-syndromic orofacial clefting and thus isolated cleft lips and palates cannot be commented upon. Demographic aspects, which are outlined in Figures table 1, table 2, table 3, and table 4, are not representative of a normal South African population as the majority of women were White not African, however other studies show that blacks are the least affected with Asians and Indians being the most affected by cleft lip and palate[22].

Other important factors affecting the quality of life and coping strategies of the parent would be the type of cleft that the child has, be it an isolated cleft lip; isolated cleft palate; unilateral cleft lip and palate; or bilateral cleft lip and palate. In order to standardise this study, the sample was limited to isolated unilateral cleft lip and palate so as to minimise the stressors that come with having the other types of clefting. Even though no corresponding data was collected in this study, it is still important as it indicates that knowledge of potential impacts related to the type of cleft and the gender of the patient. This will inevitably make it easier for healthcare professionals to identify children and families at high risk of a reduced quality of life and may help in the provision of specific support and treatment strategies.

The socio economic status of parents was not measured in this study, however should this have been done successfully, there would have been more insight given into how different socio economic groups perceive these impacts. In the study only race and employment status was examined and these showed marked changes as seen in Figure 3 and Table 9.

Furthermore, Table 9 shows that parents who were better educated had better coping strategies, and this could be related to them having better access to information via print or electronic

media; as well having communication skills needed to access information. They had however found that they could take less time off work as higher-paying jobs required more commitment to work, as opposed to mothers without a tertiary education who took more time off work. Figure 4 demonstrates that parents who received prenatal diagnosis and good prenatal and postnatal counselling found it easier to cope with problems related to caring for the sick child. Despite this, travelling to the hospital seemed to be a strain on all parents, in different ways. In all groups, parents found themselves communicating better with their partners and families coming closer together due to the illness of the child.

In this study, patients that had only unilateral non-syndromic, isolated cleft lip and palate were selected, as compared to a study conducted by Kramer *et al*.[23]; where they proved that the type of cleft played an important role in the quality of life as well as the Impact on Family Scale. In their study, children were divided according to the type of cleft of the child. The three groups thus formed represented predominantly aesthetic (CL), functional (speech and hearing) (CP) or both (CLP) insufficiencies. The groups were of similar size. Results of the IOFS indicated distinctive and differing impacts on affected families in relation to the type of cleft. Families that had a child with CLP had to deal with the most severe malformation and the child had to tolerate the most intensive medical treatment, including three operations at about six, 12 and 15 months old. Interestingly, the scores of several impacts on family dimensions were found to be lower than those of families having children with isolated CL or CP, where children usually had much smaller defects and required only a single operation for orofacial reconstruction.

Owing to the limited size of this study and limited time and access to patients, results were standardised by selecting only patients with non-syndromic orofacial clefting and it was found that most parents underwent similar levels of stress regarding the birth of the child.

Parents found that initially accepting the child was difficult as well as presentation to family members. Race distribution was not taken into account as all race groups were equally represented (demonstrated in Figure 1), also all race groups answered almost identically to the questions regarding social impact as indicated in Figure 3.

Parents from low socio-economic groups as well as families where one or more parents were unemployed exhibited high scores when answering the questions. A high score demonstrated a higher impact on the family than a lower score; the latter indicates a lower impact as compared to families where both parents were employed or were from a more affluent family. In this particular study, as can be seen in Figuren 3, parents in the African and Coloured race groups found it more difficult to cope financially as compared to parents from the White and Indian racial groups.

When analysing the results of the impact on family and the level of education of the mother, (Table 1), these results are in keeping with a study carried out by Ross et al.[24] on the Education and the Subjective Quality of life which shows that level of education directly impacts the income of a household where better-educated families have higher social functioning, better relationships as well as improved marriages and social support. They are also able to access higher-paying jobs that are more stable and full-time as opposed to the part-time work that is accessible to most other people. In this case, however, as mentioned previously, parents with higher education are more likely to have full-time employment which thus makes it difficult to get time off work as opposed to lesser-educated parents who may have part-time employment.

Mothers with a tertiary education had lower impact scores (Table 1), this could be due to their understanding the condition better or having the knowledge and ability to access more information regarding the condition. Mothers who had had a prenatal diagnosis also achieved better scores (Figures 4 and 5). In both of these cases, understanding and coping strategies were far superior to those of mothers where no prenatal diagnosis had been done, or where adequate prenatal counselling was experienced.

In all instances, parents found that support from family and friends increased due to the increased time requirements for the sick child; they found themselves more tired due to the needs of the sick infant and often did not travel out of the home as much owing to the special needs of the child as indicated in Table 8. However, on a positive note, most families grew closer and discussed problems and faced their challenges together.

In recent years, improved techniques of ultrasound diagnostics during pregnancy have increased the number of parents being notified prior to birth to expect a baby with cleft lip and palate, while the number of parents that are informed during or after birth is declining, in a South African context this is still not the case. While the accuracy of prenatal diagnosis of cleft lip and palate by ultrasound is highly variable and depends on both the experience of the sonographer and the type of cleft, the rates of successful detection of CL were reported as reaching 93%[25]. Although prenatal detection of CL/CLP does not affect the postnatal course of cleft treatment, it seems very likely that informed families may benefit practically from an early diagnosis when it comes to coping with the specific challenges of a cleft child. The present results did not validate this expectation, possibly because this analysis was performed several months after birth and some of the potential benefits might have diminished, however parents still stress that should this facility be available to them with subsequent children, they will definitely want a prenatal diagnosis made as indicated in Figure 2.

While all other dimensions were not affected markedly, the Impact on Family Scale dimension of social impact was higher in families that had been informed prenatally, as indicated in Figure 4. It might be assumed that early knowledge of cleft lip and palate contributes to the perception of enhanced social pressure on the families, which should be taken into account when prenatal diagnosis is made. Consultation with medical professionals on providing information on orofacial clefting malformations and treatment options seems particularly important immediately after the ultrasound diagnosis.

CHAPTER SIX: CONCLUSION

It has been shown in many studies that the impact experienced by the family is the most important factor in protecting a child with orofacial cleft from negative impacts that reduce quality of life. For this reason, interventions at modern cleft lip and palate centres should address both the child and the family, especially mothers. Furthermore, a detailed knowledge of the kind of impact affecting the quality of life in families whose children have orofacial clefts might support affected families, particularly when it comes to coping with the situation and providing specialised care for the patient.

In recent years, improved techniques of ultrasound diagnostics during pregnancy have increased the number of parents that are notified prior to birth to expect a baby with cleft lip and palate, while the number of parents that are informed during or after birth is declining. While the accuracy of prenatal diagnosis of cleft lip and palate by ultrasound is highly variable and depends on both the experience of the sonographer and the type of cleft, the rates of successful detection of CL were reported up to 93%[26]. Although prenatal detection of CL/CLP does not affect the postnatal course of cleft treatment, it seems very likely that informed families may benefit practically from an early diagnosis in coping with the specific challenges of a cleft child. The present results did not validate this expectation, which may be attributed to the fact that this analysis was performed several months after birth and some of the potential benefits might have diminished.

While all other dimensions were not affected markedly, the Impact on Family Scale dimension of social impact was higher in families that had been informed prenatally. It might be assumed that early knowledge of cleft lip and palate contributes to the perception of enhanced social pressure on the families, which should be taken into account when prenatal diagnosis is made, thus adequate counselling is paramount in ensuring that parents have a better quality of life due to better understanding of the condition. Parents also found that travelling to hospital put additional strain on them as well as moderate increase in financial requirements, which could be both due to hospital costs as well as travel expenses. Education seemed to be of utmost importance as parents who were better educated seemed to have better coping skills, and had better impact scores.

In evaluating the results of this study to other studies done with older and adolescent children, as well as young adults,, it can be deduced that the actual impact on the quality of life of the child, as well as the parent, starts at diagnosis regardless of whether this is prenatal or postnatal- and coping skills depends very much on the counselling received thereafter.

It was also found in this study that parents and families experience the bulk of the stress during the first two years of development because it is at this age that families are confronted with both the birth of the cleft patient and most of the operations required for reconstruction. It is especially at this time that parents need not just the medical team's support but also the social support of friends and extended family.

In conclusion, when a child with a non-syndromic orofacial cleft is born, the quality of life in affected families is influenced by the impact related to the type of cleft. It is reduced in particular in families having children with isolated cleft palate, and less so in children with cleft lip palate or cleft lip. The number of operations and hospitalisations is not related to the quality of life as long as the result of treatment is satisfactory.

Prenatal diagnosis of cleft lip and palate does not reduce the general impact on families but increases the social impact. Such families should be transferred early to medical professionals involved in cleft treatment. Professional care to improve quality of life should especially address families with young mothers and families having children with cleft lip and palate. Social and financial support also plays an important role in decreasing the stress and improving the quality of life of the parents and the child. The most important parameter that needs to be changed involves the societal views of children and the perception that it is difficult to deal with children who have cleft lip and palate. What the researcher perceived was that with proper education, most challenges are easily overcome both for the mother and the child.

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APPENDICES

Appendix A: Information form for participants

Dear patient

My name is Zaheda Bhabha. I am a post-graduate student at the University of the Witwatersrand completing my final year of study.

You have been selected for this study because your child like many others in this study was born with a cleft lip and with your assistance I am conducting a study on the quality of life of mothers after the birth of their child diagnosed with having a cleft lip and palate. You will be asked a series of questions based on your situation after the delivery of your child.

Information will be collected by the researcher via a questionnaire which will be administered to you by the researcher.

You may choose to a part of the study, should you not wish to be included in the study your care with your doctor will not be affected in any way.

You do not have to answer all the questions should you not wish to do so.

Please note that the questionnaire is completely anonymous and confidential and you cannot be identified in any way. You may withdraw from the study at any time. This study has been approved by the ethics committee of the University of the Witwatersrand. Should you wish to know the outcome of the study it will be made available to you at your request.

Thank you for your time and assistance.

Appendix B: Consent Form

CONSENT FORM

Centre:

Title of Project: An Analysis of the quality of life of mothers whose children have a cleft lip and palate.

Name of Researcher: Dr Zaheda Bhabha

Please tick to confirm

- I confirm that I have read and understand the information sheet for the above study. **?**
- I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. **?**
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. **?**
- I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from the University of Witwatersrand Family Medicine Department, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. **?**

I agree to take part in the above research study. **?**

_____ Name of Patient	_____ Date	_____ Signature
_____ Name of Person taking consent (if different from researcher)	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

When complete: one copy for researcher and one copy to remain with patient

Appendix C: Ethics Clearance Form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Dr Z Bhabha

CLEARANCE CERTIFICATE	**M090309**
PROJECT	An analysis of the Impact on the quality of Life of Mothers with Children Afflicted by Cleft Lip and Palate who Attended Cleft Clinics in Johannesburg
INVESTIGATORS	Dr Z Bhabha.
DEPARTMENT	Department of Family Medicine
DATE CONSIDERED	09.03.27
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 09.07.03 **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr A Wright

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...
.....

Appendix D: Consent from Department of Obstertrics and Gynaecology

12-AUG-2008 13:51 FROM:OBSTETRICS & GYNAECO 011 643 2522 TO:0114848254 P:1/1

011 643 2522

University of the Witwatersrand, Johannesburg

Department of Obstetrics and Gynaecology • Medical School

Johannesburg Hospital • Private Bag X39, Johannesburg, South Africa • Telephone: +27 11 488-3179 • Fax: +27 11 643-2522

12th August 2008

TO WHOM IT MAY CONCERN

I Dr. T.H. Smith working as a Principal Specialist and Senior Lecturer in the Department of Obstetrics and Gynaecology at the Johannesburg Hospital and the University of the Witwatersrand, I am aware of the study being conducted by Dr. Zaheda Bhabha, titled: **An analysis of the quality of life of mothers who have a child with a cleft lip and palate.**

In my capacity as a Gynecologist involved in the Department of Obstetrics and Gynecology at the University of the Witwatersrand and in private practice, I grant her permission to have access to all mothers attending my clinics at the University as well in my private practice.

This is provided that informed consent is obtained from all mothers prior to any participation in the study.

Signed _____

At Johannesburg

On 12 August 2008

Appendix E: Consent from Prof. L. A. Chait

PROFESSOR L.A. CHAIT
M.B. B.CH. (RAND) F.R.C.S.
- PLASTIC SURGEON/PLASTIESE CHIRURG -
PR. No. 3600440

Telephone/Foon:
Rooms/Kamers (011) 484-3703
Home/Woning (011) 786-6347

PARKLANE CLINIC
JUNCTION AVENUE/LAAN
PARKTOWN
JOHANNESBURG 2193

To whom it may concern,

I Professor L.A. Chait am aware of the study being conducted by Dr. Zaheda Bhabha, titled : **An analysis of the quality of life of mothers who have a child with a cleft lip and palate.**

In my capacity as a Professor involved in the Vodacom SmileTrain Foundation as well as in private practice, I grant her permission to have access to all mothers attending my clinics, as well in my private practice.

This is provided that informed consent is obtained from all mothers prior to any participation in the study.

Signed

at JHB

on 16/8/08

Appendix F: Consent form from School of Dentistry

School of Oral Health Sciences
Wits Dental Hospital
Faculty of Health Sciences

7 York Road, Park Town, Johannesburg.
Tel: +27 11 488-4879/1
Fax: +27 11 488-4903
bill.evans@wits.ac.za
rufaida.moosa@wits.ac.za
8th floor, Area 385, Johannesburg General Hospital, Park Town
Private Bag 3, Wits, 2050

Department of Orthodontics

15 August 2008

To whom it may concern

Dr. Zaheda Bhabha has committed to a study which is to be conducted through the Cleft Palate Clinic operating at the Wits Dental Hospital and School of Oral Health Sciences at the Johannesburg Hospital and the University of the Witwatersrand, Johannesburg.

The title of the research project is **An analysis of the quality of life of mothers who have a child with a cleft lip and palate**

In order for Dr Zaheda Bhabha to undertake the study, access is required to parents of cleft palate children who are attending the Clinic. The Clinic is under my overall direction and I am supportive of the project. I confirm that Dr Bhabha has permission to approach the mothers of the children attending the Clinic. It would be a requirement that properly approved informed consent is granted by the mothers who are to be interviewed.

Thank you for your kind attention.

Yours faithfully

Professor W.G. Evans
Acting Head of Orthodontics

Appendix G: Questionnaire

Age of mother	
Race	
Marital status	
Highest level of education of mother: primary school/ high school/ tertiary education	
Employment status of mother: employed/ not employed outside the home	
Employment status spouse/partner: employed/unemployed	
Parity of mother	
Sex of child	
Was the diagnosis made prenatally or postnatally?	
Was adequate counseling received prenatally and postnatally?	
Would you prefer to have a prenatal diagnosis on any subsequent children?	

Appendix H: Impact on Family Scale

Please answer		**1**	**2**	**3**	**4**
Absolutely true 1					
True in most aspects 2					
Not true in most aspects 3					
Not true **at** all 4					
1. An additional income is required to cover medical expenses					
2. The illness causes financial problems in my family					
3. I have to reduce time at work to care for the sick child					
4. Medical management results in reduced time at work					
5. My family gives up things often due to the uncertainty in the health of the child					
6. Neighbors treat us differently because of the illness of our child					
7. We see family and friends less due to the abnormal baby					
8. There is not much time left for family due to increased time looking after the baby					
9. I have little desire to go out because of the child					
10. We are not able to travel out of the city due to uncertainty of Childs health					
11. We often have to change plans going out at short notice					
12. We often wonder about special treatment of the child. Should I treat my child differently?					
13. I have no desire to have more children due to fear of this condition being repeated					

14. Nobody understands the burden that you have to cope with				
15. Travelling to hospital is a strain on me both mentally and physically				
16. It's like we live on a rollercoaster, happy when the child is well and sad when it is ill				
17. It's often hard to find someone to take care of our child due to them not understanding the special needs of the child				
18. We live from day to day and do not plan for the future				
19. Due to the illness/special needs of my child I am often overtired and exhausted				
20. Managing to cope with the condition of my child helped me to manage myself				
21. Due to our special experiences we have become closer as a family				
22. My partner and I often analyze problems together				
23. We have decided to treat our child as normal as possible				
24. Our relatives are not very understanding and helpful and think that they know better than me what's best for my child				

Appendix I: Cronbach's Alpha

ITEM AS IN THE IMPACT ON FAMILY SCALE	Cronbach's Alpha if Item Deleted
1. An additional income is required to cover medical expenses	.709
2. The illness causes financial problems in my family	.678
3. I have to reduce time at work to care for the sick child	.680
4. Medical management results in reduced time at work	.690
5. My family gives up things often due to uncertainty in the health of the child	.695
6. Neighbors treat us differently because of the illness of our child	.713
7. We see family and friends less due to the abnormal baby	.723
8. There is not much time left for family due to increased time looking after the baby	.700
9. I have little desire to go out because of the child	.715
10. We are not able to travel out of the city due to uncertainty of child's health	.721
11. We often have to change plans going out at short notice	.706

12. We often wonder about special treatment of the child. Should I treat my child differently	.707
13. I have no desire to have more children due to fear of this condition being repeated	.714
14. Nobody understands the burden that you have to cope with	.708
15. Traveling to hospital is a strain on me both mentally and physically	.691
16. It is like we live on a rollercoaster, happy when the child is well and sad when it is ill	.700
17. It is often hard to find someone to take care of our child due to them not understanding the special needs of the child	.712
18. We live from day to day and do not plan for the future	.698
19. Due to the illness/special needs of my child I am often overtired and exhausted	.732
20. Managing to cope with the condition of my child helped me to manage myself	.737
21. Due to our special experiences we have become closer as a family	.760
22. My partner and I often analyse problems together	.754
23. We have decided to treat our child as normal as possible	.726
24. Our relatives are not very understanding and helpful and think that they know better than me what is best for my child	.738