

https://dspace.org/

Factors influencing access to early childhood services in occupational therapy

Khan, Humaira

2019

https://hdl.handle.net/10539/29927

Khan, Humaira (2019) Factors influencing access to early childhood services in Occupational Therapy, University of the Witwatersrand, Johannesburg, <http://hdl.handle.net/10539/29927>

Downloaded from a DSpace repository. https://dspace.org/

Factors Influencing Access to Early Childhood Services in Occupational Therapy

Humaira Khan

A Research Report submitted to the Faculty of Health Science, University of Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy

August 2019

Contents

Declaration i
Presentations arising from this study ii
Abstract iii
Acknowledgements iv
List of Figures v
List of Tables vi
Operational Definitions vii
Abbreviations viii
Chapter 1 1
1.1 Introduction 1
1.2 Statement of the Problem 2
1.3 The Purpose of the Study 3
1.4 Research Question 3
1.5 The Aim of the Study 3
1.6 The Objectives of the Study 4
1.7 Justification of the Research 4
Chapter 2: Literature Review 5
2.1 Early Childhood Development 5
2.2 Developmental Delays 6
2.3 Risk Factors for Early Child Development 7
2.4 Identifying Developmental Delays 8
2.5 Early Childhood Intervention 10
2.6 Occupational Therapy in Early Childhood Intervention 12
2.7 Early Childhood Intervention Services in South Africa 13
2.8 Health Care in South Africa 17
2.9 Factors Influencing Access to Health Care 18
2.10 Conclusion 24
Chapter 3: Research Methodology 25
3.1. Type of Research 25
3.2. Research Site 25
3.3. Population 26
3.4. Sample and Selection of Sample 27
3.5. Recruitment of Sample 27
3.6. Measurement Instruments 28
3.7. Piloting Procedure 29

3.8. Data Collection Procedure 30
3.9. Data Analysis 30
3.10. Ethical Considerations 31
3.11. Conclusion 32
Chapter 4: Results 33
4.1.1. Who is accessing early childhood services in occupational therapy? 34
4.1.2. When are occupational therapy services being accessed? 40
4.2. The factors influencing access to ECI services in occupational therapy 42
4.3. Conclusion 48
Chapter 5: Discussion 50
5.1. Introduction 50
5.2. The demographics of the caregivers and children accessing ECI services 50
5.3 The factors influencing access to ECI services 55
5.4 Participants who did not access services 67
5.5 Conclusion 68
5.6 Clinical Implications 68
5.7 Limitations of the study 70
Chapter 6: Conclusion 71
Recommendations for future research 71
Appendix A 73
Interview Questionnaire 73
Part 1: Caregiver Demographic Information 73
Part 2: Child demographic information and information on the problem 71
Part 3: Access to services 2
Appendix B 76
Telephonic Interview Questionnaire 76
Appendix C 78
Information Letter 78
Appendix D 80
Informed Consent Sheet to Participate in Research 80
Appendix E 81
Letter of Support for Research from Bertha Gxowa Hospital 81
Appendix F 83
Ethical Clearance Certificate 83
Appendix G 84
Letter of Approval to Conduct Research 84

References 85

Declaration

I, Humaira Khan, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



Signed on 7th August 2019.

Presentations arising from this study

- September 2017: 2nd Early Childhood Intervention Conference
- April 2018: 38th Annual Islamic Medical Association of South Africa
- June 2019: 3rd Early Childhood Intervention Conference

Abstract

South Africa is a developing country which is facing numerous challenges. Among these is the issue of caregivers of children with developmental problems accessing early childhood intervention (ECI) services. Bertha Gxowa hospital is a district hospital situated in Germiston, running a multidisciplinary ECI service that includes occupational therapy. The service was underutilised, with poor or late access by caregivers, thereby decreasing the effectiveness of ECI. It was unclear who was accessing these services or whether these services were being accessed timeously and appropriately. The purpose of this study was to describe the characteristics of the population of caregivers and their children who accessed Occupational Therapy services for the first time and to investigate the factors (both barriers and facilitators) that influenced why caregivers accessed Occupational Therapy services for their children. Using a non-standardised, interview-based questionnaire developed by the researcher, the study collected data from 16 participants to determine who was accessing ECI services and what were the factors influencing access.

It was noted that mostly mothers were the primary caregivers of children accessing services and children accessing services were over the age of two years. It was found that there were both barriers and facilitators influencing access to the services. Although there were some facilitators, mostly barriers were identified. These were related to cost of transport, caregiver knowledge of developmental norms in children as well as awareness of the existence of the services. Limited information was available from caregivers who did not arrive for their appointments to determine influencing factors for not accessing ECI services.

This study has highlighted the need for more research to be conducted on children accessing early childhood services and the factors influencing their access to such services. This would prove beneficial and eliminate some of the barriers hindering access to early childhood services.

Acknowledgements

I would like to acknowledge the following people who assisted in the completion of this research project:

- Ms Lyndsay Koch for her constant and valuable input over the past three years.
- Bertha Gxowa Hospital for allowing me the opportunity to conduct my research at its institution.
- My family and friends for your continued support throughout this project.

List of Figures

Figures 4.1: Demographic of the primary caregiver……..……..34

Figure 4.2: Gender of the primary caregivers……..……34

Figure 4.3: The age of the primary caregiver……..……34

Figure 4.4: The socio-economic status of the monthly income of households…....35

Figure 4.5: Suburb where caregiver and child live……..……35

Figure 4.6 The ages at which children are accessing services……36

Figure 4.7: Gender of the children accessing Services……..36

Figure 4.8 Gender of the children who did not access services……..……37

Figure 4.9: Age of the children who did not access services……..……..37

Figure 4.10: Where the child is during the day……...39

Figure 4.11: Period of time over which caregivers have been concerned about the problems……40

Figure 4.12: Any other persons concerned about the child's problem……41

Figure 4.13: Difference between where the concerned persons advised the caregiver to seek help and where the caregiver actually sought help……..……41

Figure 4.14: For caregivers who work, ease of getting time off work……...42

Figure 4.15: Persons displaying concern over the child's problem……..43

Figure 4.16: Distance travelled to the hospital……43

Figure 4.17: Means of transport used to reach the hospital……..44

Figure 4.18: Referral source of the child to therapy services……45

Figure 4.19: Awareness of service available……47

Figure 4.20: Awareness of other services available for child……48

List of Tables

Table 4.1: Outcome of the participants contacted……...33
Table 4.2: Possible diagnosis as the cause of developmental problems……37
Table 4.3: Problems that the child experienced at birth……38
Table 4.4: Reason for hospital admission after birth……...38
Table 4.5: Problems that the child experienced at school……..39
Table 4.6: Reasons for caregivers not visiting the hospital……44
Table 4.7: Reasons that stopped caregivers from coming to the hospital……...45
Table 4.8: Reasons for caregivers not seeking help for their child……...46
Table 4.9: Reasons for not accessing the services……46
Table 4.10: Caregiver accepting a new appointment and reasons for this……46

Operational Definitions

- Occupation or Occupational Performance areas:

Meaningful and purposeful activities that a person engages in. It is goal-directed and valuable activities which are distinctive for the person. These daily activities are made up of: (i) activities of daily living (bathing, dressing, etc.), (ii) instrumental activities of daily living (household chores, meal preparation, etc.), (iii) rest and sleep, (iv) education, (v) work, (vi) play or leisure, and (vii) social participation. (1)

- Occupational Beings

Persons engaging in a variety of meaning and purposeful activities that make up occupations in a variety of contexts. (1)

- Early Childhood Intervention Services

Early Childhood Intervention (ECI) is a service that consists of various interventions, one of which aims to promote normal development and prevent developmental delays. The service supports the rehabilitation of those with developmental delays and at the same time allows for early detection of disabilities in children (2) (3) (4). It is targeted at the crucial years of development in children, namely, from birth to five years of age (5).

- Developmental Delays

Developmental delays or difficulties occur when a child does not reach some or all of their milestones in cognition, gross motor, fine motor, language, social and emotional developmental areas. It is likely to occur in more than one area (5) (6).

Abbreviations

ECI – Early Childhood Intervention

HIV/AIDS – Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome

HREC – Human Research Ethics Committee

UNICEF – United Nations Children's Emergency Fund

US – United States

WHO – World Health Organisation

Chapter 1

1.1 Introduction

According to the United Nations Children's Emergency Fund (UNICEF) and the World Health Organisation (WHO), children in developing countries, particularly in Africa, are at risk of some form of disability or developmental delay. This is due to exposure to high risk factors such as poor nutrition, poor living conditions as well as not being able to access adequate health care among others (7). Early childhood intervention (ECI) is a strategy developed to assist in the early identification of not only disabilities but also any developmental problems that the child may have, between birth and age five years (7). The first two years of a child's life, also known as the first 1000 days, are said to be the most crucial years in terms of the child's development (8) (9) (10). This is to ensure that children are given the opportunity to reach their full potential. Early detection and identification of developmental problems also ensured that children are more likely to complete school and contribute to the economic development of the country. Early Childhood Intervention thus helps to break the cycle of poverty and creates opportunity for the next generation to succeed (11).

South Africa is a developing country and faces the challenge of poverty as a major contributing factor, amongst many others, to children presenting with developmental delays or disabilities (2). In 2005, ECI services were implemented in South Africa. However, rates of caregivers accessing ECI for their children remained low (12) (13). This problem was brought to the attention of the Gauteng Department of Health, particularly to Rehabilitation and Specialised Services. Thus, the Gauteng ECI task team was formed in 2010 to increase the awareness of ECI in the province. The aim was to encourage health care professionals, particularly those directly involved in the early years of the child, to assist in identifying and detecting problems in the at-risk population as soon as possible (14) (15). The ECI team ideally would consist of doctors, nurses, social workers, psychologists, occupational therapists, physiotherapists as well as speech therapist and audiologists. However, this may not be the case in all public health care facilities. (16)

Previously, the focus of primary health care had been that of promotion and prevention. Although this is still a part of the ECI programme, the focus has shifted to

include ‘early detection’ and ‘identification’ of children with developmental problems and/or disabilities (7) through all levels of health care. According to the Occupational Therapy Practice Framework (2002), Occupational Therapy plays an important role in health promotion, prevention and intervention or remediation. This can be directly linked to the role that Occupational Therapists play in providing ECI services as follows:

- Health promotion of normal development in children to all caregivers of children who may not necessarily be at risk for developmental problems.
- Prevention by educating caregivers of children who are at risk for developmental problems
- Intervention or remediation by providing therapeutic services for those children presenting with developmental problems or disabilities. (1)

Berry and Albino (2013) noted, however, that although ECI services are in place, they need to be strengthened so as to benefit the larger population. In order for this to occur, there must be continuation of services in all levels of health care. Thus, areas in the ECI programmes where problems exist need to be identified and resolved for effective intervention and access to services to occur (17).

There a number of factors that influence the access to services, such as family circumstances, parent attitudes and knowledge and services factors. (18) However, when planning services for a specific community it is important to understand their specific needs. The approach used in this study was to seek the perceptions of caregivers on accessing Occupational Therapy services for their children and, based on this information, to address the problems that may be arising (19).

1.2 Statement of the Problem

Bertha Gxowa Hospital is a district hospital situated in Germiston. Here, Occupational Therapy services are offered on a daily basis, including the ECI programme. However, this ECI programme is not accessed consistently at the point when the child would most benefit from early intervention. While some caregivers bring their children to the occupational therapy department timeously or as soon as any developmental problem arise, others do not. Some caregivers of children with a form of disability or developmental problem only access Occupational Therapy services at a later stage in the child’s life when secondary complications of the diagnosis have occurred or the

severity of the diagnosis has progressed significantly. Thus, the aim of ECI ('early detection' and 'identification') is not consistently achieved.

Statistics from Bertha Gxowa ECI records indicate that in January 2015, only ten caregivers accessed ECI services for their children. A year later, in January 2016, 31 caregivers accessed ECI services for their children. (20). The number of children who attend ECI has increased over the time. However, there is still a large number of children who do not access the services despite being informed about ECI within the hospital on a weekly basis. Many of the children seen at Bertha Gxowa Hospital are exposed to one or more risk factors. Emphasis is placed on this when promoting ECI to the caregivers, nonetheless there is still poor access to the service.

Although there is literature available in the South African context on the factors (barriers and facilitators) which influence access to health care, it is unclear what the factors influencing access to ECI services are in this particular context and what the reasons may be for accessing or not accessing ECI services.

1.3 The Purpose of the Study

The purpose of this study was to describe the characteristics of the population of caregivers and their children who accessed occupational therapy for the first time and to investigate the factors (both barriers and facilitators) that influenced why caregivers accessed therapy services for their children. The results of this study could inform both occupational therapy and ECI services at the hospital in order to try and create more responsive services for the Germiston community.

1.4 Research Question

When do caregivers of children with therapy needs access occupational therapy at Bertha Gxowa Hospital and what are the factors (both barriers and facilitators) that influence the decision to access Occupational Therapy services?

1.5 The Aim of the Study

The aim of the study was to describe the population of caregivers and their children accessing occupational therapy at Bertha Gxowa Hospital for the first time as well as the factors (both barriers and facilitators) that influence caregivers' decision to access Occupational therapy services.

1.6 The Objectives of the Study

The objectives of this study were to describe:

- The demographics of the population of caregivers and children accessing Occupational Therapy services at Bertha Gxowa Hospital for the first time,
- The factors (barriers and facilitators) that influence caregivers' access to Occupational Therapy services at Bertha Gxowa Hospital.

1.7 Justification of the Research

The goal of the study was to gain information from the caregivers on seeking out Occupational Therapy services for their children, particularly in the Germiston area. It was also aimed at resolving the problems that arose from caregivers accessing therapy services for their children in the Germiston area, particularly at Bertha Gxowa Hospital. Once these factors (barriers and facilitators) were identified, the information could be used to address the arising problem areas so as to allow more caregivers to access Occupational Therapy services earlier. This was in keeping with the aim of ECI as the role of the occupational therapist is to provide therapy services upon early detection. This would in turn assist in decreasing the chances of secondary complications or the worsening of disabilities, as seen with those children currently attending Occupational Therapy services, who had begun at later stages.

The research study expands on the current knowledge of ECI services and seeks to contribute to the literature currently available on factors (barriers and facilitators) related to accessing of health care services, particularly for children accessing Occupational Therapy services. The availability of such information would be of benefit to all occupational therapy clinicians in the government sector who were facing a similar problem as that experienced in the Germiston area.

Chapter 2: Literature Review

The chapter examines existing literature on the subject of early childhood development with particular reference to risk factors that affect normal development. The review highlights the importance of identifying developmental problems, which points to the need for early childhood intervention services. The role of the occupational therapist is also examined in relation to these services. Early childhood services in South Africa are considered, followed by health care and factors influencing access to health care.

2.1 Early Childhood Development

Early childhood is the period from birth to pre-schooling age which is approximately up to the age of five years (7). The first two years of a child's life, also known as the first 1000 days, are said to be the most crucial years in terms of the child's development (8) (9) (10). During these years, vital connections develop between different parts of the brain, which grows rapidly. If a child fails to grow well or has difficulty with growth in the developmental areas, a developmental delay may occur (21) (22). As a result, connections in the brain do not develop well and/or are not mature enough to perform the desired actions required for the child's age. This, in turn, affects the child's development in multiple areas as time progresses, as the areas are dependent on each other's growth (11) (23).

Normal development in children can be seen in terms of a child achieving certain milestones at certain points in time (11). Developmental milestones are broken up into different categories, namely, cognition, gross motor skills, fine motor skills, language and social and emotional development (8) (9). Every child is unique in reaching a particular milestone at particular time (in other words has a unique developmental trajectory), nonetheless, there are norms within which developmental milestones should be achieved. For example, by the age of two, a child should have fully developed walking and should have progressed to running and jumping (24) (25).

Good development is supported by consistent and nurturing care from parents and/or caregivers who are responsive to the child's needs. Caregivers are expected to play with and stimulate the child to ensure healthy development in all areas of development (11) (10) (21). A stimulating environment is also important for strong connections to develop within the brain. If the environment is not conducive to development, neural

connections in the brain may be weak. Stimulation thus needs to be provided consistently by the caregiver throughout the life of the child (10) (23) (26). At the same time, it is also important to support the caregiver after the child is born, as the caregiver's well-being will assist in the successful development of the child (27).

Development in a child should occur as a natural process as the child grows, however, there may be aspects that interfere with normal child development (11) (2) (17).

2.2 Developmental Delays

Developmental delays or difficulties occur when a child does not reach some or all of their milestones in cognition, gross motor, fine motor, language, social and emotional developmental areas. If a child does not achieve certain milestones by a certain age, other milestones that are meant to follow are also likely to be affected, thus little or no progression occurs (7) (11) (24). Developmental delay is therefore likely to occur in more than one area (5) (6).

Children living in developing countries are more likely to experience developmental delays due to a myriad of risk factors. Statistics indicate that up to 1.5 million children in Sub-Saharan Africa and developing countries do not reach their full developmental potential (11) (26). While in South Africa, the exact numbers are unclear, conditions in the country are reported to be similar to other sub-Saharan African countries and South Africa is facing similar problems in preventing developmental delays (28) (29).

In an article in the Lancet Series entitled *Developmental potential in the first 5 years of children in developing countries,* McGregor *et al.* (2007) reviewed studies from developing countries to look at the effects of poor development on children as well as the impact of poor development later in the child's life. Developmental delays had long-term effects on the quality and type of life that the child may lead. For example, if children fail to cope at school, they may only find low income work upon reaching adulthood, which continues the poverty cycle (11). Poverty is a risk factor which, in turn, influences early childhood development.

The following section discusses the numerous other risk factors which affect early childhood development.

2.3 Risk Factors for Early Child Development

There are social, psychological, biological, cultural and economic elements that impact childhood development (30) (23). In many instances, it is not just the one risk factor that contributes to the developmental delay of the child but a number of factors, which together, create the problems being seen (31) (6).

Risk factors can appear at any stage in a child's life. Pre-natal factors are just as important since a child's development begins before birth (11) (26). During the pre-natal phase, risk factors include the age of the mother, poor maternal nutrition, poor access to health care during pregnancy, viral infections during pregnancy and substance abuse amongst many others (23). Birth asphyxia, low birth weight (23), age of the foetus upon delivery, the method used in delivery, neonatal jaundice, prolonged labour and low Apgar scores form part of the many peri-natal risk factors that may subsequently influence developmental delay (24) (23) (32). Post-natal factors such as malnutrition and stunting (10), poor infant care, poor attachment and bonding, lack of stimulation (11) (22), trauma, illnesses such as infections, lack of health care or inadequate access to health care as well as poor social and living conditions are amongst the many factors that also contribute to a possible delay in a child's development (23) (30) (33) (34).

Other risk factors such as maternal mental health also play a role in the development of the child. Post-natal depression accounts for 30 – 45% of maternal mental health concerns and has a strong association with developmental delays in children (3). Mental health concerns can lead to a lack of responsiveness by the caregiver in providing adequate care and stimulation for the growth of the child (23) (24) (35). In many instances, the child is likely to experience behavioural, social or emotional challenges as a result (36).

Another risk factor is maltreatment, which can be classified as abuse or extreme measures taken to punish a child. Maltreatment can also include neglect (4) (37). This occurs when the child does not receive adequate stimulation from the caregiver, and as a result, fails to explore the environment in order to grow and develop (25) (38). At the same time, poor environmental conditions due to poverty and a lack of community resources, for example, also affect the child's stimulation and development (26) (27).

Furthermore, family composition has an impact on the development of the child. For example, the demands placed on a single parent are far greater than those placed on both parents involved in the care of the child (26) (39). A poor style of parenting may also negatively impact the development of the child, irrespective of whether only one or both parents are involved in the care of the child (23) (26) (39). The educational level of the caregiver is also pertinent and can influence the manner in which the caregiver cares for the child, thus influencing development (24) (34) (40).

However, a common link between the risk factors is that of poverty. In South Africa, more than half of its population lives in poverty (41). Children being born into poverty stricken families are more likely to experience the pre, peri and post-natal factors as mentioned above. As a result, the child is predisposed to having medical conditions later in life which may impact on their development. Caregivers are said to be under increased amounts of stress to ensure that the basic needs of the child are met and as a result they tend to neglect their parental duties such as socio-emotional support for the child. Apart from developmental delays, this results in children having increased levels of the stress hormone (cortisol) being released which affects the child's ability to learn and develop higher order brain functions. As a result, this affects the child's academic abilities and the child is less likely to succeed in school. Furthermore, this also affects school completion which results in low income employment. Thus, the cycle of poverty continues. (4)

There are many factors within these elements that put a child at risk of delay in their development at various stages of their unborn and/or born life (31). Circumstances surrounding developmental delay as well as poor environments will continue to affect children unless early identification of the problems occur (10).

2.4 Identifying Developmental Delays

Identifying developmental delays early is a key aspect of ECI and of ensuring good development in at-risk populations. However, in many health care systems, the onus is on the family to identify problems and seek help from clinics or hospitals. As a result, developmental problems are often detected later, during the child's pre-schooling years when a teacher or child minder taking care of larger numbers of children notices a problem. This occurs after the age of three or four years (11) (22) (40). However, developmental delays in some instances can manifest as early as three to four months

of age (22). Indeed, developmental delays can occur across all age bands in a child's life depending on the risk factors in the child's life or immediate environment (22) (38). Thus, it is likely that the developmental delay will occur for a longer period of time if it goes undetected. Development can be likened to climbing a ladder: if one step is missing, it is likely that the steps to follow will not develop or will not develop to their full potential (21) (26) (30). Identifying problems at an early stage means children are more likely to be enrolled at school, complete school and be less likely to repeat a grade. This, again, breaks the cycle of poverty (24). Therefore, a form of intervention is required in terms of promotion, prevention and rehabilitation of those children faced with developmental delays or other childhood disabilities (40).

A US study by Sheldrick et al. (2012) identified the concerns of caregivers regarding their child's development and the presenting behaviour. It was found that often, caregivers misidentified developmental problems for behavioural ones. For example, a child with a language delay struggled to follow the rules of the classroom and as a result, did not do what was expected. Parents reported this problem to health care providers as a problem with behaviour at school rather than a delay in language. The study further indicated that a lack of caregiver knowledge may thus affect development (42). In support of this, Meintjes et al. (2011), in their study on *Caregivers' knowledge regarding development in Shoshanguve, South Africa,* also found that should the caregiver have knowledge of development, they would be more likely to correctly identify developmental problems and in turn, seek appropriate help for the child (28). Caregiver education is therefore an important aspect in identifying problems at an early stage (2) (43).

As frequently seen in some South African contexts, the mother of the child is sometimes unable to care for the child as she may need to relocate for work purposes or return to school in the event of adolescent mothers. Thus, the child is left with an alternative caregiver such as extended family members such as grandmothers (28) (29) (39) (44). The alternative caregivers are often unaware of what developmental delays are or the risk factors associated with developmental delay (28) (32) (45). This can be due to the fact that a developmental delay does not classically mean that the child has ill health or has sustained an injury such as a child with pneumonia or the influenza virus, for example (46). Education of the extended family is therefore also important as it allows individuals other than the mother to identify and seek help for

the child. This not only assists and supports the caregiver but also prevents stigma or exclusion from not just the family unit but also from the community or society as a whole in the event of disability or developmental delay (22) (6) (47).

2.5 Early Childhood Intervention

Early Childhood Intervention (ECI) is a service that consists of various interventions, one of which aims to promote normal development and prevent developmental delays. The service supports the rehabilitation of those with developmental delays and at the same time allows for early detection of disabilities in children (2) (3) (4). It occurs at the time when a child is in need of assistance in order to change the pattern of their development for the better (2).

Early Childhood Intervention is targeted at the crucial years of development in children, namely, from birth to five years of age, to assess any developmental issues that may be arising (5). Early Childhood Intervention aims to ensure that the child achieves their fullest developmental potential in a safe, stimulating and healthy environment (2) (21) (23). In this way, services aim to decrease both the number of children presenting with developmental delays as well as the severity of delays and disabilities, ultimately improving the functional ability of the child in their family and environmental contexts (6) (3) (47).

Early Childhood Intervention services also promote the child's right to access health care which is free at any level of the public health care system up to the age of six years in South Africa (48). It also supports early access to the health care system and eliminating waiting long periods of time before help is sought (2). ECI seeks to intervene when the neuroplasticity of the child's brain is at its highest. Neuroplasticity refers to the brain's ability to adapt and change to perform various functions (22) (6) (49). This is done by intervening at an early stage when the risk is identified or when there is an early presentation of the problem. Early intervention thus seeks to prevent severe disabilities or developmental delays from occurring (3) (47).

A study conducted by UNICEF (2013) indicated that early intervention in children with developmental delays leads to a better chance of improvement so as to achieve milestones expected of their age band (17) (6). Early intervention can help prevent irreversible or permanent developmental delays (2) (26) (32). This is seen as a primary prevention method to eliminate factors that impact normal development (21) (17) (47).

At the same time, it ensures that the costs of health care later in the child's life are kept to a minimum as early intervention is required for a shorter duration compared to late intervention to resolve multiple, progressive problems (23) (26) (34).

Worldwide, Early Childhood Intervention has been particularly promoted to identify children with developmental delays or disabilities before they reach school-going age (50) (51) (52). This initiative seeks to achieve better readiness for school in the later years of the child's life (26) (50) (53). Most problems are usually observed by the teacher once the child has started school (2). This may even be after many years of the child presenting with some developmental problems. Intervention thus becomes increasingly difficult as the therapy will need to address the primary building blocks which should have been laid down in previous age bands, before progressing to the age-appropriate milestones for the age band that the child is in (26). Therefore, having early intervention services in place has positive effects on the child when they start school as they are better prepared to cope with the demands of schooling (2) (24) (26).

Early Childhood Intervention should be done by a person other than the child's caregiver, such as medical doctors, allied health professionals or professionals trained in ECI (5) (54). The focus is aimed at a multi-disciplinary, more holistic, approach for all children from birth to up to the age of five years, and not only those at risk (5) (6). Thus, while the dietician focuses on the nutritional needs and feeding of both the mother and child (53), the speech therapist and audiologist will discuss language and hearing development and stimulation (47). Physiotherapy will address women's health for the mothers before and after having given birth (53). The occupational therapist, together with the physiotherapist, will draw the mother's or caregiver's attention to milestones as well as the necessary stimulation through play and toys (55) (56) (57). However, nurses are more likely to be the first line of contact with the child and caregiver and not necessarily the multidisciplinary team such as the occupational therapists. In primary health care, nurses are responsible for healthy baby follow ups and immunizations as well as assist with medical issues such as colds and influenza. If these nurses don't refer children with developmental delays or if the families do not understand the need for referral than the opportunity of early identification is lost. Thus, highlighting, a need for more trained professionals to perform ECI services (2) (23).

2.6 Occupational Therapy in Early Childhood Intervention

Children are also considered to be occupational beings. The most important occupation that the child engages in is that of play. Thus, if a child's development is affected, it impacts on the child's ability to engage in his/her key occupation. Therefore, this section will discuss the role of the occupational therapist in Early Childhood intervention with the basis of the Occupational Therapy Practice Framework (2002). Occupational Therapy plays an important role in health promotion, prevention and intervention or remediation which links closely with the roles of ECI. (1)

It begins with the promotion of normal development, in keeping with the principles of ECI, to target the caregivers of children (47) (58). This usually takes place in areas where there is likely to be pregnant mothers or mothers who have just given birth, such as the ante-natal clinics, post-natal wards or neonatal nurseries (21). Prevention goes hand in hand with promotion as it also focuses on mothers and caregivers in the same areas, however, specific attention is likely to be given to those at risk such as mothers and babies in the neonatal nursery who may have experienced any of the pre-, peri- or post-natal risk factors (5) (6) (53).

As part of the role of an occupational therapist, he/she will screen all at-risk children in the clinical setting for early detection and identification of any problems that may be present (5) (47) (58). Screening tools are useful to ensure objective screening and assessment of the child. There are various screening tools available that can be used to assess development (6) (49). Basic developmental milestone screenings thus far have been well suited to most contexts for screening and assessment, particularly in South Africa (2) (49). It is also easy for caregivers to understand and know what to expect of their child at each age band as well as understand how to stimulate the child to achieve this (5) (31). If the child appears to be developing normally, the occupational therapist will encourage the caregiver to continue with stimulation but will provide further education for the years ahead (57) (58) (59).

However, if a child from the screening process presents with a developmental delay, the occupational therapist will perform a full assessment before beginning with intervention or rehabilitation. This is to ensure that underlying problems are not missed (22) (47) (58). One of the most commonly identified problems is that of play (60). Play is one of many occupational performance areas in occupational therapy (1). It is an

important activity or ‘occupation’ in a child’s life and is a vital factor for development (60). Play assists in the development of the neural connections of the brain. Thus, the more the child plays, the stronger the neural connections (61). However, factors such as poverty and limited resources, for example, affect the child’s ability to play, thereby negatively impacting the development of the child (60). Thus, the occupational therapist will use play as a means of treatment as well as a treat play as an occupation, itself (55). Apart from play, there are other occupation based milestones that the child is expected to engage in on a daily basis. These include bathing, dressing, feeding and chores. Depending on the age of the child, these activities vary. Therefore, the occupational therapist will ensure that along with play, these occupations are also assessed and treated appropriately. Treatment will focus on working towards more age-appropriate milestones and occupations expected of the child.

The treatment process will also focus on both the child and caregiver as the caregiver is expected to continue the treatment in the home environment. The caregiver is important as in some public health settings, children can only be seen once a month for Occupational Therapy and it is up to the caregiver to continue stimulation until the next session (31). Caregiver inclusion is thus more likely to increase the developmental potential of the child (31) (27) (57). Only once the child has caught up to all their milestones for their age are they likely to be discharged from Occupational Therapy (56). Therefore, it can be seen that the caregiver plays a vital role in the child’s life – first by ensuring access to Occupational Therapy services and subsequently, through the continuation of Occupational Therapy (56) (57).

2.7 Early Childhood Intervention Services in South Africa

Health departments of various developing nations were targeted by the United Nations to ensure that ECI services were established as part of the health care systems of those countries. The aim was to gather the many health professionals to target the problem areas that contribute to the developmental delays and disabilities (32). As a result, in 2005, the South African Health Department began implementing ECI in the different provinces with the aim of reaching children exposed to the risk factors for delay and disability (17). This process began with the development of policies informed by the United Nations Global Millennium Developmental Goals. These goals included alleviating poverty and hunger, decreasing child mortality and increasing the number

of children who complete primary education. This was particularly important in the South African context as school completion rates were low in some provinces, leading to high unemployment, which further contributed to the impoverished living circumstances, poverty and a hunger crisis. Intervention was clearly required in order to meet these UN goals (11) (23) (26).

Policies addressing the United Nations Global Millennium Developmental Goals have thus been developed and are available. However, most policies address basic services such as water and electricity, HIV/AIDS prevention and transmission and nutritional needs. There are only limited policies addressing early childhood intervention and the importance of early childhood, together with the services available for such children (2) (10) (24). Therefore, the policy development in South Africa to address ECI has not focused on all the factors necessary to promote good development (2). Little progress has been made with the actual implementation of ECI services, despite the development of the National Early Childhood Development Policy of The Republic of South Africa (2005) (53). Thus, as a result of inadequate access to ECI services, the problems of children with developmental delays or disabilities are still going by undetected (2) (48).

According to the National Early Childhood Development Policy of The Republic of South Africa (2005), ECI programmes should consist of a range of services (53). These services should address mother and child health issues in order to decrease preventable developmental delays and deal timeously with disabilities in order to minimise their impact on children and their family's lives (62). These services should include maternal health care during pregnancy, adequate pre-, peri- and post-natal care, nutrition, family education, medical services, developmental services and screening services (2) (17) (50). The National Early Childhood Development Policy of The Republic of South Africa (2005) defined six areas for an integrated package of services (2) (10) .These include: (i) ensuring birth registrations, (ii) health promotion in pregnancy, at birth and in early childhood, (iii) nutritional care, (iv) support services, (v) referrals to health and social services to ensure grants are applied for and received and (vi) early learning and stimulation (10) (23) (26). These areas are seen as non-negotiable and are in keeping with the South African Constitution and various legislation applicable to children (24) (26). These six areas are intended to work together and should not be addressed in isolation. For example, nutritional care should

not be offered separately from stimulation as studies indicate that the combination of the two services together shows greater improvement in the child's ability to reach their potential (26) (40). The services are to target children from birth to five years of age. The ECI services should be comprehensive as well as continuous (17) (47). The aim is not to establish a new ECI package of services, but rather to build upon existing services (2) (23). In South Africa, ECI services have been identified as a priority as part of health services. The programme aims to include all areas of health care in the various health care structures such as medical and developmental aspects. For example, it is intended to address the development of the child in all areas, be it physical, cognitive, emotional, social or linguistic. All are deemed as important as child immunisations being up to date or the caregiver having information on nutrition which includes the method of feeding and the weight of the child (62).

The Gauteng Department of Health created an ECI task team in 2010 to guide and facilitate the implementation of ECI services as the importance of early childhood services was recognised. This initiative intended to address the limited number of the target population actually accessing therapy services. At the same time, it was observed that children with developmental delays were being referred too late to therapy services and children with developmental delays or disabilities were not being easily identified. The ECI task team created protocols, developed basic screening tools, early childhood development pamphlets and other materials and resources for use in hospitals and clinics (3) (47) (49) (63). This was to ensure that ECI would not stop at the primary health care level of the clinics but extend throughout the health care structure in Gauteng Province (2) (47). The hospitals and clinics are responsible for adapting the ECI programme to fit the needs of each institution (3) (47).

In 2012, Richter et al. reviewed early childhood services in South Africa in a report entitled *Diagnostic Review of Early Childhood Development.* The findings indicated that ECI was implemented in only a few South African practice settings, while in most other settings it was virtually non-existent (2). At the same time, many programmes were not applying simple developmental milestone assessments when working with children from birth. Thus, the ECI services being provided were deemed insufficient and not easily accessible. These were newer services as opposed to existing dietetics and developmental support, for example (2) (26). Furthermore, the services available for parent/caregiver support were also poor at all levels of health care (2).

A subsequent review of early childhood services was conducted in 2013 by Albino and Berry which also yielded similar findings. The report indicated that although ECI services had been established in South Africa, the continuation and development of the programme needed to be addressed (17). It was found that the ECI services being provided were inadequate and although some services were in place, the quality and implementation remained poor (17) (16). This means that there are still too many opportunities for children to be missed and for developmental delays continuing into school before they are detected and remedied.

The South African government is responsible for ensuring ECI services are in place (17) (23). Early childhood intervention services are considered essential health care and not a “luxury or privilege” (23). Many critics point to the fact that despite being aware of the need for ECI services, not enough is being done to further develop these services (23). In 2011, Statistics South Africa reported that 10.8% of children in the age band of five to nine years old presented with disabilities. The need for ECI services is clearly evident. However, it is not the expansion of current services that is lacking but access to existing services which needs to be addressed (2) (6). Richter et al. (2012) proposed strategies to promote access to ECI services by creating opportunities for accessing home and community-based services. It was also proposed that communities which have not yet accessed such services be targeted first (2).

At the same time, current ECI services need to improve the quality of the care being provided and integrate those services at all levels of the South African government systems (32) (40) (16). Working together will ensure better ECI service delivery as it would allow for national implementation and monitoring of the services being provided (17) (26) (16). To support this, government needs to ensure that the budget allocates sufficient funding for ECI services as this is currently lacking (2) (17) (26) (32) (54).

Furthermore, ECI services cannot be improved without first determining the factors that lead to poor or non-existent access to such services (2) (17) (63). Thus, there is still much work to be done in understanding barriers to ECI and promoting ECI within South Africa. Understanding how ECI fits within the bigger picture of health care in South Africa is also important.

2.8 Health Care in South Africa

Since 1994, Nelson Mandela declared primary health care as free for all, emphasising that there should be free health care to all children under the age of six at all levels of the public health care system in South Africa (48) (54) (64). According to Statistics South Africa, 90% of South Africa's population seeks out health care at a public or government facility (34) (65). In South Africa, 85% of children access public health care services (40).

The levels of public health care services are described as follows:

The primary level of health care is seen as the entry level and consists mostly of clinics or community health centres (64) (66). Services at this level of care are more likely to consist of promotion of health care and prevention programmes; namely, immunisations of infants and children and mother and child care. Services are frequently offered by nursing staff. However, medical doctors are available on a regular basis. Should an individual require care additional care which cannot be managed at a primary level, the health professional may refer the patient to the next level of health care, a district hospital. (66)

District hospitals offer additional services as compared to that of the clinic such as in-patient hospital care. (67) (68) (69) An example of the services offered include: reproductive health and management of paediatric patients with minor illness such as bronchitis who may require hospitalisation for example. (66) However, the services are not specialised. Patients who require specialised care are then referred to the Regional Hospitals, which have at least five speciality services which include paediatrics and obstetrics and gynaecology (66).

Specialised treatments or procedures for diagnosis are accessed at a tertiary level hospital, which is known as the highest level of health care. An example of a specialised paediatric service would be neonatology. A referral is usually required to access the tertiary level hospital which in most cases comes from the district or regional hospital.

Depending on the socio-economic classification of the patient, a person may have to pay a small fee for the health care services they seek out at these levels. (67) (68) (69) Nevertheless, primary health care services, including other levels of healthcare,

are limited in terms of accessibility as well as availability, particularly those services available to children (64).

Furthermore, the quality of the available services is poor. This may be as a result of poor management of the facility, large patient numbers at certain levels of health care as well as a shortage of staff and, in some instances, not enough health care professionals trained or specialised in the field of paediatrics (40) (16).

Accessibility to health care has shown little improvement over the years, with Gauteng showing the least improvement in terms of accessibility to health care for both adults and children (64). At the same time, there is limited research available to provide feedback or progress on the few services that are being delivered to children (48) (16). This makes it difficult to determine if these services are sufficient and appropriate. It also means it is difficult to motivate for more health care services for children to be implemented when children are not accessing the existing services (6) (48).

Although the South African government has policies and guidelines in place to meet the needs of child health care (10), the extent of the changes or developments with regards to health care access, particularly for children, remains unclear (2) (17). It is evident that there are gaps between what the policy intends and what is actually occurring in terms of access to health care. This may be attributed to a number of factors, however, there is little evidence in terms of research to indicate the degree of access to existing early childhood services (17) (10) (54).

2.9 Factors Influencing Access to Health Care

There are many factors that can influence access to health care. In a review entitled *Overcoming barriers to health care access: Influencing the demand side*, Ensor and Cooper (2004) state that reasons why children access health care in South Africa is limited. It was also found that although many barriers to health care were identified, there was little evidence of how to overcome these. Ensor and Cooper (2004) further indicated that the populations which have inadequate access health care can be broadly divided into the categories outlined below (70). This was supported by the framework developed by Reardon et al (2017) in their systemic review titled, “What do parents perceive are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents”. (18) The framework categorised the factors influencing access to services under four headings, namely,

1. Knowledge and Understanding of services
2. Views and attitudes towards services and treatment
3. Systemic Issues in Health Care
4. Family Circumstances

The framework will be used to discuss these factors further. (18)

Knowledge and Understanding of the services

This section aims to describe the awareness and understanding of the caregiver with regards to the problems experienced by the child, seeking help for the child and the services available. (18)

Lack of Awareness of Services

Reardon et al (2017), along with studies by Goudge *et al.* (2009) and Ensor and Cooper (2004) conducted research on barriers to healthcare. All three studies revealed that individuals indicated that they were not aware of the various services available at health care facilities in their communities and thus did not access those services despite the services being available (70). Therefore, health education and outreach programmes should be boosted to create awareness of services such as early childhood intervention services available at local health care facilities (71) (72). Community health workers are also starting being introduced into communities to assist in this regard (71).

At the same time, alternative caregivers such as grandparents or extended family members are not always seen as the legal guardians of the child whom they are caring for. They often lack the correct documentation to access the health care services for the child in the absence of the parent. In some instances, caregivers have failed to even register the child's birth, thus no documentation exists at all for the child. Therefore, if problems are noted in the child, be they medical or developmental, the alternative caregiver relies more on primary health care and may not be able to access the necessary services required for the child's health and well-being at a hospital or specialised centre (37) (39). This is made increasingly difficult if the primary health care services are distant, insufficient or not easily available (10) (23).

Insufficient Caregiver Knowledge

Apart from awareness of the services, if the caregiver is not aware of the child's problems, they are unlikely to access services, particularly those of ECI (70). Nores and Barnett (2010) reviewed ECI services in developing countries, while Sanders et al. (2009) focused specifically on ECI services in South Africa. Both reviews indicated that caregiver knowledge, particularly on development, was an important factor that influenced whether healthcare services were accessed or not (50) (40).

Statistics South Africa (2011) conducted general household surveys in an initiative entitled *Use of health facilities and levels of selected health conditions in South Africa.* Possible reasons hindering an individual from accessing a health care facility or seeking medical care were investigated. When looking at children in the age band of zero to four years, the findings showed that the majority of the population (70%) did not think that the child's problems were serious enough to seek help (46).

Views and attitudes towards services and treatment

According to Reardon et al (2017), past experiences as well as the quality of services provided at the health care facility influenced whether caregivers would seek help for the child. (18)

Experience at the Facility

Sanders *et al.* (2009) report that some individuals indicated that despite the long distance travelled or the time taken off from work, staff attitude was poor at the various levels of health care. This was a factor which discouraged both patients and caregivers of children from accessing medical care. This negatively impacts on the services as it decreases the number of children accessing the services which is already low (34).

In other instances, the individual may be required to visit the health facility a number of times over a short period of time. For example, the initial visit for the individual's current illness, the second visit for further investigations or results of previous tests and a possible follow-up visit to get feedback from the remainder of the results or to determine if the individual was improving or stable. Similarly, the individual may need to consult various health care professionals on different days in the same month. The individual must then deal with a combination of factors such as multiple days off from work, loss of income due to absence from work as well as money spent on transport to and from the health facility for multiple appointments (73).

At times, there is a breakdown in communication between the health professional and the patients and/or patient's family members. Thus, should a patient be required to follow up at the clinic for continuation of services or be referred up to the level of hospital for further management, they do not always understand this and as a result return home without having sought the necessary health care needed. Similarly, a poor understanding of the diagnosis also plays a role in type of help that the individual or his/her family members may seek for them (73) (74).

Family Circumstances

Reardon et al (2017) identified that additional barriers to seeking help for the child by the caregiver related to aspects of the family life such as the cultural views of the family or the impact on the families financial situation. (18)

Cultural Beliefs

Consideration must be given to the cultural beliefs of the community in which services are being rendered. Culture and beliefs play a role in whether or not a patient will choose to access therapy services (22). For example, a child that presents with developmental delay may not be considered to have "ill health or to have "sustained an injury" as compared to a child with pneumonia or influenza virus, thus, medical help may not be sought out (65).

If health care services are not offered in a culturally relevant way, it is less likely that community members will access these services (75). Similarly, caregivers of patients perceived that their cultures will not be respected, thus, may opt to a see a traditional healer or spiritual leader to assist in resolving the problem. Home remedies and alternative treatment methods are also part of certain beliefs and customs and as result, these may be tried first before accessing the health care facility (73). This also relates to whether community members experience a visit to the health care facility as positive or negative (22) (76) (77).

Socio – Economic Status

The number of children living in poverty in South Africa has decreased, however, there are still many who are living in poor and impoverished homes. According to Sanders et al (2012), the conditions in which a family live influences how the child will grow and develop and is a risk factor for developmental delays. This was further expanded on

to include socio – economic status as a deterrent from seeking both maternal and child services. Food insecurity is a key factor that drives the decisions of the household. Thus, children with “ill-health” are considered to be an expense for impoverished families. (34) For that reason, a caregiver may seek help for the child at the level of primary health care which is closest to the family home. However, if the child requires health care at the level of a district hospital which may not be located nearby, the caregiver is likely to return home until sufficient funds are available to visit the hospital. However, since the caregiver already struggles to provide daily meals for the family, it is likely that the health care services needed will not be accessed. (73)

Similarly, other factors may also influence whether alternative treatment methods or healthcare services are sought out such as distance from the health care facility for example. (64)

Systemic issues in Health Services

Reardon et al (2017) explored that apart from the cost of health care, indirect factors such as travel costs and distance also play a part in whether services are accessed by caregivers for children.

Distance

Distance and therefore transport to the health care facility is another factor that influences the level of access to ECI services. The cost of the transport to and from the health facility is therefore an important element, as well as patients needing to leave home or work early to be at the hospital on time (70) (77). Furthermore, Hall *et al.* (2009) reviewed health care services for children and found that distance from the health care services was a large barrier on its own (64). This was irrespective of the mode of transport used or the cost implications involved either for transport or the services required (64) (78).

Cost

Goudge *et al*. (2009) conducted a study entitled *Affordability, availability and acceptability barriers to healthcare for the chronically ill*. The findings revealed that chronically ill patients, particularly those from low to middle socio-economic backgrounds, were less likely to seek health care due to cost implications. Health care would only be sought if the individual was able gather the necessary funds and if other

basic needs such as food were first met (73). In South Africa, 64% of children live in impoverished households (3) (47). Thus, financial limitations may result in the poor access to health care, particularly for children (73) (76).

When looking at the cost of health care, some individuals may be fully exempted from health care bills whilst others are required to pay for a small percentage of the fee for the medical care received. However, due to unemployment and low income households, the patient may not even be able to afford the small fee required and as a result may not access the health service. These individuals may be required to provide proof of not being able to afford the services. Public health care facilities do not turn the patient away should they be unable to afford the services being provided for them. However, some patients perceive that should they be unable to afford the costs involved in their health care management, they will not able to access public health care (70) (73) (77).

Children under the age of six are exempted from health care bills, however, other costs may influence their caregivers accessing health care services for them. These costs may be a result of a loss of income by the caregiver due to missing work and in some instances, the caregiver might not be able to get time off from work to go to the health facility. Thus, should the caregiver miss work as a result of accessing health care for the child, they may face the risk losing their job or having unpaid leave for the day (70) (77). This also includes the costs involved for travelling to and from the health care facility for both the caregiver and the child (76).

Transport and Time

Statistics South Africa (2011) recorded the modes of transport that the population uses to access health care services. It was reported that 47% of the population walks to access health care, while 27% uses a taxi. The other 5% of the population uses alternative methods such as trains, buses, bicycles or transport services. The study also recorded that 22% use their own car to access healthcare, some of which is to access private healthcare services. Another factor to consider is the time it takes for a patient to reach the hospital or clinic. The majority of the population living in urban and peri-urban areas takes an average of thirty minutes or more to get to a health care facility (46) (76). However, there are still those individuals who are unable to afford the

transport costs and with a lack of government funded ambulances, some individuals are still unable to access health care services as a result (73).

For children, the statistics indicated that four in every ten children use public transport or walk to the nearest health care facility (64). It took 30 minutes or more to access their nearest health care facility for those residing in urban and peri-urban areas (34) (46). However, those individuals living in rural areas in South Africa take an average of 81 minutes of travel time before reaching their nearest health care facility, which in most cases was a clinic. Travel to the nearest hospital was doubled (79). The system of health care is that of 'first come, first served' if the service required is not by appointment (70) (77). Thus, patients may also wait a long period of time before being assisted (34) (70) (77).

2.10 Conclusion

Health care services is South Africa are still not accessible for all, including children (46). This includes access to services such as ECI, which is still low in terms of the affected population (23) (63). It is evident from the literature reviewed that the key problem is access to early childhood services. However, literature specific to the South African context is limited on the reasons why children fail to access health care, particularly early childhood services (23). It is also important that all factors may not be equally present in each community. Therefore it is important to investigate the factors influencing factors in specific communities in order to understand how best to tailor ECI services.

Chapter 3: Research Methodology

This chapter describes the process that was used to complete the study. It defines the type of methodology used, the population and how the sample was selected from this population. The chapter also describes the measurement instruments and the procedure for piloting. Data collection is then described along with the raw data analysis method.

3.1. Type of Research

The study adopted a descriptive, cross-sectional, quantitative and non-experimental design. The data collection occurred once-off, therefore making it cross-sectional. The design was also non-experimental as an interview took place and no intervention occurred. The study was descriptive insofar as it described the health behaviours of a community, in this case, access to Occupational Therapy services (80) (81).

This type of research design allowed for the exploration of the different groups of people accessing Occupational Therapy services. It also allowed for the description of the problems faced by those accessing the Occupational Therapy services. Furthermore, the research design made use of available information relating to ECI and access to services to build new understandings (82).

3.2. Research Site

Bertha Gxowa Hospital is a district hospital located in Germiston. The area surrounding the hospital is home to many informal settlements as well as lower socio-economic neighbourhoods. Thus, Bertha Gxowa Hospital is an access point for medical care after the various clinics situated within the community (83).

Early Childhood Intervention services were established at Bertha Gxowa Hospital at the end of 2014 by the Allied Health Team and have been growing ever since. The programme is directed by the ECI coordinator, the occupational therapist (and researcher of this study). A policy document was developed by the coordinator based on the Gauteng Health ECI policy, to describe the procedure and application of the ECI services being rendered specifically at Bertha Gxowa Hospital. The multi-disciplinary team (MDT) providing the ECI services includes occupational therapists, speech therapists and audiologists, physiotherapists, dieticians and as of 2017,

psychologists and social workers. This expansion indicates growth and development of the ECI services in the hospital over time (84). Specialized services of education, early identification of problems and early rehabilitation are included in the ECI programme.

The programme is carried out every week and consists of various tasks. The team conducts promotional talks at the outpatient antenatal unit as well as in the paediatric ward. The talks cover various topics related to development and stimulation, maternal health and mental health, nutrition for the mother and child before and after birth, the importance of care for the child as well basic children's rights. The team also visits the maternity ward for another promotion and prevention talk for all mothers whose babies have been admitted to the neonatal nursery or intensive care unit. The talks are based on similar aspects of the ones previously mentioned. The aim of the talks is to create awareness of the ECI services and the roles that the MDT plays.

In the paediatric ward, the team also screens all children for developmental delays or other disabilities, nutritional needs and signs of neglect or abuse. The aim of this is to ensure early identification of children presenting with developmental problems. At the same time, it informs the caregivers on aspects of ECI such as development, for example. This, in turn, creates awareness of the ECI programme and the services it offers (84).

Children placed in the neonatal nursery or in the cot and toddler unit are booked a three-month screening with the MDT. This is in keeping with the first 1000 days of life to monitor the child's growth and development from an early stage (49) (26) (10). This screening also occurs on a Tuesday and Thursday morning and is carried out by MDT members of the team with experience in ECI, and development in particular (84). However, it is rare for all children booked to arrive for their screening. The average arrival rate for 2016 was 22-33% babies a day. Records are kept for each service provided (84).

3.3. Population

The population of this study included all caregivers of children at Bertha Gxowa Hospital in Germiston, who accessed Occupational Therapy services for the first time over the six-month period of data collection.

3.4. Sample and Selection of Sample

Total population sampling was used for the study as all caregivers of children who accessed Occupational Therapy services for the first time over a six-month period were part of the study (80). This was also a type of purposeful sampling where the entire population relating to a specific interest was observed, such as the caregivers and children of this study who accessed occupational therapy services, regardless of age. While ECI is defined as the period from birth to five years, the study aimed to determine when children were arriving as well as the age categories at which they were arriving at occupational therapy. The referral was not taken into consideration for this study. This type of sampling also works well with an interview-based design (81).

From a review of previous records, approximately 20 caregivers accessed Occupational Therapy for the first time within a three-month period. Therefore, it was predicted that the sample for the study would be approximately 40 participants over the six-month data collection period.

3.5. Recruitment of Sample

A total of 36 referrals was received in the six-month data collection period. From this, only 21 participants (58.3%) arrived for their first appointment. Of these, five declined to participate and 16 consented to data collection.

The number of participants in the study was affected by other members of the allied team booking first time clients for occupational therapy and then many of these clients not arriving. A total of 15 first time clients did not arrive for their first Occupational Therapy appointment during the data collection period. This could have been eliminated if the occupational therapist had been able to complete the questionnaire with the caregivers when the appointment was given if they had consented to participate in the study. To try and recruit participants who had not attended their appointments, a second round of data collection was conducted via telephonic interview to investigate the reasons for the caregivers not attending the appointment. From this, the researcher was only able to reach three out of the 15 participants. This may have been due to the second round of data collection occurring a few months after the first appointment date. The researcher had made several attempts to contact the remainder of the participants. However, it was possible that telephone numbers

had changed or that the participants were unable to answer the call at the times when the researcher attempted to contact them.

3.6. Measurement Instruments

A non-standardised interview-based survey questionnaire was developed by the researcher based on the literature (Appendix A). The first section aimed to collect demographic information on the caregiver. This included their relationship to the child, gender, age, race, language and area where they lived in Germiston.

The second part of the questionnaire collected information from the caregivers on their child's birth and medical history to help determine if and when the signs and symptoms of the problem starting presenting before accessing Occupational Therapy services.

The last section, part three, gathered information on the reasons for accessing Occupational Therapy services and why or why not the therapy services had been accessed. This questionnaire included factors such as whether the caregiver was working, how easy it was to get time off work to come to the hospital, were there others available to bring the child to the hospital, how far the participants were located from medical services, whether others have noticed problems with the child and what help was sought out before accessing Occupational Therapy services.

The questionnaire was administered in the form of a structured interview in order to accommodate the low literacy rates within the population. The researcher conducted the interview with the caregiver and filled in the caregiver's answers on the questionnaire. The interview took place on the first day that the caregiver accessed Occupational Therapy services at Bertha Gxowa Hospital and took about 15 minutes to complete.

As the interview -based questionnaire was developed by the researcher, face validity needed to be checked. This was done by the ECI Task Team. The ECI Task Team is a panel of health professionals which consists of occupational therapists and other fellow allied health professionals actively involved in the field. The task team was satisfied with the content of the questionnaire. Their only suggestions were that of changing the formatting and structure of the questionnaire for easier analysis of the results. This was done for ethics submission.

For the caregivers who did not bring their child to the first Occupational Therapy session, a telephonic consent form and basic questionnaire (Appendix B) was developed so as to gather information particularly on reasons for not accessing Occupational Therapy services. The questions included were on the age of the child and gender. This was to provide the researcher with the demographics of the child not having accessed the services. The next question related to the reasons why the child was seeking out Occupational Therapy services when the first appointment had been made, followed by the reasons why the caregiver and child did not attend this appointment.

3.7. Piloting Procedure

As the interview – based questionnaire was developed by the researcher, face validity was conducted. This was done by the Gauteng ECI Task Team. The Gauteng ECI Task Team is a panel of health professional which consists of occupational therapists and other fellow allied health professionals actively involved in the field. The Task Team has knowledge of Early Childhood Services, policies surrounding ECI, participate in on-going research for ECI and are aware of the challenges faced with the implementation of ECI. This was one of the reasons why they formed the task team to ensure that ECI services is occurring throughout Gauteng. Therefore, the Gauteng ECI task team were the ideal candidates to ensure content validity.

Thereafter, the questionnaire was piloted on five caregivers who were part of population of the study but were not part of the sample. The piloting population consisted of five caregivers who had previously accessed Occupational Therapy for their child. It was also verified that the questions were able to gather the data required to answer the objectives of the study and was understandable for the end-user. Each piloting participant was asked to complete the consent form and thereafter the researcher completed the non-standardised interview-based questionnaire with each participant.

From these procedures it was found that Part one: Demographics of Caregiver, asked which suburb in Germiston the caregiver and child lived in, and later Part three: Access to Services, enquired how far the suburb was located from the hospital. Both questions were then combined together in Part one of the questionnaire as it provided

geographical information which could be used in both demographics and as a factor influencing access to services. No other aspects of the questionnaire were modified.

3.8. Data Collection Procedure

The data collection process began on 26 January 2017 after receiving permission from the Human Research Ethics Committee (HREC). Data collection occurred over six months up to 26 July 2017. All caregivers who arrived for the first time at Occupational Therapy services at Bertha Gxowa were given the option of voluntarily participating in the research study. Caregivers were given their appointments or referral letters first before they were asked to participate in the research. The researcher explained the purpose of the study and an information letter was given to the caregiver (Appendix C). The interview with the caregiver only took place once they had signed the informed consent (Appendix D). This ensured that the caregivers were not coerced into doing the interview or felt obligated to participate. The interview took no longer than 10 to 15 minutes to complete. For the purposes of confidentiality, the interview took place in a therapy room.

The researcher trained a translator in the event that the caregiver was not fluent in English. This was an occupational therapy assistant who assisted with many participants to ensure that they firstly understood the purpose of the study and that they did not feel compelled to participate. Thereafter, the translator assisted the caregiver by translating questions in order for the researcher to complete the questionnaire. Both the researcher and translator were available throughout the interview process to assist the caregiver where necessary.

3.9. Data Analysis

Data from the interviews were captured using Microsoft Excel. Still using Microsoft Excel, frequency tables were created to represent the data in terms of percentages. This was then summarised into bar graphs, line graphs and tables, also using Microsoft Excel to represent common factors that arose in the raw data collected. From this, the findings from the graphs and tables were further analysed and summarised into paragraphs. The tables used to represent the data set are available in the appendices.

Descriptive statistics were used for this study to analyse and present the data collected. This allowed for the data to be represented for better understanding when analysed. The study looked at the data collected and the raw data to describe common findings. Therefore, common factors were identified before conclusions could be made with regards to the data collected.

The researcher also investigated the caregivers' reasons for not accessing the Occupational Therapy services. Analysis of the factors influencing access to early childhood services, both barriers and facilitators was considered. Content analysis was used to explore the interview open ended questions which were then analysed according to the frequency of the issues raised. (80) (81).

3.10. Ethical Considerations

A letter of support to conduct the research at Bertha Gxowa Hospital was granted on 22 March 2016 (Appendix E). Permission from the Human Research Ethics Committee (HREC) was obtained on 25 January 2017 (Appendix F). Permission from Bertha Gxowa hospital was granted on 6 January 2017 (Appendix G).

The confidentiality of all caregivers and their children was ensured by not including any identifying information in the surveys. Autonomy was displayed by ensuring the caregivers that participation was voluntary and they would be able to withdraw from the research at any given point. This was done by asking caregivers at the time of making the appointment or at the first appointment if they were willing to participate in the research. Caregivers were also reminded that at any given point, they would be allowed to withdraw from the study. It was emphasised that declining or withdrawing from the study would not affect therapeutic services such as assessments, treatments or referrals.

Once the questionnaire was completed, the printed hard copies were placed in a sealed envelope that ensured further confidentiality of the participants. This excluded outsiders from reading or accessing the information gathered. The sealed envelope was placed in a locked cupboard that only the researcher had access to. The researcher and the research supervisor were only able to access the questionnaires thereafter.

3.11. Conclusion

Using the non-standardised interview-based questionnaire developed by the researcher, the study collected data from 16 participants – the caregivers accessing Occupational Therapy for their children – to determine who was accessing ECI services and what were the factors influencing this access. Data was captured and analysed using Microsoft Excel. Graphs and tables were used to represent the data which was then further analysed to draw conclusions.

Chapter 4: Results

In this chapter, the results of the study answer the following questions based on the aims and objectives of the study:

- The demographics of the population of caregivers and children accessing Occupational Therapy services at Bertha Gxowa Hospital for the first time, (reported as “who is accessing early childhood services”, and “when are services being accessed”)
- The factors (barriers and facilitators) that influence caregivers’ access to Occupational Therapy services. (reported as “what are the facilitators and barriers to accessing early childhood services”)

A total of 36 referrals was received in the six-month data collection period. From this number, only 21 participants (58.3%) arrived for their first appointment. Of these, five declined to participate and 16 consented to data collection. An attempt was made to contact the remaining 15 participants. The researcher was only able to collect data from three of the 15 participants who did not arrive at the first appointment. This was despite numerous attempts to call the participants on different days at different times to increase the likelihood of the call being answered.

The abbreviated telephonic questionnaire aimed to gather information on the demographics of the child who had not accessed the services as well as the reasons (barriers) to this.

Table 4.1: Outcome of the participants contacted (n=15)

Outcome	Number of participants
No answer	4
Voicemail	6
Answered	3
Wrong number	1
Number does not exist	1

Four participants did not answer the several calls made. Six calls to participants went to an automated voicemail where no voice message could be left by the researcher.

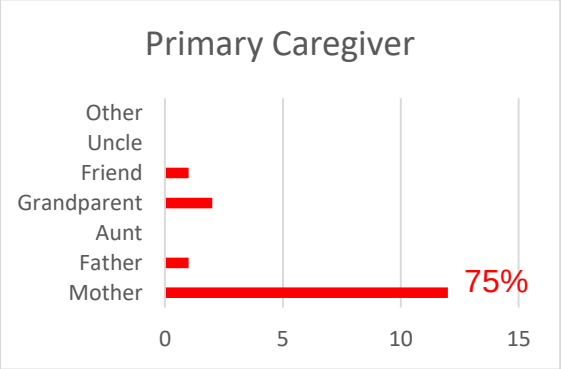
The number captured for one of the participants was incorrect and one other did not exist.

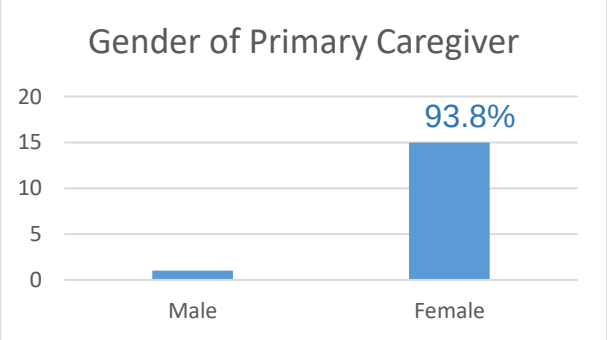
4.1. The demographics of the caregivers and children accessing ECI services

The results for this objective will be presented under two questions: who is accessing early childhood services and when are they accessing early childhood services.

4.1.1. Who is accessing early childhood services in occupational therapy?

4.1.1.1 Caregiver Demographic Results





Figures 4.1 and 4.2: Demographic results of the primary caregivers in the study (n=16).

The above figures indicate that majority of the primary caregivers were female and 75% were the mothers of the child, followed by the fathers and then grandparents. There were no aunts or uncles as primary caregivers. All participants responded to these questions.

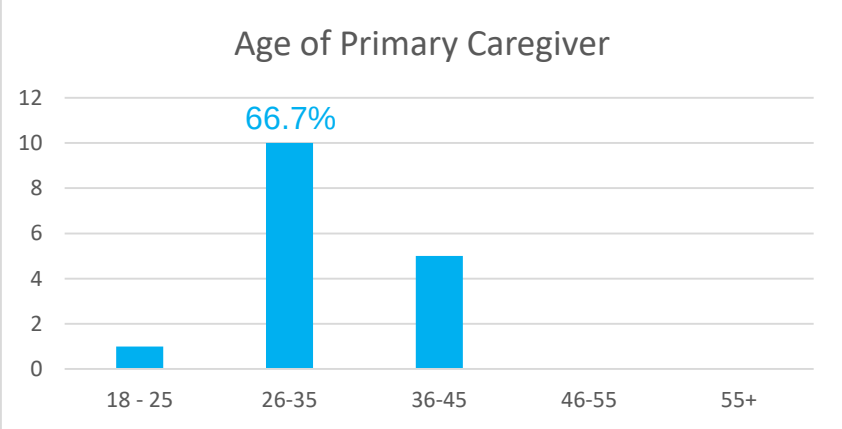


Figure 4.3: The age of the primary caregiver (n=16).

The average age of the primary caregiver was between 26 and 35 years. There were no caregivers older than the age of 45, and this included the grandparents as caregivers. There was a 100% response for this question.

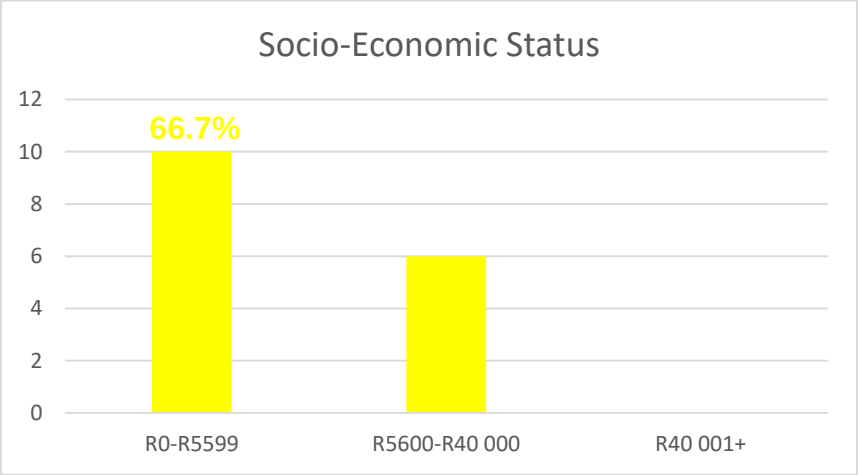


Figure 4.4: The socio-economic status of the monthly income of households (n=16)

From the sample, 62.5% of the participants were from a low socio-economic status, while the remaining 37.5% fell within the middle socio-economic status. There were no participants who were classified as high socio-economic status. Responses was received from all participants. This can be viewed as a barrier to access of services.

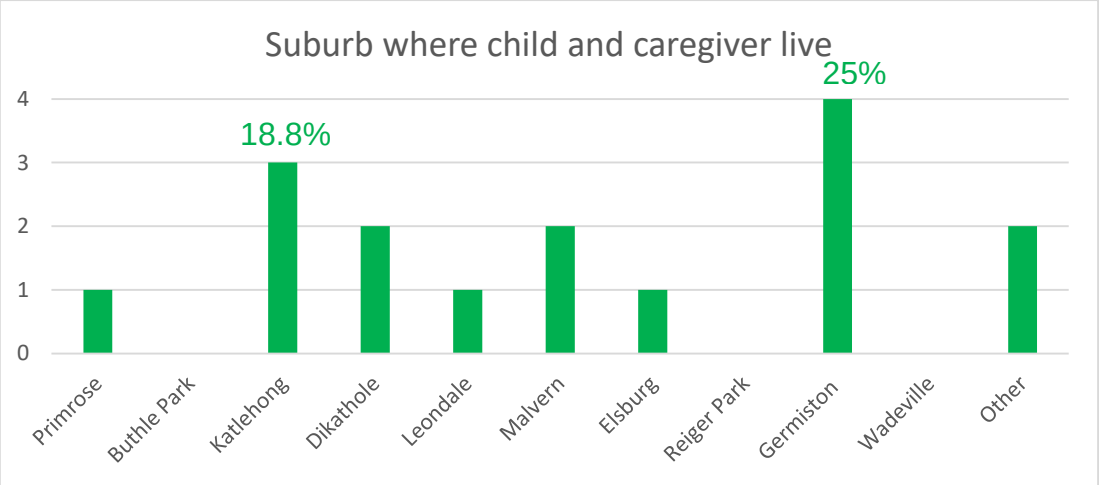
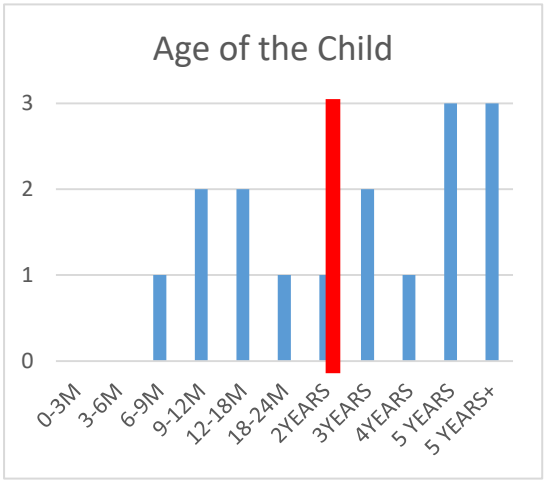


Figure 4.5: Suburb where caregiver and child live (n=16)

The figure above shows that the suburbs where participants resided were scattered over the various areas listed. However, most of the participants lived in the Germiston

area. This was followed by Katlehong. There were no participants from the sample who lived in Buthle Park or Reiger Park.

4.1.1.2. Child Demographics Results



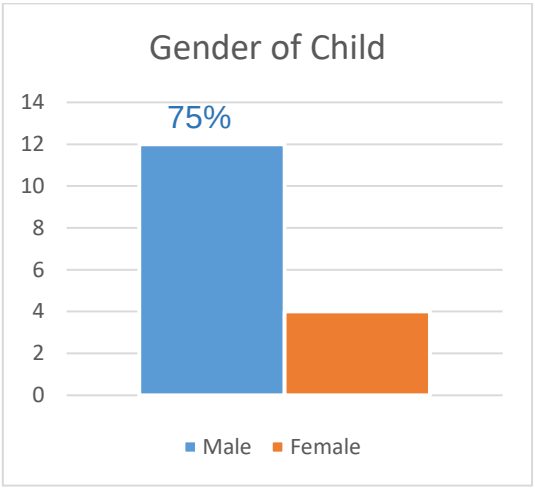
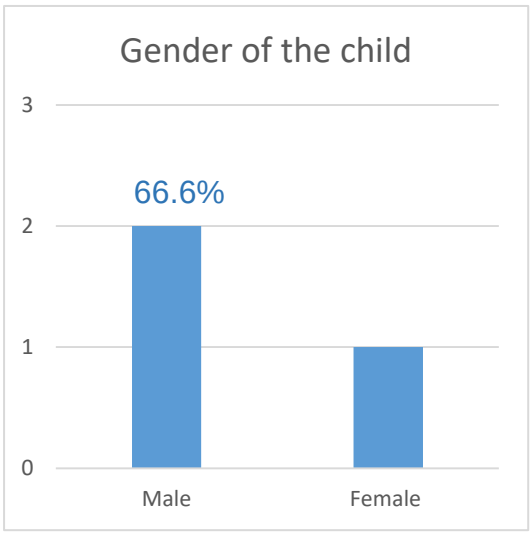
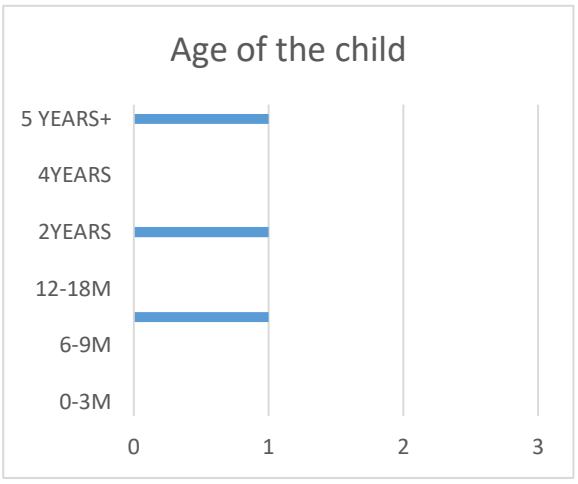


Figure 4.6 and 4.7: The ages at which children are accessing services (n= 16) and Gender of the children accessing Services (n= 16)

It can be noted that the ages at which children accessed services were distributed across the age bands, starting from six months to five years upwards. Of the participants, 37.5% were in the categories '5 years and upwards'. The red line indicator divides the ages into the first 1000 days of life (ages 0 months to 24 months). Therefore, it can be seen that only 37.5% of the participants accessed services in the first 1000 days of life. From the children accessing services, 75% were male. This does not reflect a true representations of the children accessing services as there were many who did not access Occupational Therapy services.

4.1.1.3. Child demographic results of children who did not access services





Figures 4.8 and 4.9: Demographics (gender and age) of the children who did not access services (n=3)

Two of the three children who did not access services were male. The ages ranged from nine months to five years upwards.

4.1.1.4. Information on the problem

Table 4.2: Possible diagnosis as the cause of developmental problems (n=16)

Cause	Number of children	% of Children
Retroviral Disease	1	6.3%
Autism Spectrum Disorder	2	12.5%
Developmental Delay	1	6.3%
Hydrocephalus	1	6.3%
Down's Syndrome	1	6.3%
Unknown	10	62.5%

From Table 4.2 above, it can be seen that 62.5% of caregivers were not aware of any formal diagnosis that could have resulted in the developmental problems in the child.

Only 43.8% of the children experienced problems at birth. The problems experienced at birth is represented below.

Table 4.3: Problems that the child experienced at birth (n=7)

Problem Experienced	Number of children	% of Children
Neonatal Jaundice	1	12.5%
Respiratory Distress	1	12.5%
Birth Asphyxia	1	12.5%
Born Premature	2	25%
Prolonged Labour	1	12.5%
Rubella	1	12.5%
Heart Condition	1	12.5%

Table 4.3 above shows the type of problems that the child experienced at birth which put the child at risk of developmental problems.

Children who were admitted to hospital after birth, represented 37.5% of the sample. The caregivers of these children were aware of the reasons why their child was admitted.

Table 4.4: Reason for hospital admission after birth (n=6)

Reason for Admission	Number of children	% of Children
Tuberculosis	1	16.6%
Seizures	1	16.6%
Liver cyst	1	16.6%
To insert a shunt	1	16.6%
Bronchitis	1	16.6%
Underweight Child	1	16.6%

The diagnosis and/or reasons as to why the child was admitted to hospital after birth are indicated in the Table 4.4 above.

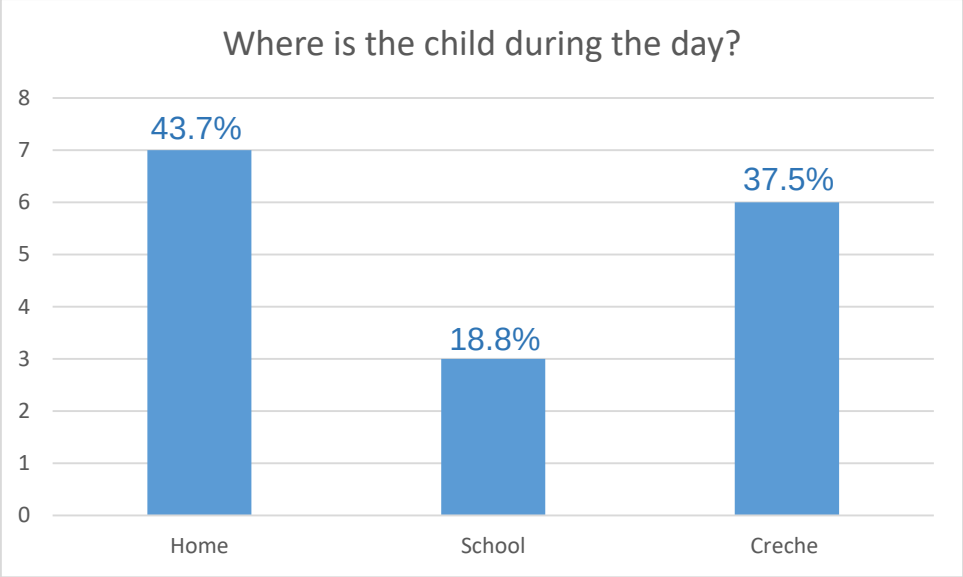


Figure 4.10: Children at school/crèche or those at home (n=16)

While 43.7% of the children spend their day at home, 18.8% of the children were at school while the remaining 37.5% were at crèche.

It was noted that 77.8% of the children attending school/crèche were experiencing some form of problem at school/crèche. Of these caregivers who answered 'yes', all were aware of the problems experienced at school. The problems experienced are represented below.

Table 4.5: Problems that the child experienced at school (n=7)

Problems experienced	Number of children	% of Children
Letter reversals	1	9%
Difficulties copying from board	1	9%
Behavioural problems	1	9%
Concentration problems	1	9%
Poor social skills	1	9%
Developmental delay	2	18%
Poor appetite	1	9%
Difficulties with handwriting	1	9%
Not speaking	2	18%

There were a varying number of problems that the children were experiencing at school, however, ‘not being able to speak’ and ‘developmental delay’ were more commonly noted.

4.1.2. When are occupational therapy services being accessed?

Figure 4.1 has already reported the age at which children were first being seen at Occupational Therapy services. In this sample almost two thirds of the children being seen for the first time were already past the 1000 day mark, indicating late referral to ECI services.

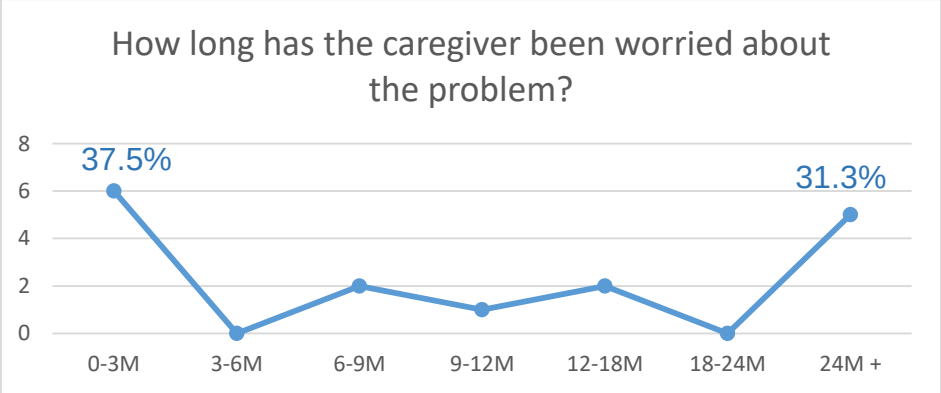


Figure 4.11: Period of time over which caregivers have been concerned about the problems (n=16)

When looking at how long caregivers have been concerned about the problem, 37.5% indicated they were particularly worried about their child’s problem for 0 to 3 months, followed by 31.3% of caregivers who became concerned from 24 months onwards predominantly.

The caregivers indicated that 93.7% of people other than themselves had been worried about the problems that the child was experiencing. This was expanded upon further in the graph below.

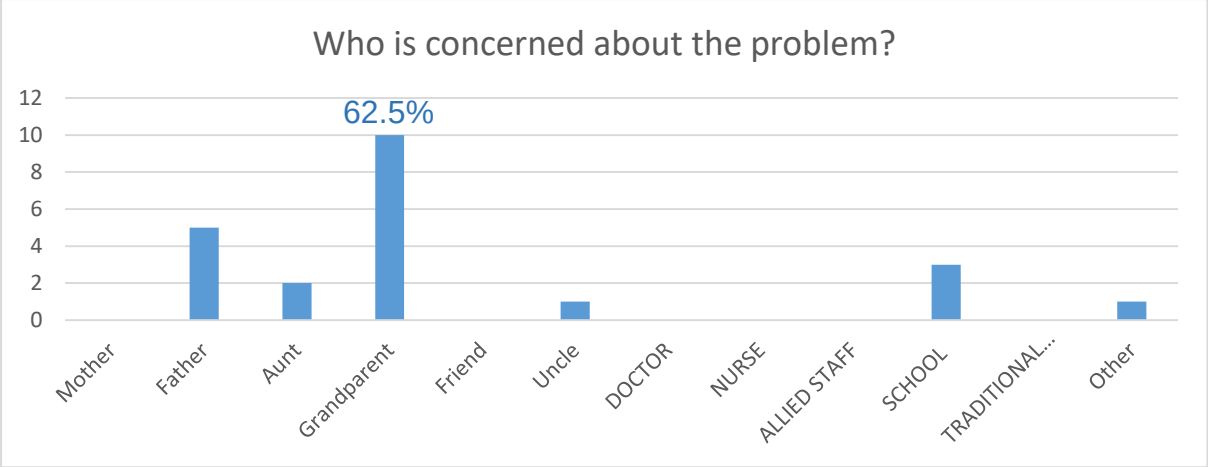


Figure 4.12: Persons displaying concern over the child's problem (n=16)

In Figure 4.12 above, it can be noted that 62.5% of the persons concerned for the child were the grandparents. This was followed by the father of the child and thereafter, the school.

Caregivers who sought help for their child prior to the study represented 68.7% of the participants. See Figure 4.13. Which indicates where the caregivers sought help from.

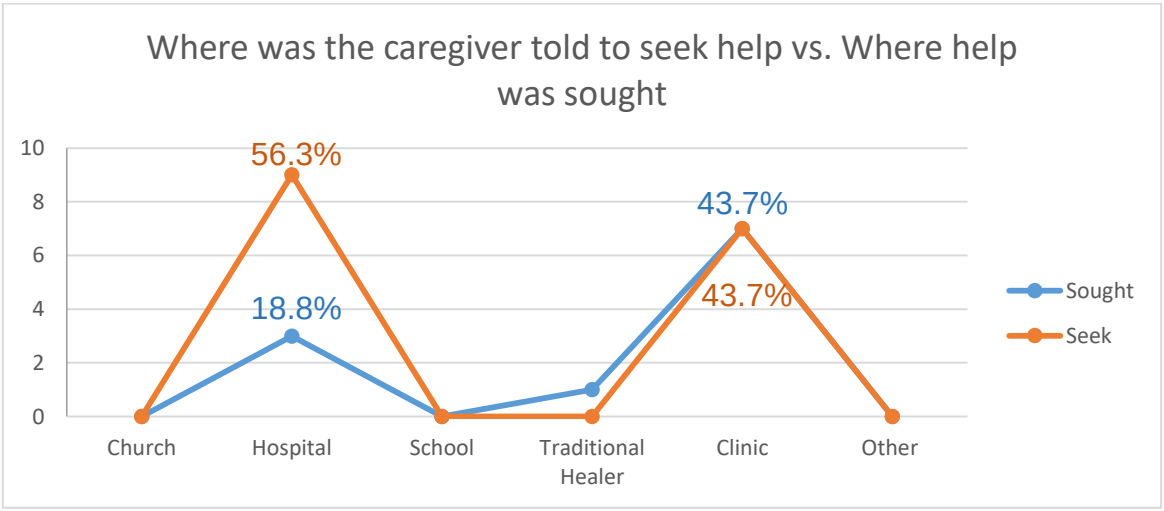


Figure 4.13: Difference between where the concerned persons advised the caregiver to seek help and where the caregiver actually sought help (n=16)

Figure 4.13 above shows that hospitals (56.3%) and clinics (43.7%) (Orange line) provided the opinion to the caregiver on where to seek help for the problem that the child was experiencing. However, from the caregiver's perspective, help was sought (blue graph) majority (43.7%) from the clinic, followed by a few participants (18.8%)

accessing the hospital. Help was also sought from a traditional healer. No help was sought out at the school.

4.2. The factors influencing access to ECI services in occupational therapy

The results for this objective are presented by answering the question what are the facilitators and barriers to accessing early childhood services in occupational therapy. The results will be presented using Reardon et al's (2017) framework as discussed in the literature review.

4.2.1. Family Circumstances

From the sample, 56.3% of the primary caregivers worked. The researcher expanded on this further by enquiring from the caregivers, who worked, how easy it would be to attend services at the hospital.

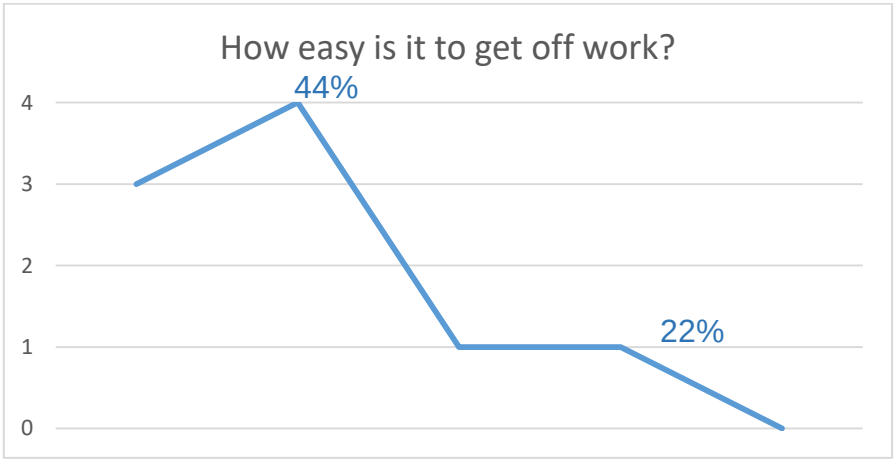


Figure 4.14: For caregivers who work, ease of getting time off work (n=9)

The ease with which time can be taken off work to come to the hospital was high. Only 22% of the caregivers who answered this question found it difficult or somewhat difficult to get time off work.

More than half of the caregivers, 66.7%, were able to send someone else on their behalf to the hospital with the child should they be unable to. The Figure below indicates who is able to bring the child to the hospital.

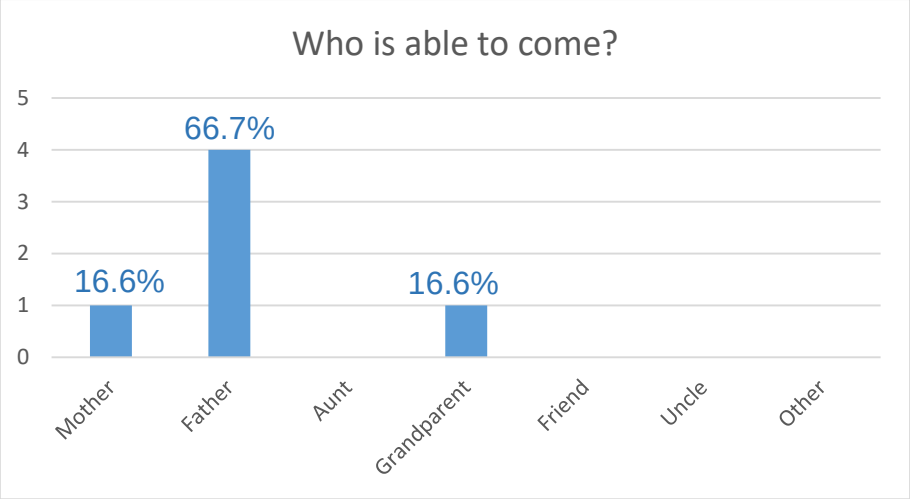


Figure 4.15: Possible persons able to take the child to hospital (n=6)

From the Figure 4.15 above, 66.7% of the participants indicated that the father of the child would be able to bring the child to the hospital should the primary caregiver be unable to. Other caregivers indicated were grandparents and the mother being the only other relatives available to bring the child to the hospital. No participants indicated that an aunt or uncle would be able to bring the child to the hospital should the primary caregiver be unable to do so.

4.2.2. Systemic issues in Health Services

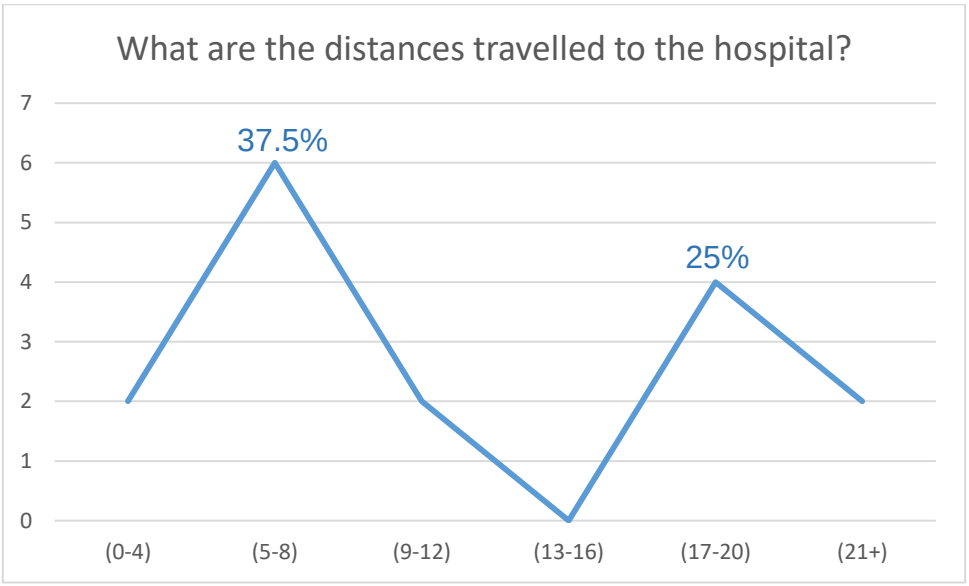


Figure 4.16: Distance travelled to the hospital (n=16)

A significant peak at the 5-8km radius and another peak at 17-20km radius from the hospital is shown in Figure 4.15 above. This links to the suburbs in which the caregiver and child live are shown in Figure 4.9

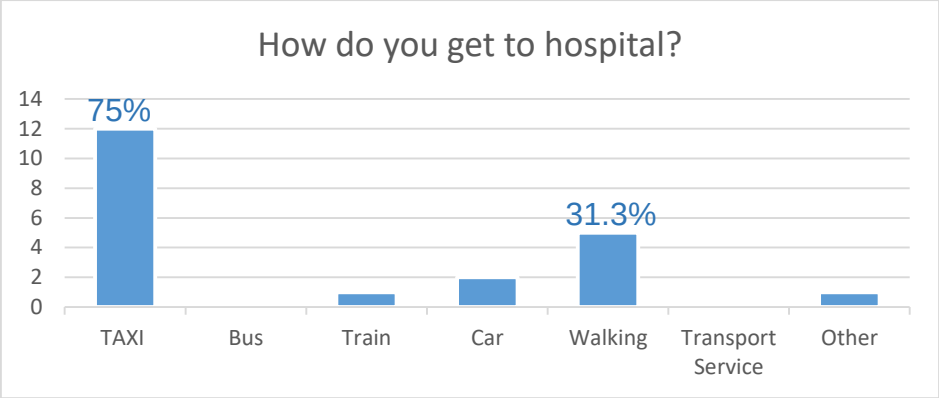


Figure 4.17: Means of transport used to reach the hospital (n=16)

As seen in Figure 4.17 above, taxis were the dominant mode of transport to get to the hospital. One participant indicated that more than one taxi was required to access services at the hospital. Walking also appeared to be more prominent than other means of transport used. Although walking was used alone in some instances as a means of getting to the hospital, it was noted in the raw data that walking was also used in combination with other means of transport such as taxi. In this data set, participants were able to indicate more than one means of transportation used to access the hospital.

4.2.3. Views and attitudes towards services and treatment

It can be noted that only 18.8% of caregivers had a reason for not coming to the hospital. The reasons were as follows:

Table 4.6: Reasons for caregivers not visiting the hospital (n=3)

Reasons	Number	%
Long waiting times	1	33.3%
Easier to access the clinic	1	33.3%
Clash of appointments between caregiver and child	1	33.3%

Reasons varied between the caregivers for not visiting the hospital.

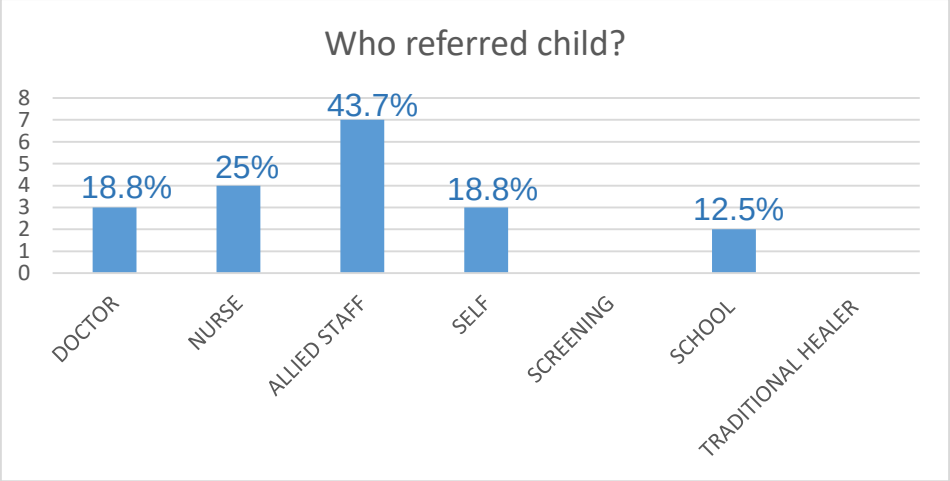


Figure 4.18: Referral source of the child to Occupational Therapy services (n=16)

There is a scattered representation of the sources of referral. However, referrals from fellow allied staff members dominated the representation. More than one source of referral was documented. No participants were referred from a traditional healer nor were there any participants who were picked up in developmental screenings. More than one referral source could have been recorded for this data set.

Only 18.8% of the caregivers were not aware of the reason for referral to Occupational Therapy services. This may be linked to the caregivers not being aware of the diagnosis of their child as noted in Table 4.3

From the participants, only 37.5% of the caregivers answered 'yes' to having a reason that stopped them from accessing the hospital.

Table 4.7: Reasons that stopped caregivers from coming to the hospital (n=6)

Reason for not coming to the hospital	Number of caregivers	% of Caregivers
The child would get better	3	50%
Problems related to transport	3	50%

Table 4.7 states the reasons why 37.5% of caregivers gave for not coming to the hospital. Of these caregivers, 50%, assumed that the child would get better while the remaining caregivers reported that transport was a problem to access help for their child.

Table 4.8: Reasons for caregivers not seeking help for their child (n=5)

Reasons for not seeking help	Number of caregivers	% of Caregivers
Unsure if the child had a problem – waited for the doctor to refer the child	1	20%
Unsure of where to seek help	1	20%
Cost of transport	1	20%
No reasons provided	2	40%

Two out of the five caregivers were unable to provide a reason for not seeking help, while the remaining three participants provided different reasons between them. No common answers or factors were noted.

From the participants who answered the call, they indicated various reasons why they were accessing Occupational Therapy. The reasons were as follows for each caregiver:

1. The school indicated learning problems.
2. The child presented with speech difficulties.
3. The child's one arm was not working well.

Table 4.9: Reasons for not accessing the services (n=3)

Reason for not accessing services	Number	%
Transport	2	66.7%
Forgot about appointment	1	33.3%

Table 4.9 above indicates why the caregivers did not attend the session. Two of the three caregivers indicated that transport was a challenge. The other caregiver reported that she had forgotten about the appointment and did not see any of the problems at the time of making the appointment that the school has reported.

Table 4.10: Caregiver accepting a new appointment and reasons for this (n=3)

Accepted a new appointment	Yes	No
Number	1	2

Reasons/Comments	Already made appointment	Do not believe child has a problem anymore

As noted in Table 4.10 above, when offered a new appointment, one of the three caregivers indicated that she had resolved the problems with transport and had already booked an appointment prior to the researcher's call. The other two caregivers opted not to access the services as they did not perceive a problem with the child anymore.

4.2.4. Knowledge and Understanding of the services

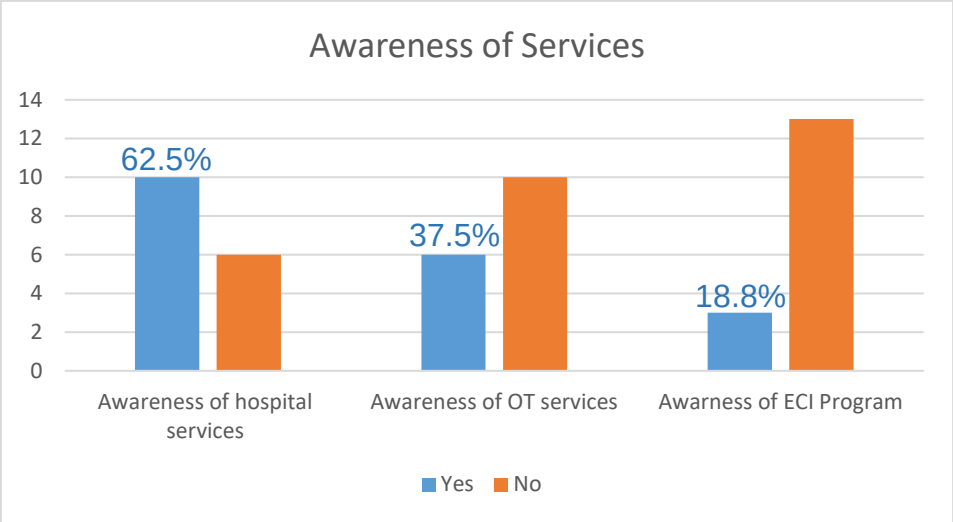


Figure 4.19: Awareness of service available (n=16)

It can be noted from Figure 4.19 above that 62.5% of participants were more aware of general hospital services than other services such as occupational therapy or the ECI programme at the hospital. Only 37.5% of the participants were aware of occupational therapy while only 18.8% of participants were aware of the ECI programme. Of the participants who were aware of ECI services, 66% of them had heard about the services from other health professionals and the remaining 33% from ECI promotion and prevention talks in the hospital.

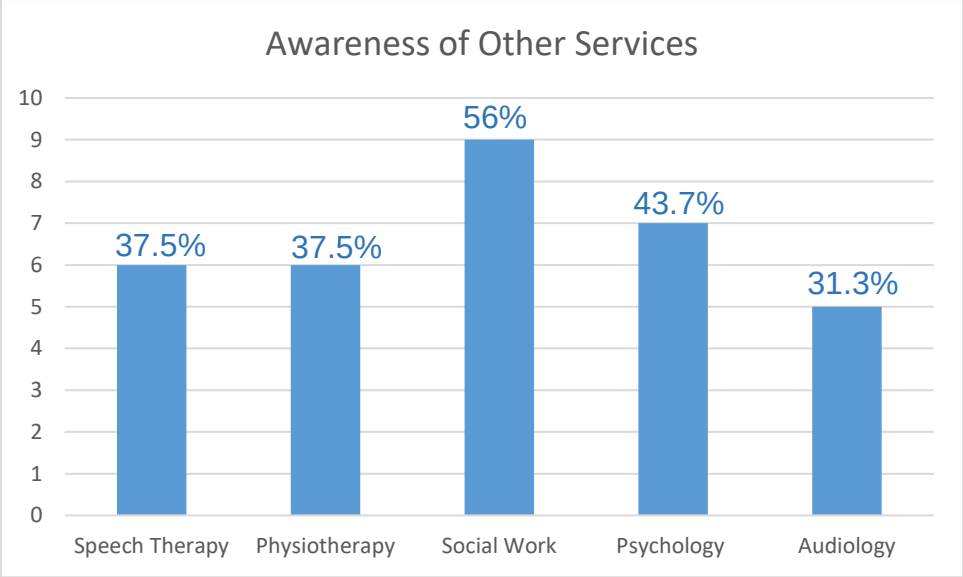


Figure 4.20: Awareness of other services available for child (n=16)

The trend in Figure 4.20 above indicates that most caregivers are more aware of the services provided by social work and psychology. Participants are equally aware of services by speech therapy as well as by physiotherapy. This is followed by audiology services, with the least awareness.

4.3. Conclusion

From the results, it can be noted that mostly mothers were the primary caregivers of children accessing services. The ages of children accessing services varied, however, more children over the age of two were accessing services. The caregivers accessed the services for their children through referrals from fellow allied health professionals. Most caregivers were not aware of the diagnosis of their child or the reasons for referral.

A key barrier to accessing services noted was that of transport services and transport costs. A few caregivers believed that their child would get better and thus, caregiver knowledge of the problem was a barrier to them accessing services for the child. Another barrier identified was that of caregivers not being aware of where to access the services as well as knowing what services were being provided, particularly for occupational therapy. This contributed to the time that caregivers were concerned about the problems.

Factors facilitating access to services were identified. These included other people identifying problems with the child and encouraging the caregiver to seek help at either the hospital or clinic.

Chapter 5: Discussion

5.1. Introduction

The aim of this study was to describe the population of caregivers and their children accessing occupational therapy for the first time as well as the factors (both barriers and facilitators) that influence the caregiver's decision to access Occupational Therapy services.

Within this chapter, the following aspects are discussed:

- The demographics of the population of caregivers and children accessing Occupational Therapy services at Bertha Gxowa Hospital for the first time, (reported as "who is accessing early childhood services", and "when are services being accessed")
- The factors (barriers and facilitators) that influence caregivers' access to Occupational Therapy services. (reported as "what are the facilitators and barriers to accessing early childhood services")

A total of 16 questionnaires were completed over the six-month period. In total, five participants declined participation. The predicted number of participants was 40. Although, this is low, the information gathered from the questionnaires was sufficient to make inferences at the hospital participating in the study only. Responses were also limited by the inclusion criteria of participants having accessed Occupational Therapy for the first time in the six-month period.

5.2. The demographics of the caregivers and children accessing ECI services

The discussion for this objective will be presented under two questions: who is accessing early childhood services and when are they accessing early childhood services.

5.2.1. Who is accessing early childhood services?

5.2.1.1 Demographics of the caregiver

The demographics of the caregiver as well as the social circumstances of the caregiver and child can influence access to services such as occupational therapy. The

caregiver also plays an important role in when and where the child accesses Occupational Therapy services.

The demographics of the study indicated that the primary caregiver of the child was primarily the mother, thus making the predominant gender female. When analysing the ages of the primary caregiver, the predominant age category (62.5%) was that of 26 to 35 years. However, there was a small percentage (6.2% and 31.3%) of caregivers falling within the 18 to 25 year old range and 36 to 45 year old categories respectively. This data set coincided with the study done by Statistics South Africa (2011) which indicates that the average age for child bearing in South Africa is between 18 to 29 years (85). This data was also similar to a study conducted in Shoshanguve, Tshwane, which looked at caregivers' knowledge of child development. The study showed that 94.4% of the caregivers were female. However, the study did not explore the age of the caregivers.

The main area in which the primary caregivers and children live is Germiston (25%), followed by Katlehong (18.7%). As Bertha Gxowa Hospital is the only district hospital in the Germiston area, this would be expected as this hospital would be the first one accessed should a person live close by. However, Katlehong was the furthest location listed from the hospital. This will be discussed in detail in section 5.3 under the heading *Availability of Services.*

Therefore, in summary, caregivers accessing services for their child were mostly the mother of the child, and living in the Germiston area.

5.2.1.2 Personal and Medical Demographics of the children

This section of the questionnaire was aimed at gathering information on the child. It also gathered brief information on the medical history of the child as well as the problems that could lead to the possible development delays.

The age of the children accessing Occupational Therapy services varied from six months to over five years. Males accounted for 75% of the children. These figures may not accurately represent the population being serviced at the hospital as 41.7% of the children who were referred to occupational therapy did not arrive for their appointments. Literature is limited in terms of the gender demographics of both adults and children accessing health care services.

It was noted that 43.8% of the children experienced problems at birth. The problems mentioned were similar to those indicated in the literature review as pre- and peri-natal risk factors for developmental delay (26) (11). Two conditions, rubella and heart disease, were not amongst the commonly mentioned risk factors in the literature. However, these are also known to be likely causes of developmental problems (86) (87). The study was limited in terms of identifying whether these 'at risk' children attended check-ups or follow-up appointments on a regular basis by a health care professional, either at the clinic or hospital. However, when analysing the data, it was found that from the children who experienced problems at birth, 25% of the children were already at school and were presenting with problems identified by the teacher. The ages of these children, who experienced problems at birth, mostly fell beyond the 1000 days of life mark. Therefore, it can be seen that the aim of ECI was not being met and as a result, children with developmental delays or disabilities were not being identified early.

From this study, the percentage difference between the children spending time at home and crèche was small. A total of 56.3% of participants were in school and crèche already. Of these, 77.8% were experiencing problems at school and were brought to the caregivers' attention. This included the children who had experienced problems at birth. Many of the children experienced problems with school-related activities such as behaviour, attention, perceptual skills and writing skills. Children were also described as not doing things that other children their age were doing or simply not speaking, with a delay in speech and language. When analysing this data, it was seen that these children were also only being discovered as having developmental problems once having the commenced school and crèche. This again highlights that the aims of ECI are not being achieved, as the children were not being identified at an early stage. Thus, the children were not entirely ready for school and as a result, were struggling to keep up with those in their age group, as expressed by caregivers in the study (26). This was similar to the information gathered in a study by Engle *et al.* (2007), which also found that children in developing countries who were experiencing developmental delays were more likely to repeat or leave school as early as Grade 1. The study went on further to implement intervention programmes to enhance the development of children. It was found that early intervention decreased the number of children leaving

school or repeating grades. (32) This highlights the importance of early identification to alleviate long term problems which may continue to contribute to the poverty cycle.

Biersteker (2012) discovered that children who attended child development centres, presented with better physical and mental health and were less reliant on health care services. (23) It was further discovered that children that attended child development centres were also more prepared to attend school and once in school, the child was able to perform academically and as a result was more likely stay in school and complete the academic program. Furthermore, Biersteker (2012) mentions, that later in the child's schooling career, children were less likely to engage in dangerous activities such as violence and crimes. This included substance abuse and unsafe sex. (23) Richter *et al.* (2012) indicate that only a limited amount of children, particularly from birth to age two, attend child development centres in South Africa. It was further explained that these development centres are aimed at not only stimulating the child but also educating caregivers on the development of the child. However, Richter *et al.* (2012), also, discovered that the centres may not be accessible for various reasons which is beyond the scope of this study.

Of the children presenting with problems, 62.5% did not have a formal diagnosis. This included those participants referred to occupational therapy by the doctor or other health care professionals. However, a few children had been preliminarily diagnosed and were also referred to occupational therapy for services. In a 2006 study conducted in Glasgow by McDonald, Rennie, Tolmie, Galloway, McWilliam, not only is early identification of developmental problems key, but the cause of the problems must also be investigated. This brings in the role of the occupational therapist, who will not only investigate the cause of developmental delay but will also assist in preventing further problems in the long term. This is necessary for a better prognosis as well as preventing the problem from reoccurring or worsening (88).

When asked if the child was admitted to hospital after birth, 37.5% of the caregivers responded 'yes'. Of this 37.5%, all caregivers were aware of the reason for admission of the child. Some of the reasons mentioned were similar to those mentioned in the literature review as post-natal risk factors for developmental delay (10) (23) (30). There were no common factors noted for the number of times admitted to hospital or the reasons for admission. Although the number of times of hospital admission was asked,

the length of stay in hospital was not gathered. This information would have been valuable to determine the effects of long-term hospitalisation on development. Similarly, this would also apply to the effects of multiple admissions to hospital and the impact on development (74). Another valuable aspect that could have been investigated was whether the child was presenting with developmental problems at the time of admission to hospital. This would have been useful in gathering information on whether the developmental problem had been identified whilst in hospital and whether the child had been referred for help to the relevant services. Furthermore, this would have also allowed the study to determine whether there were gaps in the services available that may form barriers to accessing ECI services.

Therefore, it was noted that the possible risk factors that caused developmental delay were evident in almost 80% of the children. There were no differences in the developmental problems between the children who stayed at home and those who were at school. However, those children attending school were not coping with what was expected of them as identification of the developmental problems was still occurring when the child is at school. Thus, identification and, in turn, intervention was not occurring at any early stage.

5.2.2. When are the services being accessed?

This section aims to explore when caregivers access Occupational Therapy services or the child as well as the time period in which help is sought for the child's problems. Upon analysis of the child's age in need of Occupational Therapy services, the age ranges varied from six months to over five years. However, when comparing this to the target of the first 1000 days of life in ECI (10), many of the participants fell beyond this. As many as 56.3% of participants seeking help were older than two years, as seen in Figure 4.1 This can be compared to Figure 4.11 where 31.3% of caregivers indicate that they have been concerned about the problem for two years or more. On the other hand, 37.5% of caregivers have been concerned about the child's problems for no more than three months and have sought help for the child in this time. Developmental delays can present at any stage in the child's life (22) (38) and thus, while it is encouraging that just over a third of the sample sought help as soon as they became aware of their children's problems, there was no indication of how severe the problem was before the identification happened. It is also clear that the majority of developmental problems were being identified first and foremost outside of the

healthcare system, such as at schools. Screening and early identification is important for the goals of ECI to be met (15). However, these services need to be placed where young children are likely to be seen, such as healthy baby clinics and immunization clinics (16). Community outreach may be much more important than offering services at established hospitals (71). This idea is supported by the findings from the study by UNICEF (2015), where established ECI services at a hospital were not reaching vulnerable children at the right time and where many children were still only being unidentified in the schooling system. (6)

Caregivers expressed a number of reasons for either seeking help immediately or delaying. Almost half of the caregivers (43.7%) verbalised going to the clinic before coming to the hospital for help. In some instances, they were referred to the hospital for help. Further information was not gathered on what services or help was offered at the clinic when the caregiver presented the child's problems. This may have been useful for the study to determine when and what the services offered to these children were or if they were turned away. As community outreach is an important part of ECI, the effectiveness of clinic services needs to be further explored.

Therefore, it can be seen that more than 50% of the children accessing Occupational Therapy services are not doing so before the 1000 days of life target. Caregivers were concerned about the problems for varying amounts of time which could be seen as an understanding and/or knowledge of the problem which will be discussed in the heading 5.3. specifically under *Knowledge and Understanding of Services*. This can be linked to the cause or diagnosis of the child's problems which also may not be fully understood by the caregiver. This is of great concern as it means that despite the implementation of ECI services at Bertha Gxowa Hospital, these services are not currently assisting in early identification of problems or education of caregivers and thus are not fulfilling their stated purpose. It is therefore imperative to understand the facilitators and barriers to accessing services for this population and the rest of this discussion will focus on these issues.

5.3 The factors influencing access to ECI services

This discussion for this objective are presented by answering the question what are the facilitators and barriers to accessing early childhood services in occupational

therapy. The results will be presented using Reardon et al's (2017) framework (18) as discussed in the literature review.

Views and attitudes towards services and treatment

a) Reasons for not accessing the hospital

Only 18.75% of participants verbalised reasons for not wanting to come to the hospital. Participants verbalised having to experience long waiting times at the hospital which prevented them from bringing the child to the hospital. The hospital was thus inaccessible at times of need. Results from Statistics South Africa (2011) show that only 8.7% of participants had reasons for not accessing health services. This was less than half of those compared to this study. It also made reference to 16% of participants refusing to use health care facilities due to long waiting times. In the study of Goudge *et al.* (2009), participants expressed that they were also required to wait for a long time before being diagnosed or assisted with the problem. Participants, in the same study, also verbalised that multiple visits to the health care facility were required and each visit required them to wait for long periods of time (73). This can be related to the low socio-economic status of the participants of this study, together with the cost of transport, should one have to visit the hospital more than once a month (73).

A participant verbalised that should her own clinic appointments clash with an appointment for her child, she would be more likely to attend to her own appointment than that of the child's. This highlights that the caregiver may possibly not be aware of the importance of the child attending his/her appointment. It is also likely that the caregiver is not aware that an alternative caregiver could bring the child to the appointment, should she be unable to do so. However, the health of the caregiver is just as important as that of the child, as mentioned in the literature review (10) (14). This highlights that services are not integrated, allowing both the caregiver and the child to receive health care on the same day, at the same health care facility. This may assist with decreasing the cost of transport as well as the number of times that the caregiver and child need to visit the health care facility. In the event of caregivers who work, it will also limit the number of days taken off to attend services at the health care facility. (6)

Therefore, the barriers identified are: long-waiting times at the hospital, multiple visits to the health care facility and a clash between the caregiver and child's appointments.

Systemic issues in Health Services

b) Availability of services

Upon reviewing the services offered by clinics surrounding the hospital, there were limited therapeutic services available in the area of Katlehong thus making Bertha Gxowa the next available access point for occupational therapy, by way of example. However, upon further investigation, it was found that there are areas in Germiston that offer services such as occupational therapy at clinics. These include Rondebult, Dikathole, Germiston Rehab, Ramaphoza, Boksburg, Elsburg, Reiger Park and Wannenburg (89). Based on the results gathered, there were no participants from Reiger Park accessing services at the hospital as they were likely receiving services at the clinic. This may be identified as a facilitator as services are likely being offered closer to the caregiver and child's home. However, although services are offered at the Boksburg clinic, there was a participant accessing services at the hospital. This is due to the services at the clinic only occurring twice a month and the child is not seen for Occupational Therapy on a regular basis. Similarly, this also applies to the other areas listed on the questionnaire. Therefore, insufficient or a lack of services particularly at clinics closer to home poses as a barrier to access of services such as occupational therapy and early childhood intervention. Thus, it can be determined that Bertha Gxowa is the primary access point for those in need of Occupational Therapy as services are easily available.

Whyte (2015) reports that countries such as Brazil began implementing primary health care services at the level of the household. These services were provided by health care professionals, together with trained community health workers. Community health workers were responsible for health promotion and prevention services for the population unable to access health care services. This was aimed at improving access to primary health care in accordance with the Declaration of the Alma Ata (71). Whyte (2015) further notes that although these types of services are present in South Africa in places such as Ekurhuleni Health District, the impact of these services is not measured (71). Germiston is based in Ekurhuleni Health District and it may therefore be required to involve these community health care workers to assist with educating caregivers on child development as well as the services available at the nearest health care facility to address problems as soon as they arise.

However, McLaren *et al*. (2013) suggested that the cost of transport as well as the distance to a health care facility determines where the individual may seek help (78). Therefore, it is also possible that caregivers were seeking help at clinics closer to home which may have been the case for those 15 participants who did not arrive for their appointment at Occupational Therapy. This may be influenced by the cost of transport and the distance that participants live from the hospital.

c) Transport and Distance

Transport and transport costs appeared to be a significant barrier to whether participants would access the hospital, as seen in Table 4.5, where the participant was able to access the clinic more easily than the hospital and in Table 4.6, where participants depicted the reasons that stopped caregivers from coming to the hospital. This was further expanded on in Table 4.7 which states the reasons that the caregiver would not seek help for their child was due to the cost of transport or problems surrounding transport.

It was mentioned by 37.5% of the caregivers that the cost of transport to the hospital was sometimes a challenge. Therefore, this influenced when they would access services for the child. Goudge *et al.* (2009) indicated that the general population of adults from a low or middle socio-economic status would not seek health care if they did not have the money to do so or would only seek health care if they were able to access the money for it, which may take time (73). This can then be linked to the low socio-economic status of the majority of caregivers in this study and their inability to access the money required to pay for transport to access health care for the child. As a result, the child does not receive help required timeously and the developmental problems continue or worsen in some instances. Therefore, it can be seen that despite the fact that health care is free for children under the age of six (90), other financial factors play a role in when the child accesses services.

McLaren *et al.* (2013) mention that despite health care being free in South Africa, particularly for children, factors such as the cost of transport play a role in whether services are accessed. The study goes on to indicate that South Africa, due apartheid, has left much of its population predisposed to poor living conditions or poverty. Thus, these individuals fall within the low socio-economic status. As a result, many cannot afford transport, irrespective of the means used, to health care services. Thus,

services for both adults and children are not accessed despite being readily available. Lastly, the study mentions that distance also impacts on whether services will be accessed. As seen in this study, most caregivers and children live within a ten kilometre range from the hospital. However, more than half the sample fell in the low socio-economic bracket. Thus, although distance may not be a factor, the cost of transport services continues to be problematic.

Taxis accounted for 75% of the mode of transport used for those accessing services at Bertha Gxowa Hospital. This was followed by walking (31.3%) which was the sole form of transport for those living less than or equal to five kilometres from the hospital. However, other participants walked and used a taxi as some participants needed to walk from their homes to a taxi rank or from the taxi rank to the hospital. When comparing this information to that of Statistics South Africa (2011), differences in data was found. In the study, more participants used taxis as a means of transport and less participants walked. The study conducted by Statistics South Africa only accounted for an adult visiting the health care facility and not that of an adult and child. (46) Therefore, it is possible that caregivers used taxis to get to the hospital due to distance as opposed to walking as they may have had to carry the child. This is despite the cost implications of transport for the caregiver and child. (91) Therefore, one should consider whether the caregiver and/or child have multiple appointments at the hospital in the month as the money spent on transport is extensive. Again, relating this to the majority of participants being from the low socio-economic status from Figure 4.5, many may struggle to continuously pay for transport to the hospital and may prioritise other basic needs such as food for themselves and the child (73). This impacts on accessing of services for children such as ECI and children may not be getting the necessary help that they require timeously.

Caregivers are also unable to predict the times that the taxis, for example, will arrive and leave. Thus, if the caregiver is late, he/she might miss the taxi and as a result miss the appointment at the hospital. This is then considered wasted money on transport for health care services that they were not able to receive. As the caregivers are from a low socio-economic status, it is likely that they may struggle to gather more funds to visit the health care facility again in the month (76). As a result, ECI services are then not accessed timeously and the child's developmental problems may worsen.

Further, analysis of the data was done and it was found that the one participant who used the train was from Malvern. Train fares are said to be cheaper than taxi fares, thereby making it more cost-effective for the participant to come to the hospital by train (6). However, many participants may not have access to train services despite it being cheaper.

No participants used the bus service as a means of accessing the hospital. This was despite the availability of this service and a bus stop located outside the hospital entrance. Using the Ekurhuleni website, it was noted that a single bus trip cost approximately seventeen rand (R17) for both adults and children, however, it did not travel to all areas in Germiston. It can therefore be seen that buses as a means of transport to the hospital were more expensive and not easily accessible from all the suburbs mentioned in the questionnaire (Appendix A).

Only 12.5% of participants used a car – either their own or a family member's. This was also less than that reported by Statistics South Africa (2011). Again, participants in this study are from a low socio-economic status and may not have their own cars or family members with cars. Of this 12.5%, many reported having to pay the petrol costs involved and as a result, were still paying for transport in order to access services at the hospital.

Therefore, it can be seen that using taxis and walking is the key method of transport used to access the hospital and Occupational Therapy services. However, the cost and access of transport was a barrier that influenced access to the hospital and Occupational Therapy services. This was also related to the distance from which the caregiver and child lived from the hospital as well as their low socio-economic status.

Family Circumstances

d) Socio-economic Status

McGregor *et al. (2007)* discuss the implications of low socio-economic status and poverty on child development. The study reveals that children living in poverty or poor households were at increased risk of developmental delays (11). This is an important demographic to keep in mind for this study as more than half of the sample (62.5%) was from a low socio-economic background which presents as a barrier to accessing services. The remaining 37.5% of the participants fell within the lower middle socio-

economic status, with no participants in the higher socio-economic status. When looking at the location of the hospital to the Germiston area, the hospital is surrounded by many informal settlements and peri-urban areas (83). Thus, participants accessing services from the area are more likely to be from a lower socio-economic status, which coincides with this study.

e) Caregivers who work and Getting off work

Caregivers getting time off work to bring the child for Occupational Therapy is not seen as a barrier that influences access to Occupational Therapy services. However, not being aware or not having an alternative caregiver to bring the child to the hospital can be seen as a barrier to accessing the services should the primary caregiver be unable to with the child.

From the participants, 56.3% of the caregivers worked during the day. From this, a total of 77.8% of the caregivers were able to get off work easily. The remaining 22.2% experienced some difficulty in getting off work. From these caregivers, only 33.3% were unable to send someone else to the hospital with their child. Reasons for this were not gathered and would have been useful in determining the possible support systems that the caregivers and children have available to them. Tomlinson *et al.* (2014) make reference to family support structures as a significant factor influencing whether or not early childhood services are accessed. It is further explained that family members can either support the caregiver in the care of the child, encourage them to seek help or hinder them from doing so (39). It was noted that 67.7% of the participants indicated that the father of the child would be able to come to the hospital should the caregiver be unable to attend. This was followed by the grandparents of the child (32.3%). It is possible that caregivers are unaware that they are allowed to send alternative caregivers in their place should they be unable to attend services such as occupational therapy at the hospital. This was also explored in the reasons for not accessing services. This can also be linked to the demographics of this study (Figure 4.19), where the mother of the child is noted 75% of the time as being the one bringing the child to the appointment. There is limited literature available on the implications of caregivers who work and seek access to services for the child. However, it can be linked to multiple days off work and loss of income due to absence from work in order to attend services − either for the child and/or the caregiver. Thus, caregivers may be

reluctant to attend services at the hospital as they may fear losing their jobs. Since these caregivers already fall within the low socio-economic bracket, protecting their source of income is likely to take priority (73). As a result, early childhood services may not be accessed timeously. Statistics South Africa (2011) also found that operating times of the health care facilities limited access (46). This may be a useful factor to consider for those caregivers who work as this may limit the amount of time taken off work to visit the hospital.

f) Cultural beliefs and values

The importance of family and cultural values and beliefs is strongly highlighted as an influencing factor to accessing early childhood services as described by Applequist and Bailey (2000) in their study *Navajo Caregiver's Perceptions of Early Intervention Services* (75). The importance of the parents' or close relatives' concerns in the early detection of developmental problems was also highlighted (43). This allows for the caregiver to seek help early for the child which is the aim of ECI. Tomlinson *et al.* (2014) also indicate that apart from cultural values and beliefs, family members may be reluctant to engage in intervention programmes such as ECI. This is due to families and caregivers having poor knowledge of child development, thus, ECI programmes are not recognised as a means of assisting the child (39).

When asked in this study, caregivers reported that the father or grandparents of the child were the most concerned with the child's presenting problems. Relatives recommended to the primary caregivers to either seek help at the hospital, predominately followed by the clinic. Therefore, it can be seen that family views on seeking help for the child was a facilitator in this instance as it is possible that family members had some knowledge of child development and identified problems with the child. A difference was noted after having compared this to where the caregivers actually sought help from. Only 6.3% of caregivers sought help from a traditional healer while 43.7% sought help from the clinic then the hospital (18.8%). Similar results were found by Statistics South Africa (2011) when looking at the type of health facility accessed. Clinics accounted for 61.2% of facilities accessed, hospitals 9.5% and other 1.5%, which may be traditional healers (46).

Reasons for accessing the clinic was that caregivers expressed that the clinic was sometimes easier to access than the hospital. The researcher should have expanded

on reasons for accessing the traditional healer instead of the hospital or clinic. It is possible that the caregivers who did not arrive for their appointments, may have also sought help from traditional healers or clinics. This could be due to the many barriers previously identified such as transport, cost of transport or distance, for example.

Therefore, it can be seen that in this study, family beliefs positively influence caregivers to access early childhood services from hospitals or clinics and can be identified as a facilitator. This allows for the early identification of problems which is in keeping with the aim of ECI, and also prevents detection of problems only once the child is in school (26).

Knowledge and Understanding of the services

g) Insufficient Caregiver Knowledge

Caregiver knowledge of child development along with the knowledge of services available for the child presented as one of the most significant barriers to access to Occupational Therapy and Early Childhood Services.

Caregivers, despite being aware that the child had a problem, reported that they thought the child would get better and thus did not seek help timeously for the child. This again suggests that caregiver has limited knowledge of normal development and what is expected of the child. In some instances, as alluded to by UNICEF (2015), caregivers, despite being aware of the child's problem, feared being stigmatised by the community. Believing that the child would get better, they did not seek help (6). A study conducted in Italy by Commodari (2010) pointed to the importance of the parent/caregiver in promoting health in their children as well as accessing health care (92). Barnett and Nores (2010) and Sanders *et al.* (2009) also found that caregiver education on development was lacking and that providing caregivers with the relevant knowledge would allow the child to benefit from the ECI programmes being implemented in many developing countries, including South Africa (50) (40). However, ECI educational talks are occurring in the hospital. It is possible that caregivers with limited information on development may not have attended the talks as they may not have accessed health care services at the hospital previously. Thus, the educational talks are limited to the hospital and as a result, they are not reaching all caregivers. Outreach programmes must therefore be considered to educate caregivers on developmental needs. This may be addressed through community health workers

being introduced into the community so as to ensure that the information reaches caregivers. (71) This notion is supported by UNICEF (2015), which mentions that all health care workers, irrespective of profession, have a role to play in education and identification of developmental delays (6).

Similar results were found in the study by Meintjies *et al.* (2011) where caregivers were not aware of the problems their children were experiencing due to a lack of knowledge of child development. Furthermore, caregivers expressed that they had regular contact with nurses at the clinics for immunisations and other growth monitoring. The caregivers also mentioned that since their knowledge of child development was limited, the nurse with whom they had regular contact should identify developmental problems on their behalf (52). However, this did not alleviate the problem faced, namely, that caregivers had insufficient knowledge to identify problems for themselves.

In this study, 37.5% of the caregivers thought that the child simply needed help and were not aware of the cause of the problem, thus highlighting that caregiver knowledge of the problem is limited. This was expanded on further when the caregivers were asked what they thought was the problem with their child and many verbalised not knowing what was wrong. Caregivers alluded to weaknesses pointed out to them by others (family) or the school and delays in development. This again highlights the poor knowledge that the caregiver has of the problem. Meintjies *et al.* (2011) also found that caregivers doubted their abilities in identifying developmental problems in their child. Caregivers conveyed that they relied on the child's teacher or others to detect problems (28). This can be attributed to poor caregiver education due to long-term low socio-economic factors (6). Thus, caregivers may not be motivated to learn more about child development and thus rely on those regarded as experts. However, UNICEF, together with the Gauteng Department of Education, argue that caregivers are not actively engaged by professionals in the development of the child and as a result are not capable of identifying problems when they arise (6).

As seen in the South African context, caregivers who were required to work or return to school often left the child at home with an alternative carer. In many instances, carers had little or no knowledge of development and as a result, were unable to identify problems that the child may have been experiencing. Similarly, a caregiver

who is working or at school may not be able to identify developmental problems with the child if they are spending limited amounts of time with the child during the day, particularly if their knowledge of development is limited (2). This highlights that caregiver education and early identification of developmental problems go hand in hand.

Thus, the caregiver is seen as the key to the whether or not the child accesses ECI services. Poor caregiver knowledge of the problem and developmental norms is seen as a barrier which influences when Occupational Therapy services are accessed.

h) Referrals

Although referrals by health care professionals as well as the school was occurring as seen in the study, caregivers lack of understanding of the referral was a barrier as to when they accessed occupational therapy and Early Childhood services for the child.

Health professionals were the source of 87.4% of the referrals received for the child to access Occupational Therapy services. From this, allied staff accounted for 43.7% of the referral sources, followed by nurses (25%) from a local clinic and lastly, doctors (18.8%). Thus, the awareness of the ECI programme and services offered is also limited to that of the allied health professionals working together and does not extend much further to that of others such as the nurses, doctors or any other health care professional in or out of the hospital. The remaining 12.5% of the referrals was received from the school/crèche that the child was attending. However, more participants expressed that due to not being aware of the services, they sought help through nurses and doctors based on the school/crèche raising problems that the child was experiencing.

From the referrals made, only 18.8% of the caregivers were not aware of the reason they were asked to seek Occupational Therapy for their child. More information on this was not gathered and would have proved useful in determining the caregivers' knowledge of the problem and their understanding of accessing services such as occupational therapy. Goudge *et al.* (2009) expanded on this further and found that those who accessed services at the clinic, for example, did not always understand the referral process and as a result, returned home without seeking further help (73). This may be the case with caregivers who did not access any services for the child, such as the 15 caregivers and children in this study, who did not return for the occupational

therapy appointment. In addition, sometimes health care professionals refer patients to other services but do not always explain the referral. Patients also reported that they felt disempowered and could not question the health care professional or make further enquiries on the referral (73). Relating this to the study, should the caregivers have had a better understanding of the referral and the problem, it is likely that help may have been sought sooner for the child. This would then be in keeping with aim of ECI of seeking help at an early stage (26). From those caregivers who were aware of the reason for the referral, similarities were noted around the problems that help was sought for. These were, again, mainly school-related problems and developmental delays.

The discussion above highlights that poor caregiver knowledge and understanding of the problem as well as the referral can be seen as a barrier influencing access to early childhood services.

i) Awareness of Services

Awareness of the general hospital services was high (62.5%) amongst most of the caregivers. This decreased to 37.5% when asked if they were aware of occupational therapy services. Many expressed having come across occupational therapy for the first time. A minority of the participants (18.8%) were aware of the ECI programme at the hospital as some of the participants had been exposed to it by the other allied health professionals and in turn, referred to occupational therapy. As many as 43.7% and 56.3% of caregivers were familiar with the services offered by the psychologists and social workers, respectively, as compared to the other allied and therapeutic services offered at the hospital. Thus, caregiver knowledge of the services offered by occupational therapy and the ECI programme was limited and can be viewed as a barrier. This coincided with the findings of Ensor and Cooper (2004), which suggested that individuals were not fully aware of the health care services provided (93). This was supported by Goudge *et al.* (2009) who also indicated that participants who did not have sufficient knowledge of the problem or services available may not seek out the appropriate service required. As a result, this has a negative impact on the health of the individual (73). Thus, if caregivers are unaware of the services of occupational therapy, for example, they cannot seek appropriate help for their child and as a result,

the child's developmental problems worsen. Education on availability of services is a vital factor to consider together with caregiver education on child development.

It can be concluded that caregivers do not have sufficient knowledge of the services available for their children with developmental problems and as a result, services such as ECI are bypassed. This can also be seen as a barrier influencing access to Occupational Therapy services.

5.4 **Participants who did not access services**

Due to the small number of participants for this data collection set, the age ranges were vast and varied, from nine months to five years and over. The researcher spoke to the mothers who were considered to be the primary caregivers of the children. The caregivers were asked the reason for the referral to occupational therapy services, which were indicated as school-related difficulties, speech difficulties and the child's 'arm not working well'. These were similar to those problems mentioned by the first set of participants. When asked why the caregiver and child did not access occupational therapy services, two of the caregivers reported problems surrounding transport were amongst the reasons. This coincided with the first data collection. The last caregiver reported having forgotten about the appointment. This was a reason not previously mentioned in the data collection but still important for this study. This reason was also not mentioned in any of the literature as a barrier to accessing health care services.

Following this, the caregivers were asked if they would like to make another appointment with occupational therapy. Only one of the caregivers reported that she had already done so while the remaining caregivers reported that that they did not believe that their child had a problem anymore. Thus, it is possible that the caregivers, were not fully aware of the problems that the child was experiencing and had limited knowledge of development of the child. It is also possible that the caregivers were not aware of the benefits that both occupational therapy and ECI provided. This information coincided with the study done by Statistics South Africa (2011), which indicated that caregivers did not think that the child's problems were serious enough to seek help. (46)

Due to the telephonic nature of this data collection, insufficient information was gathered in order for conclusions to be drawn on why caregivers did not access the services.

5.5 Conclusion

In conclusion, it can be seen that there are many barriers influencing access to Occupational Therapy services. These can be identified as transport costs and access to transport, the caregivers' poor awareness of the services provided such as occupational therapy and the ECI programme as well as poor knowledge of the problem and normal child development, as many problems were only being picked up by the teacher or at an even later stage. Other barriers included long waiting times at the hospital, clash of the caregiver and child's appointment, not getting off work, not being able to send someone else with the child to the appointment and lastly, the caregiver not remembering the appointment.

However, there are also facilitators influencing access to Occupational Therapy services. These include clinics offering Occupational Therapy services which are closer to the child and caregiver's place of living. However, these services are limited as they are not available every day such as services as the hospital. People other than the caregivers, such as family members, may have been concerned about the problems that the children were experiencing and encouraged the caregivers to seek help at the clinic or hospital, which they then did.

Lastly, there is only limited information available from caregivers who did not arrive for their appointments to determine influencing factors for not accessing ECI services.

5.6 Clinical Implications

While Bertha Gxowa is considered a district hospital and may be the initial point of access for Occupational Therapy services for example (66), caregivers of child with developmental delays or disabilities are still not accessing the service.

Although, not all the barriers can be addressed at the level of the hospital or the occupational therapy department itself, the following changes could nonetheless be implemented to facilitate access to early childhood services. When planning ECI services, these requirements should be taken into consideration:

- The hospital has the software available and ready to use to implementing an SMS system which reminds caregivers of the appointment date and time. It should also ask the caregivers to call the therapist should they be unable to attend the appointment.
- Before booking Occupational Therapy services, the following should be done:
    - Checking with the caregiver if the hospital is the closest facility to access Occupational Therapy services. The therapist may use the list of clinics to assist the caregiver in deciding. This will allow the caregiver to spend less on transport for example.
    - The therapists should confirm the dates and times of the appointment with the caregiver before booking it. This will allow for the caregiver to check first if she has another conflicting appointment.
    - Similarly, the therapists should ask the caregivers if they have other appointments scheduled in the hospital. If yes, the therapists should try to accommodate the child on the same day so as to limit the number of times that the caregiver has to travel to the hospital in the month, thus limiting the costs spent on transport.
    - The therapists should educate the caregivers on the importance of the child attending Occupational Therapy sessions. The referral can also be explained to the caregiver should they not be aware of the why their child may need occupational therapy.
    - With this, the therapists should also alert the caregivers that should they be unable to attend the appointment, they could send a reliable alternative caregiver with the child to the appointment. If the caregiver has no alternative, the caregiver should call the therapist to reschedule another appointment.
- Education of occupational therapy and early childhood services needs to be increased:
    - This can be done by educating new and current hospital staff on the services available. This can be done in the continuous medical education sessions occurring on a regular basis as well as the hospital orientation programme.
    - The key hospital waiting areas including the allied services area, have television sets which allow for information regarding the hospital to be

displayed. This can be utilised to display the ECI programme as well as occupational therapy services. This will allow for increased awareness of the services by all those accessing the hospital.

5.7 **Limitations of the study**

- The data collection process was interrupted by the researcher having to take leave or attend classes at university. Thus, any patients accessing services during the time that the researcher was not at Bertha Gxowa Hospital were not able to be included in the study. Thus, more participants could have been included in the study. The researcher then had to include a research assistant in the study by training another occupational therapist to assist in data collection.
- New referrals were not only received by the researcher but also by other occupational therapy staff or allied health professionals who then booked the caregiver and child. As a result, some caregivers did not access the services and could not be included in the study.
- Information was difficult to obtain from the caregivers who did not access the services as the researcher struggled to contact them. This skewed the data collected.
- The initial questionnaire was also limiting in terms of expanding on information gathered such as the support systems available to the caregivers and the possible help sought at the clinic, for example.
- The abbreviated questionnaire used to collect data telephonically from caregivers who did not access the services was limiting as it did not allow for the full understanding of the choices made by the caregivers.

Chapter 6: Conclusion

In conclusion it can be seen that there are both barriers and facilitators influencing access to early childhood services. However, there are more barriers than facilitators; these impediments can be summarised as follows: availability, cost and access of transport appeared to be a significant barrier in terms of accessing ECI services. The caregiver's knowledge of the problem as well as developmental norms was also noted as a barrier as it influenced the time in which services was sought. This also points to the lack of the caregiver's awareness and limited knowledge of the services available such as occupational therapy and the early childhood programme.

Other barriers included the caregiver forgetting the child's appointment and the caregiver and child's appointments clashing on the same day. Although only a minority of the caregivers reported difficulty in getting time off work or having to send someone else to the hospital for the child's appointment, this was nonetheless noted as a barrier. Waiting times were also reported to be a barrier to accessing services at the hospital.

The facilitators, although few in number, included having Occupational Therapy services offered at the various clinics. These clinics were said to be closer to the caregiver and child's place of residence and thereby limited the cost of transport to the hospital. However, the barrier to this was that Occupational Therapy services offered at the clinic were not available on a daily basis as opposed to those at the hospital. Having others concerned about the problems experienced by the child was seen as a facilitator as it showed that others such as family members had some form of knowledge of the problem and suggested help at the clinic or hospital. This implied that these individuals may have had some knowledge and awareness of the services being offered such as occupational therapy or the ECI programme.

Despite the limitations in this study and the small sample size, the results were not generalizable to outside of Bertha Gxowa Hospital.

Recommendations for future research

This study has highlighted the need for more research to be conducted on children accessing early childhood services and the factors influencing their access to such services. It has also highlighted the need for further research on the knowledge of caregivers on child development and the services available to address the child's

problems. This would prove beneficial and eliminate some of the barriers hindering access to early childhood services.

Appendix A

Interview Questionnaire

Part 1: Caregiver Demographic Information

- **Who is the primary caregiver?**

☐ Mother	☐ Grandparents	☐ Other Relative:
☐ Father	☐ Friend	_____
☐ Aunt	☐ Uncle	

- **Gender of the primary caregiver:**

☐ Male	☐ Female

- **Age of primary caregiver:**

☐ 18 – 25	☐ 36 – 45	☐ 55+
☐ 26 – 35	☐ 46 – 55	

- **Age of the person accompanying child (if not primary caregiver):**

☐ 18 – 25	☐ 36 – 45	☐ 55+
☐ 26 – 35	☐ 46 – 55	

- **Relationship of person accompanying child:**

☐ Mother	☐ Grandparents	☐ Other Relative:
☐ Father	☐ Friend	_____
☐ Aunt	☐ Uncle	

- ***Socio – economic Status:**

☐ R0 – R5599	☐ R5600– R40 000	☐ R40 001+

- **Language:**

☐ English	☐ IsiZulu	☐ Northern Sotho
☐ Afrikaans	☐ Venda	☐ Other:
☐ Sesotho	☐ Tswana	_____
☐ Sepedi	☐ Tsonga	
☐ Xhosa	☐ Swazi	

- **Which suburb do you stay in? (kilometres from the hospital)**

  - □ ±5 km from Primrose
  - □ ±4km from Dikhathole
  - □ ±7km from Elsburg
  - □ ±12km from Buhle Park
  - □ ±17km from Leondale
  - □ ±10km Reiger Park
  - □ ± 20km from Katlehong
  - □ ±10km from Malvern
  - □ ±5km Germiston
  - □ ±9km from Wadeville
  - □ Other:_____

<u>Part 2: Child demographic information and information on the problem</u>

- **Age of child:**

  - □ 0 – 3 month
  - □ 3 – 6 months
  - □ 6 – 9 months
  - □ 9 – 12 months
  - □ 12 – 18 months
  - □ 18 – 24 months
  - □ 2 years
  - □ 3 years
  - □ 4 years
  - □ 5 years
  - □ 5 years +

- **Gender of child:**

  - □ Male
  - □ Female

- **Race:**

□ Caucasian □ African □ Other: _____

□ Indian □ Asian

- **Diagnosis (If any):** _____
- **Were there any problems at birth:**

  - □ YES
  - □ NO

    - **If yes, explain?** _____

      _____

      _____

- **Has the child been admitted to the hospital?**

  - □ YES
  - □ NO

- **How many times has the child been admitted to hospital?**

  - □ 1
  - □ 2
  - □ 3

□ 4 □ 5 □ or 5+

- **Do you know why the child was admitted to hospital?**

  □ YES □ NO

  - **Reason/s: _____**

    _____

- **Where is the child during the day:**

□ School □ Crèche □ At home

  - **Has there been any problems at school/crèche?**

    □ YES □ NO

    What are the problems? _____

    _____

<u>Part 3: Access to services</u>

- **Does the primary caregiver work?**

  □ YES □ NO

  If YES, answer the following:

  - **How easy is it to get time off to go to the clinic or hospital?**

    Very easy Somewhat difficult Difficult Very difficult

  - **Are you able to send someone else to the clinic or hospital?**

    □ YES □ NO

    - **Who?**

□ Mother □ Grandparents □ Other

□ Father □ Friend Relative:

□ Aunt □ Uncle _____

- **How do you get to the nearest clinic or hospital? Do you use one of the following and how many of the following?**

□ TAXI _____ □ WALKING

□ BUS _____ □ TRANSPORT SERVICE ____

□ CAR □ OTHER: _____

□ TRAIN _____

- **Are there reasons why you would not go to the clinic or hospital?**
  - □ YES □ NO
  - **Reasons:** _____

- **Who referred the child?**

□ DOCTOR □ SCREENING □ OTHER:

□ NURSE □ SCHOOL _____

□ ALLIED STAFF □ TRADITIONAL

□ SELF HEALER

- **Do you know the reason why you have been referred here?**
  - □ YES □ NO
  - **Explain:**_____

    _____

- **What do you think is the problem?** _____

_____

- **How long have you worried about this problem?**

□ 0 – 3 month □ 9 – 12 months □ 24 months +

□ 3 – 6 months □ 12 – 18 months

□ 6 – 9 months □ 18 – 24 months

- **Why have you come to the hospital now?** _____

_____

- **Was there something stopping you from coming before?**
  - □ YES □ NO
  - **If yes, what stopped you?** _____

    _____

- **Has anyone else been worried about this problem?**

  □ YES □ NO

  - **If yes, who?**

□ Doctor □ Traditional Healer □ Grandparents
□ Nurse □ Friend
□ Allied Staff □ Mother □ Uncle
□ Religious Leader □ Father □ Other: _____
□ School □ Aunt

  - **Where did they say you must go?**

□ CHURCH □ CLINIC □ TRADITIONAL HEALER
□ SCHOOL □ HOSPITAL

- **Did you seek help before this?**

  □ YES □ NO

  - **Why?** _____
    _____

- **Where have you go for help before this?**

□ CHURCH □ HOSPITAL □ OTHER: _____
□ SCHOOL □ TRADITIONAL HEALER
□ CLINIC

- **Are you aware of the services offered by the hospital?**

  □ YES □ NO

- **Are you aware of the services offered by Occupational Therapy?**

  □ YES □ NO

- **Which of the following other services are you aware of that offer service to children?**

□ Physiotherapy □ Speech Therapy □ Audiology

□ Psychology □ Social Work

- **Are you aware of the Early Childhood Intervention programme offered at the hospital?**

  □ YES □ NO

  - **If yes, where did you hear about the Early Childhood Intervention programme?**

    □ Promotion and Prevention Talks
    □ Advertisements on the hospital TVs
    □ Pamphlets
    □ Word of mouth (Who: _____)
    □ Hospital staff
    □ Other: _____

Appendix B

Telephonic Interview Questionnaire

Good day. My name is Humaira Khan I am the Occupational Therapist at Bertha Gxowa Hospital. You had an appointment for your child in (state month). I am calling you to find out why it is you didn't come to the session. I would like to ask you a few questions for research purposes.

Please note that your information such as your number, name and child's information will be kept private. Any information that you provide me with will not be traced back to you.

Is it ok for me to ask you a few questions?

Verbal consent:

- ☐ YES
- ☐ No

1. How old is your child?
   - ☐ 0 – 3 months
   - ☐ 3 – 6 months
   - ☐ 6 – 9 months
   - ☐ 9 – 12 months
   - ☐ 12 – 18 months
   - ☐ 18 – 24 months
   - ☐ 2 years
   - ☐ 3 years
   - ☐ 4 years
   - ☐ 5 years
   - ☐ 5 years +
2. Gender of child:
   - ☐ Male
   - ☐ Female

3. What do you understand is the problem with your child?

   _____

   _____

4. What are the reasons for not coming to the hospital?

   - Transport

     _____

   - Work

     _____

   - Other:

     _____

Appointment or assistance will be offered to the caregiver to the child – new appointment or referral to clinic.

Thank you for your time.

Appendix C

Information Letter

Study title: Factors influencing access to early childhood services in Occupational Therapy.

Dear Caregiver

Introduction:

I, Humaira Khan, am doing research on who comes to the occupational therapy department at Bertha Gxowa Hospital for the first time and what the reasons for coming to the occupational therapy department are. In this study I want to learn about when caregivers bring their children to the occupational therapy department and why they bring their children. I also want to learn about what makes it easier for caregivers to come to the hospital and what makes it more difficult. This will help us at the hospital to create services that are right for the needs of our community.

Invitation to participate: I am asking you to take part in this research study.

What is involved in the study – I am asking caregivers who bring their children to the occupational therapy department for the first time to take part in this research study and only people coming to Bertha Gxowa Hospital will take part in this study.

If you agree to take part in this research study, I will conduct an interview with you. This interview will take place in a closed therapy room. During this interview I will ask you questions about yourself, your child as well as the environment you live in. I will write your answers down on a questionnaire form. This questionnaire will not have your name or your child's name on it and all the information on the questionnaire will be unidentifiable. The interview should take about 15 minutes. Once the interview is finished, your participation in the study is also finished.

The information I collect on the questionnaires will be processed to try and help us at Bertha Gxowa understand what factors help you get to the hospital to use services and what prevents you from getting to the hospital to use services. This will help us plan our services to try and meet the needs of our community. If you would like to know about the results of this study, you can ask me and I will show you the report.

Risks – there are no risks in taking part in this study.

Participation in this research study is voluntary. You do not have to take part in this research study if you do not want to. If you choose not to participate, your child will still receive all the therapy and care that he/she needs. If at any time during the interview you feel like you want to stop and you do not want to participate anymore, you may tell me and we will stop. You will still be able to get all the therapy and care that your child needs.

Confidentiality: I will not write your name, your child's name, your hospital number or your address anywhere on the questionnaire. Once the interview is finished and the questionnaire is complete, the information will be unidentifiable and nobody will be able to connect your answers to you. When I share results with the hospital, there will be no identifying information in the results. Therefore, when people read the results they will only know that these answers come from caregivers who came to Bertha Gxowa Hospital during this time, but they will not know specifically who you are.

Should there be any concerns about the research, please contact the chairperson of the Human Research Ethics Committee (Medical) Professor Cleaton-Jones. Professor Cleaton-Jones can be contacted through Zanele Ndlovu at 011 717 1252 or Zanele.ndlovu@wits.ac.za.

For any other queries; please contact the researcher, Humaira Khan, on the email address listed below: humairasayed301@gmail.com

Thank you for your time.

Kind regards,

Humaira Khan

Appendix D

Informed Consent Sheet to Participate in Research

I, _____, the undersigned, have read the informational letter regarding the research study and understand what is required of me if I participate in the research entitled: Factors Influencing Access to Early Childhood Intervention Services in Occupational Therapy and agree to participate. As an indication of my consent, I return this signed document to the researchers.

Name _____

Signature _____

Date _____

Appendix E

Letter of Support for Research from Bertha Gxowa Hospital

EKURHULENI HEALTH DISTRICT BERTHA GXOWA HOSPITAL
OCCUPATIONAL THERAPY DEPARTMENT

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Mrs. H. Khan
Tel no: 011 089 8607
Humaira.Sayed@gauteng .gov.za

TO: Ms Smook – Allied Manager
Dr K Ncholo - Clinical Manager
Dr. N. Mtshali Hadebe – CEO

From: Humaira Sayed Khan
Occupational Therapist

SUBJECT: Support during postgraduate MSc OT Research

Purpose:
To request for support from the Allied department Manager as well as the Executive management of the hospital to conduct my postgraduate MSc OT Research at Bertha Gxowa Hospital

Background:
I, Humaira Khan, am currently studying through University of Witwatersrand to complete my postgraduate studies in Masters of Occupational Therapy. The course requirements is to conduct research in a field of interest. I have focused my research on the paediatric aspect of Occupational Therapy, particularly early childhood development.

I would like to request your support in the above, as I would like to conduct my research at Bertha Gxowa Hospital Occupational Therapy Department. The research data collection will only take place once ethical clearance is granted by the Human Research Ethics Council. Clearance will be provided to the hospital timeously before any data collection will take place.

Data collection will not interfere with the basic services or the operation of the OT Department as the data collection is aimed at new OT paediatric referrals. Therefore, the information gathered during the initial interview in the first OT session will suffice for the data collection.

Informed signed consent will be taken from the caregivers who have come to the session before conducting the research. The caregiver participants will informed that they are able to withdraw from the study at any given time without any consequences.

The research being conducted in the Bertha Gxowa Hospital OT Department will be beneficial to both the department and hospital as it will highlight any issues related to early childhood intervention services. The OT aims to use the information gathered from the study to improve and provide more beneficial early childhood intervention services to caregivers and their children.

If required, the completed research report will be made available to review the results of the study.

Conclusion:
Kindly assist me by supporting my postgraduate studies in Masters of Occupational Therapy.

Much Appreciated

Kind Regards

Humaira Khan
Occupational Therapist

Signature: _____ *Date:* 16/03/2016

Ms. L Smook
Allied Manager

Signature: _____ *Date:* 16/03/2016.

Supported/ not supported/ supported with amendments

Dr. Ncholo
Clinical Head

Signature: _____ *Date:* 22/3/2016

Supported/ not supported/ supported with amendments

pp Dr. N. Mtshali Hadebe
Chief Executive Officer – Bertha Gxowa Hospital

Signature: _____ *Date:* 22.03.2016

Approved/ not approved/ approved with amendments

Appendix F

Ethical Clearance Certificate

R14/49 Mrs Humaira Khan

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160846

NAME: (Principal Investigator)	Mrs Humaira Khan
DEPARTMENT:	Occupational Therapy Bertha Gxowa Hospital, Germiston
PROJECT TITLE:	Factors Influencing Access to Early Childhood Intervention Services
DATE CONSIDERED:	26/08/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Lyndsay Koch
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	25/01/2017

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 in Room 301, Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. 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 resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in August and will therefore be due in the month of August each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

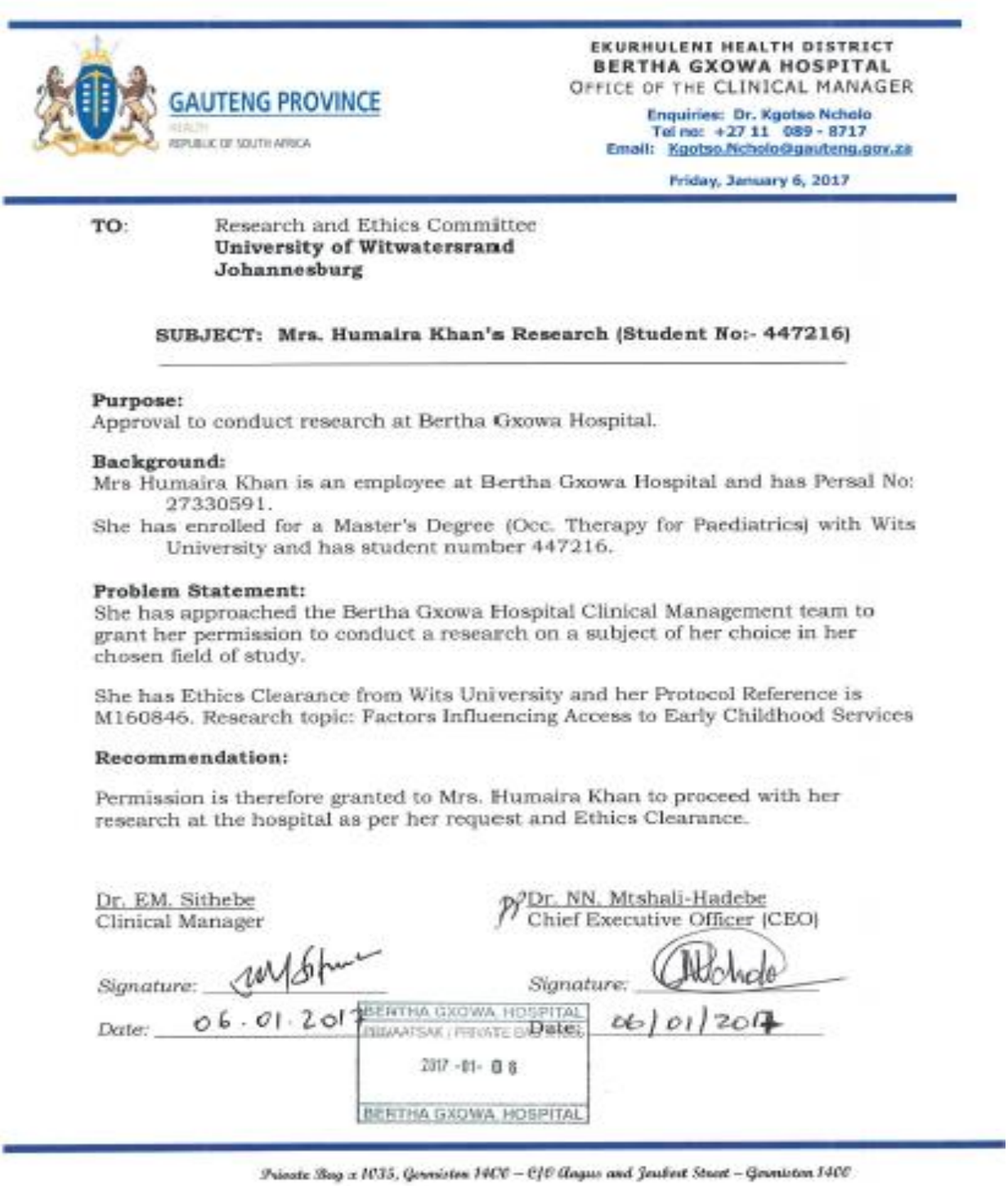
Principal Investigator Signature

Date 25/01/2017

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix G

Letter of Approval to Conduct Research



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

EKURHULENI HEALTH DISTRICT
BERTHA GXOWA HOSPITAL
OFFICE OF THE CLINICAL MANAGER
Enquiries: Dr. Kgotso Nchelo
Tel no: +27 11 089 - 8717
Email: Kgotso.Nchelo@gauteng.gov.za

Friday, January 6, 2017

TO: Research and Ethics Committee
University of Witwatersrand
Johannesburg

SUBJECT: Mrs. Humaira Khan's Research (Student No:- 447216)

Purpose:
Approval to conduct research at Bertha Gxowa Hospital.

Background:
Mrs Humaira Khan is an employee at Bertha Gxowa Hospital and has Persal No: 27330591.
She has enrolled for a Master's Degree (Occ. Therapy for Paediatrics) with Wits University and has student number 447216.

Problem Statement:
She has approached the Bertha Gxowa Hospital Clinical Management team to grant her permission to conduct a research on a subject of her choice in her chosen field of study.

She has Ethics Clearance from Wits University and her Protocol Reference is M160846. Research topic: Factors Influencing Access to Early Childhood Services

Recommendation:

Permission is therefore granted to Mrs. Humaira Khan to proceed with her research at the hospital as per her request and Ethics Clearance.

Dr. EM. Sithebe
Clinical Manager

Signature:

Date: 06.01.2017

pp Dr. NN. Mtshali-Hadebe
Chief Executive Officer (CEO)

Signature:

Date: 06/01/2017

BERTHA GXOWA HOSPITAL
2017 -01- 06
BERTHA GXOWA HOSPITAL

Private Bag x 1035, Germiston 1400 – C/O Angus and Joubert Street – Germiston 1400

References

1. AOTA. Occupational Therapy Practice Framework: Domain & Process. American Journal of Occupational Therapy. 2002;(56).

2. Richter L, Biersteker L, Burns J, Desmond C, Feza N, Harrison D, et al. Diagnostic Review of Early Childhood Development. ; 2012.

3. Slemming W. Building partnerships and establishing linkages for early childhood intervention (ECI). In ; 2012; Johannesburg.

4. Richter LM, Daelmans B, Lombardi J, Heymann J, Boo FL, Behrman JR, et al. Investing in the foundation of sustainable development: pathways to scale up for early childhood development. The Lancet Series. 2017; 389(10086).

5. Shevell M, Ashwal S, Donley D, Flint J, Gingold M, Hirtz D, et al. Evaluation of the child with global developmental delay. Neurology. 2003; 60(12): p. 367-380.

6. UNICEF , Department of Basic E. Study on Children with Disabilities From Birth to Four years old. https://www.unicef.org/southafrica/SAF_resources_childdisability0to4.pdf. Pretoria:; 2015.

7. WHO , UNICEF. Early Childhood Development and Disability: Discussion Paper. https://www.unicef.org/disabilities/index_65317.html. Switzerland:; 2012.

8. Jolly R. Early Childhood Development: the global challenge. The Lancet. 2007; 369(9563).

9. Lake A. Early Childhood Development - Global action is overdue. The Lancet. 2007; 378(9785).

10. Berry L, Dawes A, Biersteker L. Getting the basics right: An essential package of services and support for ECD. South African Child Gauge. 2013;: p. 26-33.

11. McGregor SG, Cheung YB, Cueto S, Glewwe P, Richter L, Strupp B. Developmental Potential in the First 5 years of children in developing countries. The Lancet. 2007; 369(9563).

12. Sleeming W, Balton S, Samuels A. Early Childhood Intervention in South Africa in Relation to the Developmental Systems Model. Infants & Young Children. 2012; 25(4): p. 334-345.

13. UNICEF. UNICEF South Africa. [Online].; 2011 [cited 2016 May 9. Available from: http://www.unicef.org/southafrica/media_9634.html.

14. Sleeming W. Building partnerships and establishing linkages for early childhood intervention (ECI). In ; 2012.

15 Ngwetsana N. Gauteng Province Education. [Online].; 2016 [cited 2016 May 9. . Available from: http://www.education.gpg.gov.za/Media/news/Pages/GAUTENG-TO-BREAK-BARRIERS-IN-EARLY-CHILDHOOD-DEVELOPMENT.aspx.

16 Viviers A, Biersteker L, Moruane S. Strengthening ECD service delivery: . Addressing systemic challenges. South African Child Gauge. 2013;: p. 34-43.

17 Berry L, Albino N. Early Childhood Services in South Africa: What are the next . steps? South African Child Gauge. 2013;: p. 78-81.

18 Reardon T, Harvey K, Baranowska M, O'Brien D. What do parents perceive are . the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies. European Child & Adolescent Psychiatry. 2017 January; 26: p. 623-647.

19 Ramey CT, Ramey SL. Early Learning and School Readiness: Can Early . Intervention make a Difference? Merrill-Palmer Quarterly. 2004; 50(4): p. 471-491.

20 Khan H. Bertha Gxowa Hospital Allied Department ECI Statistics. 2015-2016.. .

21 Daelmans B, Darmstadt GL, Lombardi J, Black MM, Britto PR, Lye S, et al. Early . childhood development: the foundation of sustainable development. The Lancet Series. 2016; 389(10086).

22 Wallace K. Early Intervention for Young Childen at Risk for Developmental . Mental Health Disorders. In Alers , Rosemary , Crouch , Vivyan , editors. Occupational Therapy in Psychiatry and Mental Health.: John Wiley & Sons; 2014. p. 239-347.

23 Biersteker L. Early childhood development services: Increasing access to benefit . the most vulnerable children. South African Child Gauge. 2012;: p. 52-57.

24 Sacks A. Perceptions and Experiences of Early Childhood Development (ECD) . Held by Caregviers in an Under-Resourced Community in Gauteng. Unpublished Research Report for the Degree Master od Educational Psychology, Faculty of Humanities, University of Witwatersrand. Johannesburg:; 2014.

25 Machel G. Good Early Development: The Right of Every Child. The Lancet . Series. 2017; 389(10086).

26 Desmond C, Harrison D, Linda Richter LB, Biersteker L, Martin P, Naicker S, et . al. National ECD Programme Policy: Early Childhood Development. 2014. https://www.unicef.org/southafrica/resources_19229.html.

27 WHO. The importance of caregiver–child interactions for the survival and healthy . development of young children.

https://www.who.int/maternal_child_adolescent/documents/924159134X/en/. ; 2004.

28. Meintjes JS, VanBelkum C. Knowledge Assessment of Caregivers regarding Early Childhood Development in a Resource Poor Community. Africa Journal of Nursing and Midwifery. 2011 January; 15(2).

29. Turok I. Urbanisation and Development is South Africa. Cape Town:; 2012.

30. Moura D, Costa J, Santos I, Barros A, Matijasevich A, Halpem R, et al. Risk factors of suspected developmental delay at age 2 years. Paediatric and Perinatal Epidiology. 2010; 24(3): p. 211-221.

31. Walker SP, Wachs TD, Grantham-McGregor S, Black MM, Nelson CA, Huffman SL, et al. Inequality in early childhood: risk and protective factors for early child development. The Lancet. 2011; 378(9799).

32. Engle P, Black M, Behrman J, Gertler P, Kapriri L, Martorell R. Strategies to avoid the loss of developmental potential in more than 200 million children in the developing world. The Lancet. 2007; 369(9563): p. 229-242.

33. Schonhaut L, Armijo I, Perez M. Gestational Age and Developmental Risk in Moderately and Late Preterm and Early Term Infants. Pediatrics. 2015; 135(4).

34. Sanders D, Lake LRaL. Addressing inequities in child health: Opportunities and challenges. South African Child Gauge. 2012;: p. 58-64.

35. Sroufe A. Early Relationships and The Development of Children. Infant Mental Health Journal. 2000; 21(1): p. 67- 74.

36. Oyserman D, Mowbray CT, Meares PA, Firminger KB. Parenting Among Mothers With a Serious Mental Illness. American Journal of Orthopsychiaty. 2000 July; 3(70).

37. Skonhoff J, Radner J, Foote N. Expanding the evidence base to drive more productive early investment. The Lancet Series. 2017; 389(1).

38. Chan M, Lake A, Hansen K. The early years: silent emergency or unique opportunity? The Lancet Series. 2016; 389(10086).

39. Tomlinson M, Rahman A, Sanders D, Maselko J, Rotheram-Borus MJ. Leveraging paraprofessionals and family strengths to improve coverage and penetration of nutrition and early child development services. Integrating Nutrition and Early Childhood Development Interventions. 2014; 1308(1): p. 162-171.

40. Sanders D, Bradshaw D, Ngongo N. The status of child health in South Africa. South African Child Gauge. 2009-2010;: p. 29-40.

41 Wilkinson K. Africa Check. [Online].; 2018 [cited 2018 August 23. Available from: https://africacheck.org/factsheets/factsheet-south-africas-official-poverty-numbers/.

42 Sheldrick C, Negar E, Perrin E. Concerns about development, behaviour and learning amongst parents seeking peadiatirc care. Journal of Development and Behavioural Pediatrics. 2012 February; 2(33).

43 Glascoe F. The value of parents' concerns to detect and address developmental and behavioural problems. Journal of Peadiatrics and Child Health. 2002 April; 38(2).

44 Gracia M, Pence A, Evans J. Early Childhood Care and Development in Sub-Saharan Africa https://scholar.google.co.za/scholar?q=Early+Childhood+Care+and+Development+in+Sub-Saharan+Africa , editor. Washinton: The World Bank; 2008.

45 Glascoe F, Altemeier W, MacLean W. The Importance of Parents' Concerns About Their Child's Development. JAMA Pediatrics. 1989; 143(8): p. 955-958.

46 Lehohla P. Use of health facilities and levels of selected health conditions in South Africa: Findings from the General Household Survey. Statistics South Africa. Pretoria:; 2011.

47 Slemming W. Prevention and Early Childhood Intervention. In Department of Community Peadiatrics; 2011; Johannesburg: University of Witwatersrand.

48 Proudlock P, Mahery P. Children's rights to health. South African Child Gauge. 2009-2010.

49 Slemming W, Saloojee H. Beyond survival: The role of health care in promoting ECD. South African Child Gauge. 2013;: p. 50-55.

50 Nores M, Barnett S. Benefits of Early Childhood Interventions Across the World. Economics of Education Review. 2010; 29: p. 271-282.

51 Jacobs K, Jacobs L. Quick Reference Dictionary for Occupational Therapy Middletown: Slack Incorporated; 2009.

52 Majnemar A. Benefits of Early Intervention for Children with Developmental Disabilities. Seminars in Pediatric Neurology. 1998; 5(1): p. 62-69.

53 Ngcobo-Mbere M. National Early Childhood Development Policy of the Republic of South Africa. 2005. https://www.unicef.org/southafrica/SAF_resources_integratedecdpolicy.pdf.

54 Mazaleni N, Bamford L. Strengthening community-based child health services in South Africa. South African Child Gauge. 2009-2010;: p. 71-76.

55 Case-Smith J, O'Brien JC. Occupational Therapy for Children. 6th ed. Missouri:
. Mosby Elsevier; 2010.

56 Turner A, Foster M, Johnson S, editors. Occupational Therapy and Physical
. Dysfunction. 5th ed.: Churchill Livingston; 2002.

57 Kingsley K. Evidence for the Effectiveness of Different Service Delivery Models in
. Early Intervention Services. American Journal of Occupational Therapy. 2013;
67(4): p. 431-436.

58 Arbesman M, Lieberman D, Berlanstein D. Method of the Systemic Reviews on
. Occupational Therapy and Early Intervention and Early Childhood Services. The
American Journal of Occupational Therapy. 2013; 67(4): p. 389-394.

59 Clark GF, Jackson L, Polichino J. Occupational Therapy Services in Early
. Childhood and School Based Settings. The American Journal of Occupational
Therapy. 2011; 65(6): p. 46-54.

60 Ginsburg K. The Importance of Play in Promoting Healthy Child Development
. and Maintaining Strong Parent-Child Bonds. Pediatrics. 2007 January; 119(1).

61 Goldstein J. Play in children's development, health and well-being. 2012.
. https://www.ornes.nl/./Play-in-children-s-development-health-and-well-being-feb-
20.

62 Balton S, Slemming W, Prinsloo A, Vallabhjee A, Hassan N, Matsusi R, et al.
. Early Childhood Intervention Policy. 2018.
https://www.gov.za/documents/national-programme-action-children-framework.

63 UNICEF. South Africa stands to benefit significantly from investing in its young.
. https://www.unicef.org/southafrica/media_13635.html. Cape Town:; 2013.

64 Hall K, King NN, Shung M. Child health: The general context. South African Child
. Gauge. 2009-2010;: p. 110-114.

65 Lehohla P. Use of health facilities and levels of selected health conditions in
. South Africa: Findings from the General Household Survey. Pretoria:; 2011.

66 Cullinan K. Health services in South Africa: A Basic Intorduction. 2006. Health-e
. News Service.

67 Westwood A, King MS, Lake L. Basic health care services for children. South
. African Child Gauge. 2009-2010;: p. 58-63.

68 Jobson M. Structure of the health system in South Africa. Johannesburg:; 2015.
.

69 Harrison D. An Overview of Health and Health care in South Africa 1994 – 2010:
. Priorities, Progress and Prospects for New Gains. Muldersdrift:; 2009.

70 Cooper TES. Overcoming barriers to health service access. Health Policy and
. Planning. 2004; 19(2): p. 69-79.

71 Whyte C. Implementation of the ward based primary healthcare outreach teams
. in the Ekurhuleni health district. 2015. A research report submitted to the Faculty of Health Sciences,University of the Witwatersrand, in partial fulfillment of the requirements for the degree of Master of Medicine in the branch of Community Health.

72 Maillacheruvu P, McDuff E. South Africa's Return to Primary Care: The Struggles
. and Strides of the Primary Health Care System. The Journal of Global Health. 2014 April;(1).

73 Goudge J, Gilson L, Russell S, Gumede T, Mills A. Affordability, availability and
. acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. BMC Health Services Research. 2009 May; 9(75).

74 Commodari E. Children staying in hospital: a research on psychological stress of
. caregivers. Italian Journal of Pediatrics. 2010; 36(40).

75 Applequist KL, Donald B. Bailey J. Navajo Caregivers' Perceptions of Early
. Intervention Services. Journal of Early Intervention. 2000; 23(1).

76 Harris B, Goudge J, McIntyre D, Nxumalo N, Jikwana S, Chersich M. Inequities
. in access to health care in South Africa. Journal of Public Health Policy. 2011; 31(2).

77 Coovadia H, Jewkes R, Barron P, Sanders D, McIntyre D. The health and health
. system of South Africa: historical roots of current public health challenges. Lancet. 2009; 374(9706): p. 817-834.

78 McLaren Z, Ardington C, Leibbrandt M. Distance as a barrier to health care
. access in South Africa. Cape Town: University of Cape Town, Southern Africa Labour and Development Research Unit,; 2013.

79 Tanser F, Gijsbertsen B, Herbst K. Modelling and understanding primary health
. care accessibility and utilization in rural South Africa: An exploration using a geographical information system. Social Science & Medicine. 2006 August; 63(3).

80 Marie K. First Steps in Research Pretoria: Van Schaik Publishers; 2007.
.

81 Polgar S, Thomas S. Introduction to Research in Health Sciences. 5th ed.
. Philadelphia: Churchill Livingstone; 2008.

82 Kielhofner G. Research in Occupational Therapy: Methods of Inquiry for
. Enhancing Practice Philadelphia: FA Dvais Company; 2006.

83 Department of H. Gauteng Department of Health. [Online].; 2013 [cited 2017
. February 26. Available from: www.health.gpg.gov.za/hospitals/pages/Bertha-Gxowa-Hospital.aspx.

84 Khan H. Bertha Gxowa Hospital Allied Department Standard Operating
. Procedure for Early Childhood Intervention Services. 2017..

85 Lehohla P. Fertility in South Africa. Statistics South Africa. Pretoria:, Statistics
. South Africa; 2011. Report No.: www.statssa.gov.za/publications/Report-03-01-63/Report-03-01-632011.pdf.

86 Mari MA, Alchieri MMCaJC. Congenital Heart Disease and Impacts on Child
. Development. Brazilian Journal of Cardiovascular Surgery. 2016; 31(1).

87 Duszak RS. Congenital rubella syndrome - major review. American Optometric
. Association. 2009; 80(1).

88 McDonald L, Rennie A, Tolmie J, Galloway P, McWilliam R. Investigation of
. global developmental delay. Archives of Disease in Children. 2006 August; 91(8).

89 GautengDepartmentofHealth. Gauteng Health Clinic List. 2017.
. https://www.joburg.org.za/services_/Pages/City%20Services/Joburg%20Cares/Joburg%20Cares%20links/List-of-public-hospitals-and-clinics.aspx.

90 Jobson M. Structure of the health system in South Africa.
. https://khulumani.net/active-citizens/item/1164-the-health-system-in-south-africa-actions-to-secure-the-right-to-health-in-south-africa.html. Johannesburg:; 2015.

91 Taxi Map. [Online]. [cited 2018 March 26. Available from:
. http://www.taximap.co.za/routes/944.

92 Commodari E. Children staying in hospital: a research on psychological stress of
. caregivers. Italian Journal of Pediatrics. 2010; 36(40).

93 Cooper T, Stephanie E. Overcoming barriers to health service access. Health
. Policy and Planning. 2004; 19(2): p. 69-79.

94 Harrison D. An Overview of Health and Health care in South Africa 1994 – 2010:
. Priorities, Progress and Prospects for New Gains.
http://ftp.bhfglobal.com/files/bhf/overview1994-2010.pdf. Muldersdrift:; 2009.

95 UNICEF , Department of Basic E. Study on Children with Disabilities From Birth
. to Four years old. Pretoria:; 2015.