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Exploring the factors affecting the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Bojanala District

By

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A Research Report submitted in partial fulfilment of the requirement for the degree of Master in Public Health

At

Witwatersrand University

Supervisor: Dr. Richard Cooke

Co-Supervisor: Jacqui Couper

23 September 2019

DECLARATION

I, Andrea Abrahams, declare that this research report is all my own work except to the extent indicated in the reference citations and acknowledgements. It is being submitted for the degree of Master in Public Health in the field of Rural Health, to the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination at this or any other University.

The Human Research Ethics Committee at the University of Witwatersrand approved the study unconditionally. The medical ethics clearance certificate number is M160423.

Student Signature: _____

Date: _____

DEDICATION

To my late Father, Andreas Johannes Fortuin

1937 -2017

who strongly believed that education was the cornerstone of every Nation

and

To every child in South Africa aged 0-5 years who are the future foundation of our Nation.

ABSTRACT

Introduction

One of the building blocks for early identification of disabilities in children aged 0-5 years is implementing appropriate measures that are able to identify developmental delays. Seemingly, the RtHB that is being used in South Africa is either not being used in a correct way or the book as a standalone is not sufficient enough to detect developmental delays.

Aim

To explore Registered Healthcare Nurses perceived factors currently affecting the early identification of developmental delays in children aged 0-5 years in selected facilities in Bojanala District.

Method

This study applied a qualitative research design using in-depth and semi-structured interviews. Three Key Informants and nine Registered Nurses participated in the study. A thematic analysis was conducted on the data collected.

Results

Twelve themes were derived as answers for three of the four study objectives. Measures used to detect developmental delays include surveillance, screening, reported information, and knowledge of developmental delays. Health system factors affecting early identification include infrastructural and organizational issues, re-engineering of PHC, Integration of services at PHC facilities, protocols to guide PHC nurses, and fragmentation of services among the different levels of health care facilities. Factors currently contributing to detection of developmental delays were based on service delivery issues, attitude of parents and inaccessibility. Thus, the factors affecting early identification of developmental delays are; the use of informal measures without diagnostic instruments to identify developmental delays, lack of sufficient support from the health system, and limited collaboration between different governmental sectors in detection of childhood disabilities.

Conclusion

The evidences from the study findings are strong enough to conclude that there are many factors impacting negatively to the detection of developmental delays in children in Bojanala district. There is need for support from the national health sector and collaboration among governmental and non-governmental sectors.

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GLOSSARY OF TERMS

Developmental Delay: Developmental delay is a term used when a child experiences a significant variation in the achievement of an expected milestone for their actual or adjusted age (1-3).

Developmental Domains: In Psychometric literature developmental domains are a theoretical concept typically referred to as 'constructs'(4). These developmental domains consist of cognition, language, motor and socio/emotional domains(4).

Developmental Milestones: Developmental milestones are specific skills that are attained in a predictable sequence, over a period of time showing the interaction of a Child's developing neurological system with the environment (5).

Developmental Screening: Developmental screening is the use of standardised tools to test populations of children at specific ages to detect those who are at high risk for developmental problems (6).

Developmental Surveillance: Developmental surveillance is the informal approach to continuously monitor a child's development over a certain period of time(7).

Disability: According to the *International Classification of Functioning, Disability and Health: Children and Youth Version* (ICF-CY) , Disability is neither purely biological nor social but instead the interaction between health conditions and environmental and personal factors(2).

According to the ICF-CY Disability can occur at three levels:

- an impairment in body function or structure, such as a cataract which prevents the passage of light and sensing of form, shape, and size of visual stimuli;
- a limitation in activity, such as the inability to read or move around; and
- a restriction in participation, such as exclusion from school.

The Convention on the Rights of Persons with Disabilities (CRPD) states that "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (8).

Early Identification: To find, observe or discover something as soonest possible to ensure that an intervention can occur.

Global Developmental Delay: A global developmental delay refers to a child younger than 5 years old who is presenting with a delay in two or more developmental domains(9).

Registered Healthcare Nurses (RN): A Registered Healthcare Nurse or Professional nurse in this context is a person who has met the prescribed education requirements for registration with the South African Nursing Council as a professional nurse and midwife(10).

NOMENCLATURE

ACRWC: African Charter on the Rights and Welfare of the Child

ASQ: Ages and Stages Questionnaire

CDATs: Childhood Developmental Assessment Tools

CHWs: Community health workers

CWD: Children with disability

DCST's : District Clinical Specialist Teams

DoH: Department of health

HIC: High income countries

HIV/AIDS: Human immune-deficiency virus/ Acquired immune deficiency syndrome

HPCSA: Health professional council of South Africa

ICF: International Classification of Functioning, Disability and Health

IMCI: Integrated Management of Childhood Illness

INDS: Integrated National Disability Strategy

LMICs: Low and middle-income countries

MDGs: Millennium Development

MhGAP: Mental Health Gap Action Programme

NQF: National Qualifications Framework

PEDS: Parents Evaluation of Developmental Status

PHC: Primary health care

RN: Registered nurse/s

RtHB: Road to health booklet

RtHC: Road to health chart

SANC: South African Nursing Council

SAQA: South African Qualifications Authority

SDGs: Sustainable development goals

TQS: Ten Question Disability Screen Tool

UNCRC: United Nations Convention on the Rights of the Child

UNCRPD: UN Convention on the Rights of Persons with Disabilities

WHO: World Health Organization

CHAPTER ONE

INTRODUCTION

This chapter begins with a background on legislation and policies pertaining to children with disabilities (CWD) in South Africa and the lack of direct recognition of these children related to early identification of disabilities. After this is a definition of developmental delays and disability as described by the World Health Organization (WHO). Thereafter, a literature review discussing the detection of childhood disabilities, co-ordination of health systems in early identification of CWD, and factors contributing to early identification of developmental disabilities in children internationally and in South Africa. The problem statement, study justification, aims objectives and operational definitions are addressed at the end of this chapter.

1.1 Background

The South African government has shown considerable growth in encompassing all children, including CWD, in applicable legislation and policy documents. The Bill of Rights in the constitution encompasses the specific rights of children(11). Furthermore, the South African government has committed itself to realising the rights of CWD through the ratification of international treaties, such as, the United Nations Convention on the Rights of the Child (UNCRC), the African Charter on the Rights and Welfare of the Child (ACRWC or the African Charter), and the UN Convention on the Rights of Persons with Disabilities (UNCRPD)(11). However, the concern remains that there is a lack of direct recognition of CWD and the importance of early identification of disabilities, especially within Africa(12). The early identification of developmental delays precedes the early intervention of childhood disabilities(13). The focus of this study is to identify the factors affecting early identification of developmental delays by Registered Health Care Nurses (RN) in the Bojanala District in the North West Province of South Africa.

1.2 Literature Review

South Africa was an active participant in the WHO's Millennium Development Goals (MDGs) and is also striving to sustain these goals until 2030 as required by the sustainable development goals (SDGs) which commenced in 2016. Thus, it is

implementing interventions needed to reduce and maintain low mother and child mortality rates.

Lack of early identification and implementation of appropriate treatment regimens for children are problematic in developing countries. Low and middle-income countries (LMICs) are experiencing a marked decline in mortality among children under 5 years of age (1, 13, 14). The 22% reduction in child mortality, partly due to world campaigns to eradicate or reduce the impact of Human immune-deficiency virus/ Acquired immune deficiency syndrome(HIV/AIDS), tuberculosis, malaria, and malnutrition, still lags behind the target set by the United Nations(13). However, as the survivor rate within this age group increases, it is estimated that more than 200 million children will present with developmental delays or disabilities worldwide (1, 13, 14).

Studies conducted by the WHO, Fisher et al., and Mohale & Mulaudzi have found a high prevalence of neurodevelopment delays, cerebral palsy and intellectual disabilities among survivors of HIV/AIDS and malaria (13, 15, 16). The increasing number of CWD introduces urgency for early identification, because it ensures optimal treatment and rehabilitation (11, 14). The studies referred to earlier, clearly indicate that there is a growing population of children with CWD in LMICs who need to be attended to in the planning and practice of health care systems (13, 15).

Mainly due to a lack of epidemiological studies, the true prevalence of disability in South Africa is unclear. It is estimated that there is a 4-6% prevalence of moderate to severe CWD in South Africa(17). In three separate surveys conducted in South Africa between the years 1992-2002, it was estimated that there is a 1.1-6.3% prevalence of disability(18). In a more recent study conducted in the Valley of a Thousand Hills in KwaZulu Natal, a disability prevalence of 7% among children aged 2-9 years living in this area was found(19). The results of these studies are all very small and thus cannot be generalised as the prevalence rate of disability among all South African children. The National Census 2001 implies that there are at least 474 000 CWD in South Africa(11). This survey, however, only looked at severe disabilities and if mild and moderate disabilities were taken into account, the numbers could increase.

The Definition of Developmental delay and Disability

When a child experiences a significant variation in the achievement of an expected milestone for their actual or adjusted age, it is referred to as a developmental delay (1-3). Milestones are grouped according to motor, cognitive, language and personal or social domains.

A global developmental delay refers to a child younger than 5 years old who is presenting with a delay in two or more developmental domains (9). Developmental delays can be mild, moderate, or severe(1). A developmental delay may not be permanent, but it can provide an opportunity to identify children who may experience a disability(1, 2).

The developmental domains are as follows:

Motor Domain

Motor development refers to both gross and fine motor development. The gross motor refers to the large muscle groups of the body, and Fine motor refers to the small muscle groups of the body, especially those of the hand. Gross motor movement is needed to move, stabilise, and control the body while exploring its environment (20). Fine motor movements are needed for self-help skills and also drawing and writing(20). It is needed for small object manipulation (21).

Language and Cognitive Domain

Language development refer to the development of verbal and non-verbal communication skills. It encompasses receptive speech and expressive speech. Cognitive development which is the ability to solve problems, reason, learn, retain, and apply information is also captured under this domain(21).

Social/Emotional Domain

Personal/Social development includes activities of daily living such as dressing, eating, bathing, as well as, responding to other people, building, and maintaining relationships (21).

Disability

The challenge for CWD begins by defining the variety of disabilities currently existing worldwide. Clarity on definitions of disability will assist policy makers in ensuring that all disabilities are catered for in early detection programmes. The International Classification of Functioning, Disability and Health (ICF) looks at three aspects of disability namely; the impairment, for example, hearing loss; activity limitation, such as, inability to hear without a hearing aid; and participation restriction including, not being able to be participate actively in class(2). It looks at how the affected individual perceives themselves in terms of environmental and personal factors(22).

However, a clear definition for the term disability in the absence of a national programme to direct the early detection of childhood disabilities in South Africa, can have detrimental outcomes for CWD(23). Defining, conceptualising, and measuring disability is a complex process which has affected the disability data in South Africa(23). Therefore, estimates of disability prevalence in children from different studies are not comparable because of differing definitions of disability and methods of data collection(11).

If this can be addressed, it could assist researchers and policy makers to link early identification programmes to specific policies, legislature or government guidelines. Early identification is thus very important to introduce the correct interventions for delays(1).

Detecting Developmental Delays

Many High Income Countries (HIC) strongly endorse early identification strategies which are in place in their policy statements (8, 14). However, in South Africa and other LMIC, HIV/AIDS, infant mortality and Tuberculosis receive higher priority than early identification(14). These are the same conditions that can cause secondary developmental delays and disorders in young children(24, 25).

There are two main methods used to detect developmental delays in children, namely; developmental surveillance and developmental screening. Thereafter formal standardised evaluations can be administered to determine the specific developmental disorder or disability of a child.

Developmental surveillance

Developmental surveillance is the informal approach to continuously monitor a child's development over a certain period of time(7). According to Thomas et al., it is a flexible and continuous process during which a child's development is longitudinally monitored (6). It assists to detect when milestones are reached and when a child might be at risk. Healthcare workers and caregivers play a very important role when implementing it.

Developmental surveillance can be done by evoking parental concerns, maintaining an accurate history during healthcare visits, using observations, and can be administered by various well-trained health care services providers (7, 26). It needs reactive and proactive healthcare workers and caregivers in order for it to be effective(7).The role of the caregiver in identifying delays is becoming more important, especially as the Primary health care (PHC) system in South Africa may be inadequately equipped to deal with the current patient load(27, 28).

Most parents realise when something is wrong with their child, and studies evaluating the role of parental concern in developmental surveillance emphasise the need to pay attention to these concerns(29). There is a direct association between parental concern and increase in detection of developmental delays and mental health risks later in life(30). In addition, a strong parent-provider relationship decreases the frustration and maternal guilt when an actual delay is diagnosed(31).

Deviations detected should result in further investigation by skilled healthcare professionals(32). However, developmental surveillance in isolation is not the best manner in detecting developmental delays because it is associated with poor sensitivity (21, 26).

An evidence based clinical guideline called the Mental Health Gap Action Programme (MhGAP) Intervention Guide for the assessment and management of priority mental, neurological, and substance-abuse conditions by non-specialist primary healthcare workers were recently launched by the WHO(15). This guide has a decision-making flow chart for detecting and managing developmental disorders at primary healthcare level(15).

However, according to Fischer the lack of assessment tools and monitoring of child development suitable for use by non-specialists in low-resource settings impedes the

possibility of mainstreaming this guideline into child healthcare services(15). Thus although the WHO has this guideline, it may not be suitable for a country like South Africa that has areas that are extremely under-resourced. Although there is an international agreement regarding the importance of developmental surveillance, agreement has not been reached on how monitoring should be performed, what form it should take and what tools should be used(33, 34).

Developmental Screening

Developmental screening provides a quick gauge of a child's health and developmental status and helps to inform whether further evaluation is required to identify possible difficulties that might need interventions or special education services(35). Developmental screening tools or checklists are basic and easy to use. Screening tools should meet the following criteria(15):

1. Have good validity and reliability.
2. Acceptability to both administrators, patient, and referral professional.
3. Teaching, learning and administration should be easy.
4. Administration time should be short.
5. Cost effectiveness.
6. Clear referral guidelines should be in place.
7. Must take the context of where it is administered into consideration.
8. Be administered in an appropriate language.
9. Be culturally appropriate.
10. Should be collected in a form which enables statistical analysis.

Over the last few decades many developmental screening tools have been developed and validated internationally(36). The following has been indicated in a systematic review behind the evidence on developmental screening instruments (36).

- The Denver Developmental screening test/DENVER II (Frankenburg, 1992) with 58 research studies(37).
- The Ages and Stages Questionnaire/ASQ (Squires, 2009) with 45 studies(38).
- The McCarthy Screening test (McCarthy, 1978) with 40 research studies(39).
- The Parents Evaluation of Developmental Status (PEDS) (Glascoe, 1997) with 20 research studies(40).

The PEDS present with the largest body of supporting evidence of screening tools ranging from birth to kindergarten(36). The PEDS reportedly has higher sensitivity and specificity ratings than those of the DENVER-II despite the DENVER–II being evaluated in larger numbers (58 studies) that then PEDS (36, 37). In addition the PEDS and ASQ are the only parent administered tests, whereas the McCarthy Screening test and the DENVER-II are both clinicians administered tests.

A study conducted in the United States of America (USA) found that the type of screening methods and tools used in their Public Health Sector are not standardised(41). In order to identify children who are in need of early intervention, the use of a valid developmental assessment tool is required(42). The challenge in early identification of developmental disabilities is using the correct tools that respond to local differences, such as, cultural perceptions in the meaning of disability and being able to use it in different countries(42). The important role of tools is acknowledged in identifying children with developmental delays.

The Ten Question Disability Screen Tool (TQS) is an alternative developmental screening tool specifically geared toward LMICs(15). It consists of 10 questions administered in the form of an interview, and it engages the caregiver to provide the information. Research has also shown that the TQS can effectively identify children that should be referred for further assessment(42). Considering the challenges South Africa is facing with limited and overburdened nursing staff, this tool offers the advantage that it can be administered by people who have no background in disabilities(42).

Additionally only a few Childhood Developmental Assessment Tools (CDATs) are available in LMICs(4). Other parent administered screening tools are the Modified Checklist for Autism in Toddlers(M-CHAT) and the Childhood Development Inventory (CDI)(21). Unfortunately none of these parents administered screening tools, including the ASQ, have been validated for use in a South African setting(43).

However, a recent study conducted in the private healthcare setting in South Africa confirmed the accuracy of the PEDS tools(44).

The selection of a screening tool should be determined by the population served, the setting and the clinicians preference(45). The PEDS and ASQ display reasonable

characteristics for developmental screening in PHC settings(45). However, the PEDS is considered more appropriate in the South African context compared to the ASQ because the materials of this test are more expensive(43).

In addition the PEDS can be used in combination with the Parents' Evaluation of Developmental Status: Developmental Milestones(PEDS:DM)(46). The PEDS:DM identifies parental concerns, as well, as the presence /absence of domain specific developmental milestones(46).The PEDS:DM and the PEDS have equally demonstrated high sensitivity scores and specificity scores for developmental delays in infants from birth to 12 - 18 months (46).

In addition the PEDS tools have an algorithm of evidence based support for health care personnel to aid in the decision making process(46). It takes less than 10 minutes to conduct this test which is a positive in contexts like Primary Healthcare settings(46).

Lastly, the Bayley Scale of Infant Development-III is used internationally to detect developmental delays in children. This standardised tool has been validated for use in South Africa. However, according to a study conducted by Rademeyer & Jacklin, it is only for use on the black urban African population in Gauteng(47).

Algorithm Combination

In the USA, policy statements support the use of an algorithm which combines both developmental surveillance and screening tools(48). In a recent research, Thomas et al., concluded that using both developmental surveillance and screening tools in the PHC contexts in the USA are the most effective method of identifying infants and young children who require further evaluations for developmental delays or disorders(6). Thomas et al. further stated that these children should be monitored at each clinic by means of developmental surveillance and only be screened at the age intervals, 9 , 18 and 24 months (**Figure 1**)(6).

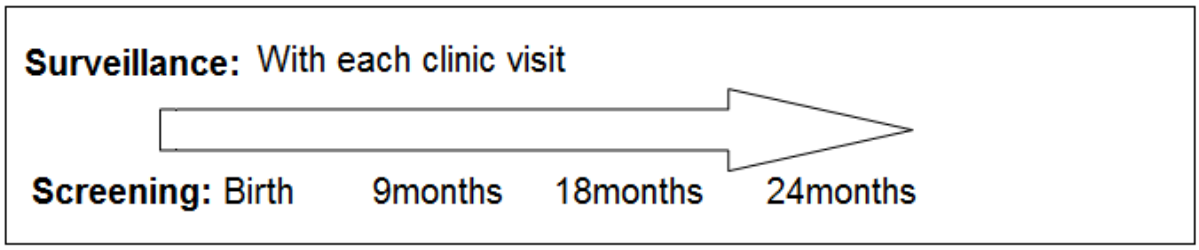


Figure 1: Intervals of developmental screening and surveillance (6).

There is limited research available for LMIC including South Africa on the improvement of early detection of developmental delays amongst infants and young children through the use of or implementation of developmental surveillance and screening tools(49-51).

The Road to Health Booklet (RtHB) is a parent held record used to monitor and promote child health, growth and development in South Africa (52, 53). This booklet is distributed by the Department of Health (DOH) to all new born at state and private facilities to be checked periodically at well baby visits (53, 54). Currently, the RtHB developmental screening tool is the only tool available in South Africa to health care workers in the public health context to conduct screening for developmental delays and disorders.

The Road to Health Booklet Developmental Screening Tool

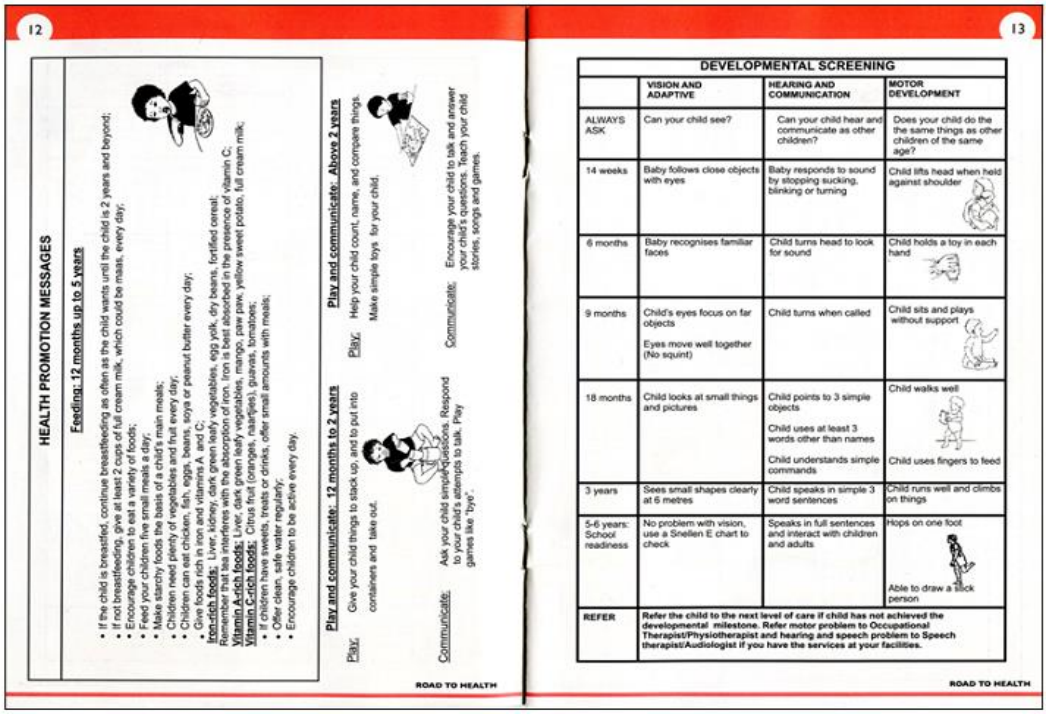
Screening programmes and tools are not new to the South African Public Healthcare (PHC) system. Road to Health Card/Charts (RtHC) have been used in South Africa since 1973 and over 40 different designs were used until 1987 when a RtHC with a common design was implemented(55). The RtHC's main purpose was to serve as a record of immunisation and growth monitoring(55).

In 2010, in the absence of an early identification of childhood disabilities policy and the lack of continuity in HIV-related care, the Department of Health replaced the parent-held RtHC with a RtHB to serve as a national assessment and monitoring tool for child health(16, 56). The RtHB is a tool which includes records for immunisation, developmental screening, oral health, health promotion, growth monitoring, infectious diseases, Vitamin A supplementation, and deworming (56). All infants in South Africa must be immunised four times in their first year of life.

This ensures that they attend the Well Baby clinics. Monthly well baby visits, for services such as, growth monitoring, oral health and developmental screening, are encouraged and sick child visits may also occur(25). During these visits the caregiver needs to bring the RtHB along. Included in the RtHB is the developmental screening tool.

The developmental screening tool guides health practitioners on when to assess childhood development, where to refer children and includes three specific questions related to motor, speech, and eye development **(Figure 2).**

Figure 2: The RtHB developmental screening checklist



The RtHB developmental screening tool consists of 21 questions in total. The first three questions must be asked to caregivers at every visit.

Additionally there are three questions that must be asked when infants are fourteen weeks, six months, nine months, eighteen months, three years, and then between five to six years of age. The following developmental domains are included: sensory functioning such as sight and hearing; communication; gross motor; and fine motor

development. There are, however, discrepancies in that not all the domains are covered at all the age intervals.

No clear referral criterion has been specified for use with the screening tool(57). Thus, there are few guidelines to assist the health care workers who need to make decisions regarding who should be referred, when they should refer children, and whom they should refer children too.

A study conducted in 2014, revealed that the RtHB developmental screening tool needed to be adapted or replaced, as it failed to identify more than half of infants at risk for developmental delays or disabilities within the PHC setting(43). This information is vital when exploring the factors affecting the early detection of developmental delays or disorders and could partially explain the poor reporting of disabilities in children under the age of five years(43).

In January 2018 a new RtHB was launched and distributed to all the Provinces. The screening tool in the new RtHB appears to be more detailed and in-depth. However, the referral route remains insufficient. For the purpose of this study, the author did not reflect on the new card because it was not the focus of the study.

Knowledge/Training

In the USA, PHC staffs are generally considered the best-informed professionals with whom families have regular contact over the child's first five years of life(43). South Africa, however, faces challenges in this area, as PHC personnel lack both the knowledge and resources to identify developmental delays and disorders in infants and young children(58). Over the past seven years, nurses have been tasked with using the RtHB developmental screening tool when children visit the PHC clinics for their immunisations or other check-ups.

Nurses working in the community need a strong foundation of knowledge and skills regarding normal growth and development to be able to guide parents in the promotion of the normal development of infants, as well as the early identification of developmental delays and appropriate referrals for further examination(41).

Nurses basic training should equip them to recognise typical or delayed growth and development in infants in order to make the necessary referrals support for the infants and their parents during intervention(59). The diversity of roles played by the nurse

within the healthcare setting causes the role of screening for disability within a paediatric setting to be facilitated by the nurse(60).

Primary Healthcare facilities in South Africa can be an enabler to early identification. This system consists of initial medical consultations at PHC Clinics, that are mainly nurse-driven(11). Nursing staff thus can play a pivotal role in early identification of developmental delays.

The Nursing Cadre in South Africa is divided into three categories, namely, professional (registered) nurses with four years of training; enrolled nurses with two years of training and nursing assistants or auxiliaries with one year of training(10). According to the Nursing Act, professional (registered) nurses are also midwives, and these terms are used interchangeably(10). A professional nurse in this context is a person who has met the prescribed education requirements for registration with the South African Nursing Council as a professional nurse and midwife(10).

The Nursing curriculum in South Africa is closely monitored by the South African Nursing Council (SANC) and guided by the South African Qualifications Authority (SAQA). SAQA is guided by the National Qualifications Framework Act Nº 76 of 2008 and the objectives include creating a single integrated national framework for learning achievements(61).

Nursing education qualifies as “higher education” under the provision of the Higher Education Act Nº 101 of 1997 giving it the same status as education in other professions(62). Due to this higher education status, nursing education programmes are obliged to comply with SAQA’s requirements of exit points(62).

The Unit Standards included in training programmes for nursing assistants including, Registered nurses (RN) (National Qualifications Framework (NQF) Level 4-7), that equip nurses to monitor development of the child are:

- Monitor and stimulate the growth and development of a child and/or adolescent.
- Manage childhood illnesses in an integrated manner.

These form part of the basic unit standards required for training in a National Diploma in Nursing and in the Bachelor of Nursing. The purpose of the first unit standard is to equip nurses to assess the level of development of a child, identify factors that may

affect growth and development, and to stimulate the growth and development of a child(63).

Furthermore, the SAQA Qualification for Further Education and Training Certificate: Nursing (NQF Level 4), includes a core component for the growth and development of a child and adolescent which is monitored according to a prescribed tool, such as The Road to Health Booklet(61). This qualified nurse (enrolled nurse) may only work under the supervision of a registered nurse or other professional members of the health team(61).These Unit standards are included in basic nursing qualifications and enable nurses to engage in developmental screening of children once they are qualified.

To further support qualified nurses, the IMCI (Integrated Management of Childhood Illness) strategy was introduced in South Africa. The IMCI is a strategy developed in early 1995 by the WHO and UNICEF and was adopted by South Africa in 1996(64). This strategy was introduced with the aim of reducing mortality and morbidity of children under the age of 5 years caused by diarrhoea, acute respiratory infections, measles, malaria, and malnutrition(64).

According to the SAQA Course, “Manage childhood illnesses in an integrated manner”, prior learning that need to be in place before starting this course is the following:

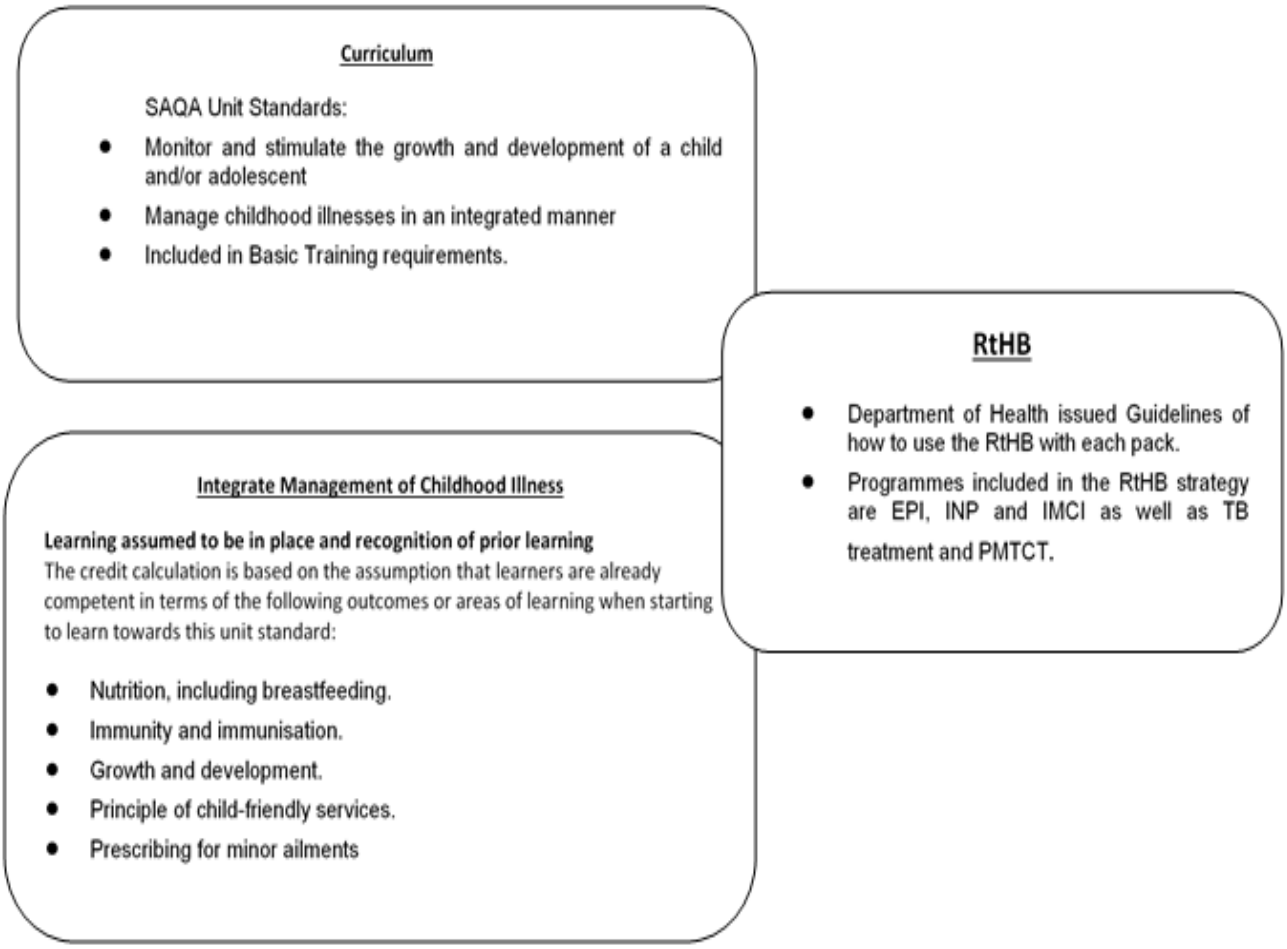
- Nutrition, including breastfeeding.
- Immunity and Immunisation.
- Growth and development.
- Principal of child-friendly services.
- Prescribing for ailments.

Thus Nurses, who have received training in IMCI should have a basic foundation of child development. The IMCI is the primary child-care approach of choice in South Africa(65). All RN working in PHC facilities received 11 days training on the strategy, which includes both initial skill acquisition and skill reinforcement(64).

This strategy is furthermore based on human rights to essentially attempt to improve health of all children younger than five by addressing the knowledge gaps, skills, and community practices regarding children’s health(66). The IMCI strategy in South Africa is utilised by doctors, nurses, and other healthcare professionals who consult sick

children and infants(64). The guidelines provided by the DoH, the curriculum and the IMCI are all attempts to equip nursing staff with the foundation for developmental screening of children attending PHC facilities.

Summary of child development integrated into the nursing curriculum, IMCI, and RtHB in South Africa



Source: *Information derived from (35-38) and formatted.*

Co-ordination of health systems in the early identification of developmental delays

Several studies conducted in developed countries have found that early detection of developmental difficulties is possible because developmental surveillance is an important part of the health care system(13). These countries have also linked early detection services to early intervention services(13).

A functional healthcare system should be supported by appropriate policies; guidelines; monitoring and evaluation tools; and well-trained and equipped staff. According to the WHO, most LMICs do not have a model for the (I) promotion and monitoring of the development of children, (II) prevention and early identification of risk factors associated with developmental difficulties or disabilities and (iii) early interventions(14).

Early identification of childhood disabilities in South Africa is straddled across the following three Government departments: the Department of Health (DoH) which covers the birth to 9 years of age cohort; the Department of Education (DoE) which is responsible for the 5-9 year old age cohort; and the Department of Social Development (DSD) which is focused on the birth to 4 year old age cohort (67).

The *White Paper on an Integrated National Disability Strategy* (INDS) recognizes that there are outstanding policies in a number of areas, particularly in the area of identification of disabilities(68). The INDS explains that policies aimed at prevention of disabilities do not have clearly demarcated links to identification and early intervention policies(68).

It is clear that for effective early identification of childhood disabilities to occur, these three departments will have to work in close collaboration with each other. The evidence suggests that there is a lack of integration of knowledge, as well, as formal implementation of policies within the governmental departments, which has led to a lack of integrated ECD service planning and delivery for the full development of the child, including the child living with a disability (69).

The programmes that are closely linked between the three departments are specifically tailor made for children of school going age. It also accentuates that although South Africa has a constitution embracing children and CWD's rights, ratifications with international bodies, specific programmes linked to mother and child mortality and Early Childhood Development (ECD) programmes, its' current focus is not on ensuring an effective early identification programme of developmental delays.

The National Workshop for developmental screening group outlined criteria for developmental screening in South Africa(33). This group recommended that any

developmental screening tool should only be used if there are appropriate interventions, management continuums, and clear referral strategies(33). Furthermore, they emphasised that caregivers should be part of developmental screening(33).

The Western Cape Province adopted the developmental screening program as a formal policy in 1999, which includes developmental screening at 0-6 weeks, 9 months and 18 months of age(33). An evaluation conducted in 2001, discovered that only one in nine facilities were following the protocol for the developmental screening(33). The barriers revealed in this evaluation were not unique to policy implementation in South Africa. Barriers identified were inadequate training of nurses, unclear referral protocol, incorrect referral practice, and lack of availability of intervention programs(33). It was also evident that the results of the screening tests were poorly documented on the RtHC(33).

Access to early intervention services in either public or private sector can be through various channels such as, self-referral, referral from other organisations, other health or education professionals, or through existing intervention programmes usually based at tertiary level health facilities(70). In rural parts of South Africa access to required specialists are even more difficult where families may travel for two days or more to get to a clinic and where chances are that the required specialist might not be available on the day of their arrival (70, 71). In addition to this, lack of clear hospital policies and protocols can further restrict access within institutions(70).

Re-engineering of PHC in South Africa

PHC is well recognized as the most cost-effective strategy for delivering essential health interventions(72, 73). According to the Declaration of the Alma-Ata, PHC, “addresses the main health problems in the community, providing promotive, preventive, curative, and rehabilitative services accordingly…. [it] relies, at local and referral levels, on health workers, including physicians, nurses, midwives, auxiliaries, and community workers as applicable, as well as traditional practitioners as needed, suitably trained socially and technically to work as a health team and to respond to the expressed health needs of the community” (74).

The PHC system in South Africa opened up opportunities for more communities and individuals to access health services. The PHC Facilities Survey 1998 and 2000 stated that there was an improvement in emergency vehicle response times, antenatal services, and the daily immunisation programs for infants and children signifying an improvement in health care services in rural and urban areas(75).

Despite these improvements on the PHC level in some areas of service delivery, Tertiary hospitals remained overburdened(43). According to Mohapi & Basu, patients are not entering the health care system at PHC level resulting in tertiary hospitals continuing services for primary, secondary, and tertiary care(76). This leads to poor quality of care for patients and over-expenditure of resources(76). In addition, the capacity for evaluating neurodevelopment of children in many LMIC's, including South Africa, is poor due to a limited number of specialist healthcare professionals especially in rural area(77).

In order to address various challenges in the PHC system, the Minister of Health adopted the Brazilian Family Health Programme in 2011(78-80). This programme demonstrated increased access to healthcare and improved health outcomes for a substantial amount of their population(81). The South African government inspired by the success of the Brazilian model formulated a PHC re-engineering strategy in 2011(79-81).

This strategy prioritises four streams; namely: (i) Ward- based PHC Outreach teams (WBOT's), (ii) Enhanced School Health Services, (iii) District Clinical Specialist Teams (DCST's) supporting maternal, neonatal, and child health services, and (iv) contracting private General Practitioners to provide public services(78).

The PHC re-engineering strategy entailed each municipal electoral ward to deploy WBOT's with an average of one team per 1500 households(78). The WBOT's role is to strengthen health prevention and promotion and secondly, to identify and support vulnerable individuals and families(78). Each team should consist of a Professional Nurse, five to six Community Health Workers (CHW's), as well as a health promoter, and an environmental health practitioner(78). The Department of Health decided to formalise the training of CHW's to ensure that all are similarly trained and have a clear and standardised scope of work ensuring that they integrate into the district health

system(78, 80). However, there is no mention of screening as part of the CHW's responsibilities(25).

The North West Province(NWP) was one of the earliest to implement the WBOT strategy and is regarded as one of the provinces that made the most systematic and sustained progress in implementing PHC outreach teams(82). In 2015 the NWP had a coverage of 72.6% of wards with at least one WBOT team(83). The NWP began implementation in 2011 with a pilot of 24 WBOT's with at least one team in each of the sub-districts(78). A number of evaluations have been conducted to document the unfolding implementation of the WBOT's in the NWP(82, 84-87). The NWP recorded improvements in a number of PHC coverage indicators, such as early antenatal booking and vitamin A coverage possibly influenced by the WBOT's(78). In contrast these improvements were also documented in other provinces who had lower levels of WBOT coverage and which furthermore could have been affected by other interventions such as the DCST's(78). The great investment in WBOT's has introduced an increased need to assess the impact and contribution of these teams to the PHC outputs and health outcomes(78).

The current PHC system is invaluable as a potential environment for developmental surveillance and screening(43). In addition, the well-child clinics provide a platform for periodic evaluation of a child's development(88).

According to Scherzer, all levels of specialities of health care workers who provide treatment for children in South Africa should be aware of children's development and behaviour by means of regular developmental surveillance and timely referrals to allied healthcare professionals when delays in development are detected(54).

However, this remains a challenge against the backdrop of staff shortages especially in rural areas in South Africa. Although health worker density in South Africa has increased steadily since 2000 and already meet the WHO targets, a minority of doctors and nurses are working in PHC facilities, with rural areas experiencing the greatest shortages of qualified staff(72, 73). According to Wilcox 2015, unless funding is secured to recruit and retain staff in these areas, training programmes will not improve health worker density because trained staff will continue leaving to work in more resourced areas(72). Another study conducted found that healthcare workers

movement was more influenced by high stress levels and low work satisfaction than under-compensation(89).

Developmental assessments are currently not being routinely carried out at PHC level(25). The shortages of appropriately skilled staff and resources to conduct assessments and provide follow up care are further challenges experienced(25). Currently, rehabilitation services are few and not available at over 70% of public health facilities in South Africa(25, 90).

Early identification of developmental delays is a complex system which requires high-quality assessments by trained professionals; effective information sharing and collaboration by practitioners, working with parents to develop joint action plans; locating needed services within and outside the clinic or hospital, arranging successful referrals and conducting on-going monitoring and evaluation of intervention(25, 70).

In conclusion, major barriers in the monitoring and surveillance system in South Africa are as follows; a lack of leadership, poor collaboration between the various government departments, the lack of regulation concerning provision of private healthcare services, and the absences of a national database on children at risk for developmental delay and children with established disabilities(70).

Furthermore, the absence of clear protocols, the low priority status of child development with nursing and medical professionals, as well as the variations in families access to health services due to financial, geographical, transport, and other constraints, make it difficult to ensure that children's development is monitored effectively(70). Professional and political forces in the public health care sector need to be mobilized to monitor, and where necessary, intervene to improve child development in order to ensure that early childhood development becomes a priority (91).

Factors contributing to early identification of developmental delays in children

According to Peters et al., people in poor countries have less access to healthcare services than those in richer countries, and within these poor countries, people from a low socioeconomic background have less access to healthcare services than better-off citizens(92, 93). According to the WHO, Africa has the greatest disease burden of any continent and the poorest health services (94-96).

The Healthcare system is often the only system that can hopefully reach all young children and their families(13). Over the past seven years, nurses have been tasked with using the RtHB Developmental screening tool when children visit the PHC clinics for their immunisations or other check-ups.

However, there has been a reduction in the number of nurses and the demands experienced by nurses in rural areas are profound(23). A study conducted in 2008 found that the emotional and physical strain experienced by nurses in rural PHC facilities became barriers to effective provision of high quality care and created tension between the nurses and their clients(23). This study also revealed that newly qualified nurses were forced to run facilities independently without the necessary years of experience(23). Studies conducted by Rising, Baron & Averill; and Babes & Sarma reported that health practitioners may shorten their service time (in some cases without being aware) when there are many patients waiting to be attended to (97, 98). Concerns such as these, provide reasons why nurses in PHC settings in rural areas could not be prioritising the early identification of developmental delays.

To further exacerbate the problems faced in South Africa's healthcare system is the migration of health professionals to wealthier countries seeking better employment opportunities(70, 99). This results in the children who are need the services the most, especially in poor rural areas of the country, having little or no access to these services(70).

The important role of tools is acknowledged in identifying children with developmental delays. However, the wisdom needed to apply these in settings where specialized training is not widely available and contacts with health services are limited is highly questionable(42). This opens up an opportunity to explore how parents, caregivers or Community Health Workers (CHW) are currently engaging and assisting in early detection of CWD.

Parental Challenges

According to Guralnick, infants receiving early identification services make greater progress following early detection by means of developmental screening and/or surveillance as first point of access when the whole family is involved(100). Health care providers consider parents a good resource when conducting screening tests

because they are usually the first to identify their children's developmental difficulties(46). However, parents or caregivers may face various challenges in accessing services.

Despite South Africa being relatively well off, compared to neighbouring countries, poverty is still a big challenge for a large majority of the population and universal and equitable access to health care is still out of reach(93). Rural areas in South Africa still tend to be the most under-served and historically neglected(101). Almost 40% of the South African population live in rural areas(102). Lack of visible improvement after therapy and cultural belief systems may influence the decisions of people using health care services(93, 103).

Communities across Africa view people with disabilities negatively because they believe that it is a punishment from God and is of a spiritual nature(104, 105). Perceptions like these can prohibit families from accessing healthcare services or seeking help when they become aware of developmental difficulties.

Guralnick highlighted the lack of focus on assessment of stressors affecting parents, such as, information needs, interpersonal and family distress, resource needs, and confidence threats(70, 106). Environmental conditions such as poverty, HIV/AIDS and risks associated with childhood disability provide a favourable environment for the development of stressors which may impact family patterns of interaction(106).

Conclusion

In conclusion, lack of early identification and implementation of appropriate treatment regimens for children have been problematic in developing countries. As the population of CWD in LMICs increase, more planning and practice of healthcare systems are needed(13, 15). Unfortunately, due to the lack of epidemiological studies the true prevalence of disability in South Africa is unclear.

The need to understand the complex system of developmental surveillance and developmental screening is becoming increasingly urgent in South Africa. Especially because of the limited research available in South Africa on the improvement of early detection of developmental delays amongst infants and children through the use of or implementation of developmental surveillance and screening tools(49-51).

The RtHB has been used as a monitoring tool in South Africa since 2010. It is therefore of utter importance to attempt to understand the challenges facing the Nursing Cadre who are administering this tool in South African communities. This study attempts to explore factors associated with the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in PHC facilities.

1.3 Problem Statement

A study conducted in 2001 to evaluate the progress of the developmental screening programme that was adopted as a policy in the Western Cape found the following:

- Recording of developmental screening results was poorly conducted and not according to the protocol.
- Referrals were not conducted according to protocol, 30% of children in the Western Cape were still being referred to Tertiary Institutions and standard referral forms were not being used.
- Minimal children were being identified with developmental disability and accessible intervention by rehabilitation services was problematic(33).

Unfortunately, this is the only study conducted in South Africa to date that gives an indication of the challenges faced in implementing a developmental screening programme that has been adopted as a policy in South Africa. Although this was only conducted in the Western Cape, it gives us a guideline into the challenges other provinces could be facing and the reason behind the poor early detection of children being identified at schools, such as Nokuthula Special School in Gauteng. The author has anecdotally, but frequently observed many examples of poor early detection at Nokuthula Special School over the past five years.

The abovementioned study, however, did not explore or highlight any challenges faced by the nurses that could have resulted in the poor recording of the developmental screening results or the lack of adherence to protocol and the minimal children being identified with developmental disabilities. A tool on its own cannot tell a complete story and thus it is utterly important to explore any challenges surrounding the implementation of the screening tool by the nurses to further understand the complexities that need to be dealt with around this subject.

1.4 Study Justification

Early identification of children below 3 years of age with disabilities has become a high priority for the WHO lately, especially because it can lead to a reduction in the impact of impairments(15).

Despite various policies available in South Africa for children, screening and early intervention is not directly mentioned in any local legislative provision (107). The right to basic health care in the Constitution and the best interest of the child standard in combination is the closest link to the right to early screening and identification of services(107). This is further complicated by the lack of implementation of a national screening programme (108, 109).

Although a developmental screening tool was included in the RtHB, the correct implementation and efficacy has not been explored. Studies conducted in 2003 revealed the lack of availability of developmental screening tools and their implementation in public hospitals in South Africa(33). Nursing staff are the backbone of health services in South Africa and constitute more than 60% of health professionals and about 10% of the total civil service in South Africa(110). They are pivotal and necessary in discovering the existing challenges in the health system to identify early developmental delays and disabilities.

The benefits of early identification of children with development delay or disability have been well documented. These benefits include the correct provision of intervention, adaptation to minimise the disability and the provision of social and emotional support to the family(111). In contrast, there can be long-term disadvantages and high costs to the absence of early identification and intervention of disabilities in children(11). It is vital that early identification consists of collaboration between families, communities, health professionals, department of health, department of education, department of social services, and the ministry of women, children, and their disabilities.

As research is limited in the area of improving the early identification of children under the age of five years, through developmental surveillance or screening tools in South Africa, this study aims to explore factors associated with the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in PHC facilities.

Other factors to be explored are the different types of screening tools and screening models used, embracing the family or community in early identification, cultural influences and differences, and the co-ordination between all key role players.

1.5 Aims and Objectives

1.5.1 Study Aim

To explore Registered Healthcare Nurses perceived factors currently affecting the early identification of developmental delays in children aged 0-5 years in selected facilities in Bojanala District.

1.5.2 Research Question

What do Registered Healthcare Nurses currently perceive as factors affecting early identification of developmental delays in Primary Health Care facilities in Bojanala District?

1.5.3 Study Objectives

1. To describe how developmental delays are currently detected in PHC facilities by Registered Healthcare Nurses in the Bojanala District.
2. To understand how the co-ordination of the health system in Bojanala District currently affects the early detection of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Primary Healthcare Facilities.
3. To explore the factors currently contributing to the detection of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Primary Health Care facilities in Bojanala District.
4. To make recommendations to enhance the early identification of developmental delays in children aged 0-5 years by RN in Primary Health Care facilities in Bojanala District.

CHAPTER TWO

METHODOLOGY

2.1 Introduction

This chapter focuses on the methodology used to conduct this study. The study approach is discussed followed by the participant selection criteria. Thereafter data collection method, the instruments used and the data collection procedure are explained. The pre-testing of tools and data management are discussed followed by data analysis. Finally, this chapter ends with the ethical considerations of the study.

2.2 Research Design

A qualitative research design was used for this study. Qualitative Research is interested in explaining how people make sense or meaning of their experiences and the views of the world (112). Qualitative methods produce a wealth of detailed data using a much smaller number of people and cases(113). It provides depth and gives a voice to the issues experienced by the study population, namely, like in this study the Registered Healthcare Nurses in the PHC Facilities(114).

In-depth and semi-structured interviews were the methods used to gather data from the KI and participants, respectively. According to Kvale, qualitative research interviews seek to describe the meaning of central themes in the world of the subjects(115). The main purpose in interviewing is to gain an understanding of what the interviewees are saying(115). Kvale further expands that qualitative research interviews seek to explore at both factual level and meaningful level, though it is more difficult to interview on a meaning level(115). Interviews allow an interviewer to purse in-depth information around the topic(115).

The study design chosen allows for an in-depth understanding of the perceived factors affecting early identification of developmental delays in children by the Registered Healthcare Nurses in the selected PHC Facilities.

2.3 Selection of study sites

Districts

Purposeful sampling was used to select the two participant sub-districts. Purposeful sampling is used when one wants to understand something about certain cases without needing to generalize these cases(116).

The North West Province in South Africa has four Districts. The study was conducted in the Bojanala Platinum District because the researcher had been working with a local community called Kgabalatsane over the past three years as part of the Masters in Public Health, Rural Health requirements.

The Bojanala District has approximately 1,3million people, the largest population in the North West Province(117).The district has five sub-districts, namely; Kgetleng (four PHC), Madibeng (17 PHC), Moretele (17 PHC), Moses Kotane (34 PHC), and Rustenburg (16 PHC). The majority of the district has been classified as rural according to the Department of Health's District profile(117). Rustenburg has been classified as the more urban district and Moses Kotane as the more rural sub-district. These two sub-districts were purposefully selected for the purposes of this study because of their contrasting urban and rural elements.

Clinics

Convenience sampling was used to select the clinics in each sub-district. Ten clinics were needed in total so that one RN could be selected at each clinic. In order to select five clinics in each sub-district, convenience sampling of appropriate PHC Clinics was conducted to ensure that clinics offering immunisation to infants at six, ten and fourteen weeks were a prerequisite.

2.4 Sampling Technique

2.4.1 Study Population

The study was designed to gather data from two different populations. Sampling was conducted purposively. Purposive sampling can ensure that in-depth information is received from information rich individuals for a specific subject(114).

The first population consisted of KI encompassed any Health Professionals who had a sound knowledge in the subject of early identification and preferably access to the field of early identification and screening processes in the public health sector in South Africa. These three individuals ranged between Speech Therapists to Doctors or Occupational Therapists. Health Professionals needed to be registered with the Health Professionals Council of South Africa (HPCSA). Snow balling or word of mouth technique was used.

The second study population consisted of RN based in PHC Expanded Immunisation Clinics in the sub-districts of Rustenburg and Moses Kotane. The RN should be working at the facility for a minimum of two years. The researcher believes that a minimum of two years working experience in the field will equip the Registered Nursing staff to have a good understanding of the healthcare system and the community they are serving. Registered Nursing Staff needed to be registered with the South African Nursing Council (SANC).

The researcher approached the participants deliberately to ensure getting the perspective of RN working in the Immunisation clinics. Purposive sampling accommodates the specific selection of participants based on the criterion the researcher considers to be appropriate(118).

2.4.2 Sample Size

A sample size of three Key informant participants was decided upon to inform the study. If saturation was not reached, more Key Informants (KI) would have been included. However, it was not necessary after the conclusion of the third interview; saturation of the data was reached.

A sample size of 10 participants for the second population was included in the study as this is viewed as an acceptable size for a qualitative study(119). The researcher interviewed ten participants individually. A maximum of one participant was interviewed at each clinic.

2.5 Participant Selection

As indicated earlier there are two groups of participants that were interviewed, namely KI and RN. A set of criteria is used by researchers to determine whether participants are suitable for a study (120).

2.5.1 Participant selection criteria used to select KI for the study

- Health Professionals currently registered with the HPCSA.
- Health Professionals who are identified by their colleagues as knowledgeable about early identification and screening in the public health sector in South Africa.
- Health Professionals who are identified by their colleagues as having access to the field of early identification and screening processes in the public health sector in South Africa.

2.5.1.1 Description of Key informant participants

Table 1 below describes the three Key informant participants. Two participants were from the government sector and one participant from a South African tertiary institution. The three participants were from three different healthcare disciplines.

Table 1: Description of Key informant participants

Profession	**Highest Qualification**	**Role in Early Identification of developmental delays in South Africa**
Physiotherapist	BSc (Physiotherapy)	-Development of early intervention programmes. -Division of Community Paediatrics at Tertiary Institution. -Part of teams working on ECD Policy, diagnostic review of early childhood development. -Provincial work on ECI (early childhood intervention) and ECD (early childhood development) agenda.
Speech-Language pathologist	-Degree in Remedial education	-Part of teams working on ECD Policy, Provincial work on ECI (early childhood intervention) and ECD (early childhood development) agenda.

	-Masters in Speech Therapy -Masters in Remedial Education -Masters in ECI -PHD in ECI	
Developmental Paediatrician	-MBChB -Diploma in Developmental Paediatrics	-Head of Paediatrics Department at Public Hospital. -Special projects early childhood stimulation and long term effects thereof.

2.5.2 Participant selection criteria used to select Registered Healthcare Nurses for the study

The participants were selected from Registered Healthcare Nurses who work in PHC in the Rustenburg and Moses Kotane Sub-districts.

- Nurses who have undergone either a Degree or Diploma course in General Nursing, Midwifery, or Community Health Nursing and have obtained practicing licence or registration with SANC
- Registered Healthcare Nurses who were currently registered with the SANC.
- Registered Healthcare Nurses who have been working at the current facility for a minimum of two years.

2.5.2.1 Description of Registered Healthcare Nurse Participants

Table 2 below describes the participants in the urban setting and Table 3 describes the participants in the rural setting. Ten Registered Healthcare Nurses participated in this study. The participants included five participants from urban located clinics and five participants from rural located clinics.

Participant **MOS1's** data was not included in the study because they did not meet the selection criteria of two years PHC experience. This was the only Registered Healthcare Nurse available at the clinic on the day.

Table 2: Description of Registered Healthcare Nurse participants in urban settings

Participant	Years of experience in PHC setting	Highest Qualification	Year of Graduation	Additional Training
RUS4	5 years	Diploma in Comprehensive Nursing	1996	Currently, specialising in Primary Healthcare Diploma in Midwifery
RUS5	2-3 years	Professional Nurse/Midwife	1996	None
RUS1	10 years	Professional Nurse/Midwife	1997	Diploma in Midwifery
RUS2	4 years	Professional Nurse	2012	PC101
RUS3	15 years	Professional Nurse	2003	Diploma in Midwifery

Table 3: Description of Registered Healthcare Nurse participants in rural settings

Participant	Years of experience in PHC setting	Highest Qualification	Year of Graduation	Additional Training

MOS2	32 years	Professional Nurse/Midwife	1988	Higher Diploma in Community Nursing Primary Healthcare in Nursing
MOS3	29 years	Professional Nurse/Midwife	1989	Primary Healthcare in Nursing B.Ed Admin Community Health Nursing
MOS4	29 years	Professional Nurse/Midwife	1994	None
MOS5	20 years	Professional Nurse/Midwife	2009	Primary Healthcare in Nursing

2.6 Data Collection Method

2.6.1 Data Collection for KI

As research is limited in the area of improving the early identification of children under the age of five years, through developmental surveillance or screening tools in South Africa (4, 11, 15, 42), three KI were used to ensure that the interview guide for the Registered Healthcare Nurses would be able to extract the correct information for this study. Individual in-depth interviews were used to gather information from the KI regarding best practice for early identification in the PHC setting and progress made in this area regarding policy development or best prescribed screening tools.

The KI data was used as an information guide to formulate the interview guide and provide parameters for the study, and not as data to inform the study. The role of the KI were to provide clarity of definition, provide a reference standard to differentiate study participants one from the other and to enrich the discussion of the study results for consideration of the literature and Key Informant input.

Individual in-depth interviews were used to gather information from the KI regarding best practice for early identification in the PHC setting and progress made in this area regarding policy development or best prescribed screening tools. Two of the interviews were held at the location of preference of the KI and one interview was held telephonically due to the distance of the Key informant at the time.

The Key informant interviews were conducted over a period of four weeks due to the availability of the participants. Three KI were interviewed individually using the interview schedule for KI (Appendix 2).

2.6.2 Data Collection procedure for the Key informant participants

1. The researcher submitted the research proposal to the University of Witwatersrand Human Research Ethics Council (HREC) and a provisional ethical clearance was obtained (Appendix 4).
2. The researcher submitted a letter of request to the North West Provincial Department of Health to conduct the proposed research study in the Bojanala District (Appendix 5).
3. Thereafter provisional Ethical clearance was obtained from the North West Provincial Department of Health (Appendix 6).
4. The researcher submitted the North West Provincial Department of Health's provisional ethical clearance letter to the University of Witwatersrand HREC. Thereafter ethical clearance was obtained from the University of Witwatersrand HREC (Appendix 7).
5. The researcher then submitted the University of Witwatersrand HREC clearance letter to the North West Provincial Department of Health upon which ethical clearance was obtained to conduct the study in the North West Department of Health, Bojanala District (Appendix 8).
6. Only, once full clearance was confirmed was the researcher able to contact people to assist in finding the appropriate KI for the study. The researcher started at the University of Witwatersrand Occupational Therapy Department and from there the researcher was directed to different people who could be possible KI.
7. The researcher emailed every lead that was given. After emailing and having eight telephonic conversations the researcher found three suitable participants who were eager to participate in the study.

8. The researcher emailed an information sheet (Appendix 9), consent to participate in the study (Appendix 10) and consent to be audio recorded (Appendix 11) to the participants one week prior to the agreed telephonic interview or face-to-face interview.
9. The participants returned these aforementioned documents one day prior to the interviews.
10. Two of the KI were interviewed individually in a private room secured by the KI. One key informant was interviewed telephonically.
11. All three interview sessions were recorded and transcribed verbatim by the researcher. After transcribing was completed by the researcher the transcriptions were verified and checked for corrections by an independent colleague of the researcher. All the results were analysed.
12. These results were used to inform and make corrections to the interview guides for the Registered Healthcare nurse participants (See Table 5).
13. These results were further used to inform the results of this study.
14. A final report was compiled.

2.6.3 Data Collection for Registered Healthcare Nurse Participants

Semi-structured interviews were used to gather data from the Registered Healthcare Nurses on the factors affecting the early identification of developmental delays in children aged 0-5 years in PHC. Semi-structured interviews allowed participants adequate flexibility in sharing their experience and opinions about a topic(121). The interviews took place at the clinics at which the Registered Healthcare Nurses were employed due to convenience. The participants informed the Researcher of suitable times to participate in the study, and this was agreed and adhered to. Ten Registered Healthcare Nurses were interviewed individually using the interview schedule for Registered Healthcare Nurses (Appendix 3).

The interviews happened over a period of one week in September 2016 for the Urban Sub-district and the interviews for the rural sub-district occurred over a period of one week in March 2017. Two of the Registered Healthcare Nurses declined to be audio recorded during the interviews and these interviews were not recorded. These were one participant from each sub-district respectively. However, the researcher received permission to take detailed notes during these two interviews.

Data collection began by identifying key areas and questions asked during the interview as explained below on Table 4. The interviews for the KI were approximately 45 minutes to an hour and half in duration and were recorded using a Dictaphone. The interviews for the Registered Healthcare Nurse participants were approximately 25 – 35 minutes in duration. Most of these interviews were more challenging for the participants due to long patient queues and shortage of staff at the facilities. A Dictaphone was also used to record these interviews. During the interviews the researcher established and maintained rapport by smiling, keeping eye contact, and using verbal, neutral encouragements (122).

2.6.4 Data collection procedure for the Registered Healthcare participants

1. The researcher submitted the research proposal to the University of Witwatersrand Human Research Ethics Council (HREC) and provisional ethical clearance was obtained (Appendix 4).
2. The researcher contacted the District Manager of Bojanala Platinum District requesting access to Rustenburg and Moses Kotane Sub-Districts. This permission was granted verbally.
3. The researcher then sent an email to the sub-district managers of Rustenburg and Moses Kotane sub-districts requesting permission to conduct the research study in their sub-districts. Both sub-district managers requested a personal meeting before any permission could be granted.
4. The researcher was given two separate appointments to attend an interview session with the sub-district managers of the aforementioned sub-districts. The researcher attended both these meetings and subsequently permission was granted to access the sub-districts.
5. Once permission was granted, the sub-district managers informed the Clinic Managers that the researcher would be visiting their clinics during the stipulated and agreed time and that access should be granted to the researcher to conduct the interviews.
6. The researcher visited every clinic a day prior to the interview to meet the Clinic manager and to leave an Information Sheet (Appendix 12) for the Registered Healthcare Nurses that would be interested and available to participate in the study.

7. The following day the researcher returned to the clinic and asked RN who received the information sheet if they would be interested in participating in the study. All participants approached, agreed to take part in the study.
8. All participants were required to fill out a permission to participate in the study (Appendix 10) and consent to be audio recorded form before the interview was conducted (Appendix 11).
9. The Registered Healthcare nurses of each clinic were interviewed individually in a private room allocated by the Clinic Manager (Appendix 3).
10. Eight interviews were recorded and transcribed verbatim by the researcher. After transcribing was completed by the researcher the transcriptions were verified and checked for corrections by an independent colleague of the researcher. Two interviews were not recorded but detailed notes were taken during the interviews. All the results were analysed.
11. A final report was compiled.

2.7 Data collection instrument

2.7.1 Procedure for the Formulation of Data Collection Tool

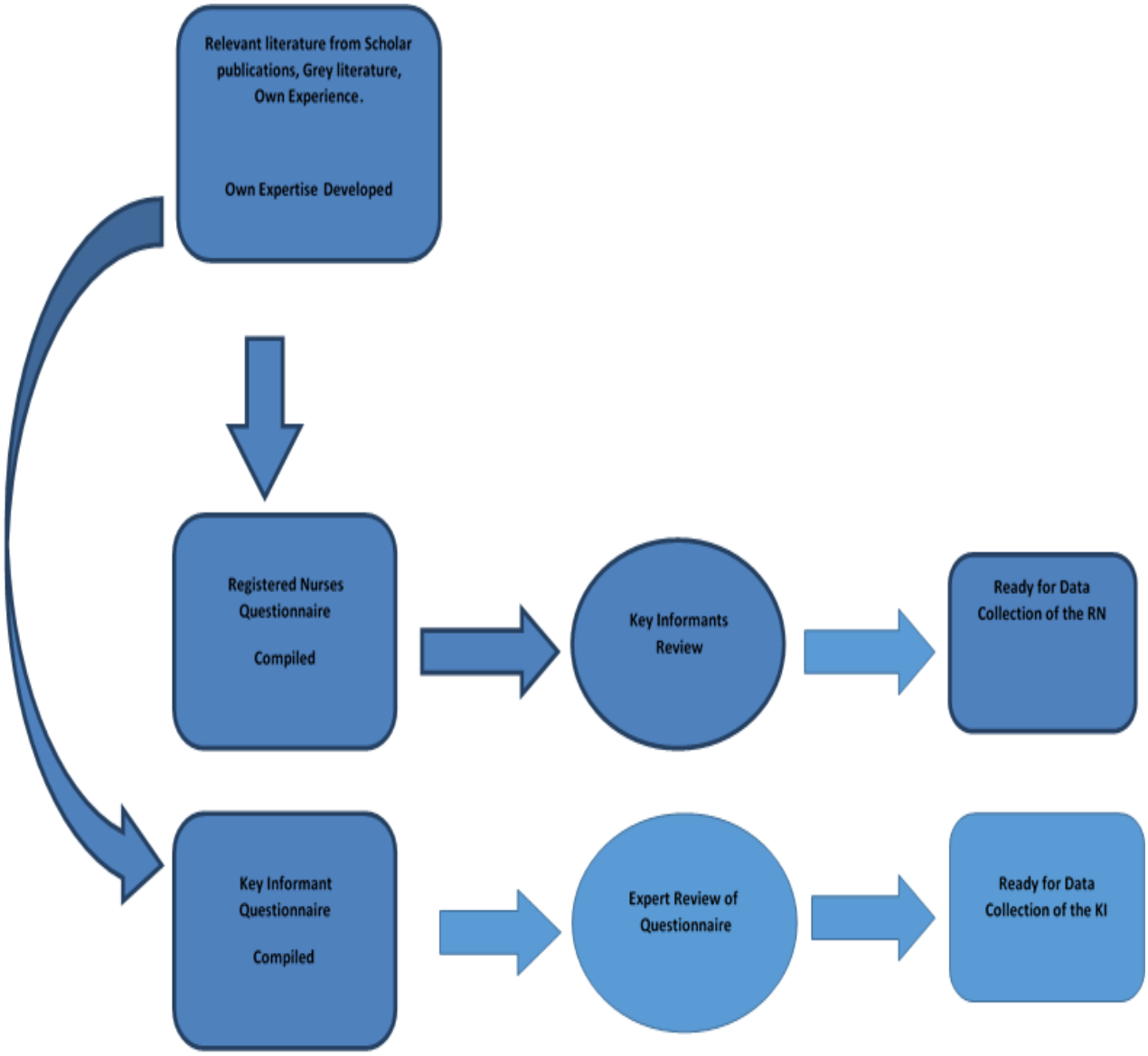


Figure 3: Diagram showing procedure for the formulation of interview Guide.

2.7.2 Data Collection Tool

The instrument used for data collection for both the KI and the Registered Nurse participants was an interview schedule.

Open ended questions were used to ensure specific intent (123). The specific areas, the number of questions, and the evidence for including these areas are provided below on Table 5, in Chapter 3.

2.8 Pre-Testing of Tools

2.8.1 Expert Review

An expert review of the Key Informant interview guide was conducted telephonically. The researcher contacted one of the health professionals who was listed as a possible Key Informant but who could not be part of the study due to time constraints.

Permission was granted for a 20 minute telephonic interview to guide the researcher on the interview guide for the KI. The expert reviewer agreed and the key informant interview guide (Appendix 2) was emailed to the expert reviewer one week prior to the review. During the telephonic conversation the reviewer shared that no alterations were needed and thus none were made prior to the interviews held with the KI.

2.8.2 Alterations to the interview schedule for the Registered Healthcare Nurses

The Key Informant information collected during the interviews was used to correct and guide the registered healthcare nurses' interview guide.

Table 4: Alterations to interview schedule after Key Informant interviews

Area	**Change Required**	**Amendment**
Length of interview	None	None
Clarity of questions		
Original Question 5:	**Question 5:** Simplifying the question or divide it into two questions.	**Question 5:** Please describe the challenges you experience using these screening tools?
Ki1: So I would ask that question separately. You know so if you were to ask…. Ask about challenges and then ask what makes it easier.		
Question 1:	**Question 1:** Prompt to be given by Researcher for developmental delay.	**Question 1:** The term developmental delay had to be prompted or guided without influencing the participant
Ki1: And but also some of the things they were asking I think was, was a level too high. **Ki1: So if you are now asking it's also that thing about the level at we are pitching it**		

2.9 Data management

The audio recordings and back-up documents of the KI' and the Registered Healthcare nurses' interviews are kept in a lockable safe at the researchers' place of residence and are password encrypted for a period of two years. It will be destroyed thereafter.

The transcriptions are also held in a lockable safe for two years and does not have any names of the individuals who participated in the study attached(124). After a period of two years all written data pertaining to the study will be destroyed by shredding(124).

2.10 Data Trustworthiness

Data trustworthiness involves assessing any or all five alternatives, which are credibility, conformability, dependability, transferability, and authenticity(125). Four of the above were assessed in the present study. The following perspectives for establishing credibility, conformability, dependability, and transferability were observed:

-Credibility- The interview guide was designed based on objectives of the study. Knowledgeable experts who did not form part of the study participants reviewed the interview guide. Prolong interview with KI was also conducted. Responses from the pre testing of the interview guide by experts and from the study KI were checked and used to inform the final version of the RN interview guide. The researcher conducted the interviews without the aid of any research assistant. The researcher is confident in the truth of the data and the findings presented.

-**Conformability**-Interviews were recorded and or written down.

As such there is evidence of agreement between the interpretation or presentation of findings and the actual data collected. All findings for the study were only withdrawn from the data and not the interviewers' views concerning the investigation. Peer review of the meaning and relevance of the findings of the data was conducted.

-**Dependability**: Study design was clearly stated. Interviews as the only method for data collection were also clearly stated.

The selection and inclusion of KI and RN was clearly stated. As such if this study is repeated by another researcher at any time with the same participants, the same data will be obtained.

-**Transferability:** It is worth mentioning that generalization is not considered viable in qualitative data due to the contexts in which the data collection occurs. However, the use of purposive sampling technique in the present study addresses the issue of transferability since information obtained was maximized because data was collected from experts and nurses. The factors influencing the early identification of developmental delays in children identified in the present study could be generalized for nurses in PHC settings in South Africa.

2.11 Data Analysis for KI and Registered Healthcare Nurses

Thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within data(126). It minimally organises and describes your data set in (rich) detail. However, it also often goes further than this and interprets various aspects of the research topic(126). Thematic analysis offers a more accessible form of analysis for the novice qualitative researcher(126).

According to Braun and Clark themes or patterns can be derived in two ways, inductively or deductively(126). Inductive coding means the researcher can link the themes strongly to the data itself (127). Inductive analysis is a process of coding the data without making it fit into preconceived frames(126). Deductive coding is more analysts driven and provides a more detailed analysis of some aspects of the data(126). Coding can either be done manually or through a software programme(126). The researcher coded manually.

The researcher followed the steps below to develop themes and sub-themes for both the KI data and the RN data:

Step 1: The researcher transcribed all the interviews verbatim and made notes during this process that was used later during the coding process. The process of doing the transcriptions assisted the researcher to become more familiar with the data.

Step 2: The researcher then read and re-read the transcripts to familiarise herself with the data. At this point the researcher identified statements that related to the topic, and initial codes were identified.

Coding ensued with the researcher reading and re-reading the data to identify important and common themes related to the main aim of the study. The study objectives guided deductive coding, and the researcher searched for opportunities for coding inductively any new data surfacing during the study. The researcher separated relevant and irrelevant information from the interviews by cutting and pasting the relevant information from each interview together. The researcher then broke down the relevant information into smaller segments (e.g. sentences or phrases) that each reflected a specific thought pattern. The researcher systematically went through each key informant data set, highlighting interesting aspects and cutting and grouping the data together under a relevant code. The researcher used Microsoft Excel for the RN Participant transcripts and manual cutting and pasting into a code book for the KI.

Step 3: After collating all the initial codes the researcher started searching for common themes. The researcher sorted similar codes into potential themes and thereafter looked for relationships between themes on all levels. At the end of step 3, the researcher had collated themes and sub-themes according to the three researcher aims.

Step 4: During this step the researcher reviewed all the themes and checked whether they were relevant or not or needed to be sub-themes.

Step 5: During this step the researcher started defining each theme and ensuring that each theme was well defined and not repeated anywhere else.

After a set of codes had been established by the researcher, the data was checked by a fellow MPH VI student with whom the researcher established inter- coder agreement to code the themes, using the themes and definitions the researcher developed. This ensured consistency in coding. After establishing consistency the researcher established patterns and relationships across the themes.

This pattern continued by including the study aims, objectives and comparing the information collected from the KI and the RN. In order to ensure data trustworthiness, coding discrepancies were rechecked by the researcher.

The data was then interpreted and validated with findings from other published researchers before report writing ensued. Discussion of these findings will occur in Chapter 4 in order to relate the findings to the aim and objectives.

Theoretical sampling basically ended when any category ceased to produce new information and when the data was saturated.

2.12 Ethical Considerations

Ethics approval for this study was applied for from the Human Research Ethics Committee (HREC) of the University of Witwatersrand, South Africa were the researcher is currently a fourth year MPH student (Appendix 4). Thereafter the Researcher applied for Ethics clearance at the Provincial and District Research Council in the North West Province (Appendix 5 and 6).

2.12.1 Informed Consent

Prior to signing informed consent forms the researcher ensured that all participants knew that participation in the present study was strictly voluntary and participants were free to withdraw at any time it pleased them. The rights and welfare of the participants were first preference at all time during this study and therefore the choice to participate or not was given.

All participants invited to participate were given the full details of the study and only after this information was shared were they required to make a decision to participate or not (Appendix 9). They were then required to voluntarily sign an informed written consent which gave the researcher permission to interview them, as well, as to record the interviews (Appendix 10 and 11).

Two interviewees consented to take part in the study but they did not consent to be recorded during the interview. For these participants (MOS4 and RUS5), their responses were hand written by the interviewer.

Consent forms for KI were emailed to them prior to the telephonic interview and the researcher ensured that they were received back at least 24 hours prior to the scheduled interview.

2.12.2 Confidentiality

The Researcher acted with integrity, by being honest and collecting objective and accurate data. Participants anonymity was maintained and protected at all levels during the study and thereafter, as they received participant codes. Participants based at the clinics were assured that the information they shared would not be shared with

their managers or supervisors. Confidentiality was maintained at all times and at all levels during the research process. As indicated earlier all audio data, back up recordings and transcripts are kept in a lockable safe and destroyed two years after the completion of the study.

Results of the study were shared with the North West District Department of Health.

2.12.2 Beneficence

To ensure beneficence in the study the Researcher treated all participants equally by explaining the purpose of the study as detailed as possible, opening up the conversation to any questions and then ensuring that written consent was received from the participants before the study ensued. The Researcher also asked the participants if they were comfortable being interviewed in English and all participants agreed and assured the Researcher that they were comfortable being interviewed in English.

2.12.3 Non- Maleficence

The researcher observed non-maleficence by respecting those participants who chose not to be audio recorded during the interview. The researcher refrained from making further enquiries regarding the participants choice and instead immediately informed the participants that the only difference would be that the interview process might take slightly longer because the Researcher would be taking handwritten notes. The Researcher made the recorder visible to all the participants and showed those who chose not to be recorded that the recorder was indeed off. This helped set these participants at ease.

CHAPTER THREE

RESULTS

This chapter presents the results on how Registered Healthcare Nurses perceive factors currently affecting the early identification of developmental delays in children aged 0-5 years in selected facilities in B District. The researcher interviewed a total of 10 RN on 3 main areas which were; (1) Detection of developmental delays (2) Co-ordination of the health system and (3) Factors contributing to the detection of developmental delays. One Registered Nurse was excluded from the study because they did not meet the all the criteria.

The Key Informant data shaped the interview guide and therefore provides a framework for the discussion which will follow this chapter. Table 5, below, provides evidence of how the Key Informant data and the literature review provided a framework for the study participants interview schedule.

Table 5: Key Informant and Literature review evidence for including questions for the Registered Nurses interview schedule

Questions used in the RN interview schedule	**Evidence for including this area in the RN interview schedule**	**KI evidence for RN Interview Schedule**
Area: Early Identification		
Please share your understanding of developmental delays?	Clarity on definitions of disability will assist policy makers in ensuring that all disabilities are catered for in early detection programmes. However, a clear definition in the absence of a policy on early identification or a national programme to direct the early detection of childhood disabilities in South Africa, can have detrimental outcomes for CWD(23). Defining, conceptualising and measuring disability is a complex process, which has affected the disability data in South Africa(128).	Information received from all the KI confirmed that there is no consensus on the term developmental delays. KI1 explained "Developmental difficulties - it is a continuum or spectrum that children operate on that is developing normally and doing all the things you would expect at the times you expect". KI2 understanding of the term. "...Also involves developmental surveillance where child's development is monitored across all developmental domains like motor, communication, eating, and drinking."

		KI3 explained that "... It takes into consideration the four areas of development. It would also be necessary to determine if it is a global delay or a delay in only specific areas. Delay differs according to the age of the child."
What has your experience in providing care for child/ren with developmental delay/s been like?	Several studies conducted in developed countries have found that early detection of developmental difficulties is possible because developmental monitoring is an important part of the health care system(13).	KI noted that there is no formal way of doing referrals and feedback. "Referral process is non-existent."KI1 "It depends where you are in SA. Some provinces are underserviced. There is shortage of professionals to do the work. So it is important to train community health workers to do the first basic interventions."KI3 "It depends on the severity of the problem, if it is mild, the parents are advised and a follow-up is made every month or after six weeks. Or they get referred to a more specialized service depending on the child's need."KI2
Do you view developmental screening as part of your job description? Yes, how often do you do it? No, please share your reasons	The diversity of roles played by the nurse within the healthcare setting causes the role of screening for disability within a paediatric setting to be facilitated by the nurse(60).	The KI agreed that although everyone can be involved; no one is taking full responsibility. "Therapist does assist in some facilities... Community health workers have so much to do but have limited capacity because they might not have had training on child development or the training might not have been fit for purpose. KI1 "Doctors, therapists at PHC level would be good. Community outreach programmes to crèches, children homes or anywhere where a family with a child comes in contact with any kind of service provider be it education

		or health; screening should be done appropriately." KI2 "It's a trans disciplinary, social development and health. The community health worker." KI3
Please describe the tools or methods you use for screening developmental delays at your clinic?	Additionally only a few childhoods developmental assessment tools (CDATs) are available in LMICs(4).	According to the KI only the RtHB is being used; yet at the same time anything is being used. "Road To Health Booklet is the only one." KI1 "You can use the Road To Health chart……or a parent questionnaire."KI3
Please describe the challenges you experience using these screening tools.	A study conducted in 2014, revealed that the RtHB Developmental Screening Tool needed to be adapted or replaced, as it failed to identify more than half of infants at risk for developmental delays or disabilities within the PHC setting(43). This information is vital when exploring the factors affecting the early detection of developmental delays or disorders and could partially explain the poor reporting of disabilities in children under the age of five years(43).	The KI voiced that there are challenges around using this tool because from experiences, very few health chart of referred children with developmental delays were filled at the PHC level. "RTHB is the tool that is advisable but it is not being used because with most of my patients, that section is always empty and they confirm that no one ever asked about the child's development."KI2 "RTHB but to be honest, it is not being used. A study reported that only 30% are actually filled.." KI3 Main challenges they highlighted were shortage of nurses at PHC level, workload, attitudes and willingness to do screening. "Proper staffing and human resources and the willingness to do it.." KI3 "They were only trained on the changes with EPI and growth

		monitoring but not other things. It was not a priority."KI1 "So much is often expected from nurses."KI2
Area: Co-ordination of Health System		
Tell me about the particular protocol guide you use to screen the developmental delays at your clinic?	According to the WHO most low and middle income countries (LMICs) do not have a model for the i) promotion and monitoring of the development of children, ii) prevention and early identification of risk factors associated with developmental difficulties or disabilities and iii) early interventions(13). The *White Paper on an Integrated National Disability Strategy* (INDS) recognizes that there are outstanding policies in a number of areas, particularly in the area of identification of disabilities(68). The INDS explains that policies aimed at prevention of disabilities do not have clearly demarcated links to identification and early intervention policies (68).	KI were not sure about and existing policy guiding PHC Nurses at PHC settings to ensure the efficient detection of developmental delays. "..But there is nothing. Early intervention of developmental difficulties is in the ECD policy. None except the RTHB from the National and this book doesn't tell you how to do it."KI1 "I don't know if there are any specifically. KI2 "I am not sure. I checked some time ago online but it's not available. But surely, there should be a policy that would guide." KI3
Please tell me who is responsible for early detection of developmental delays at your clinic?	Nurses' basic training should equip them to recognise typical or delayed growth and development in infants in order to make the necessary referrals support the infants and their parents during intervention(59).	There is no existing norm but PHC nurses because they have primary contact with children like during immunization. "There is no norm." KI2 "Nothing that I am aware of." KI2
Please describe the process that follows once a delayed developmental milestone is	According to the WHO most low and middle income countries (LMICs) do not have a model for the I) promotion and monitoring of the development of children, II) prevention and early identification of risk factors associated	The KI highlighted different processes ranging from the non-existence of a referral process to taking into account the severity of the child's condition to the fact that some areas do not have specialist and therapist for such

detected at your clinic?	with developmental difficulties or disabilities and iii) early interventions(13).	children to be referred to. In addition, they noted that there is no formal referral system that PHC nurses do follow. "There is no mechanism." KI1 "None." KI2 "There is no formal way of doing referrals and feedbacks."KI3
Area: Factors contributing to the detection of developmental delays		
Please share specific context or situations that typically influence or affect your experiences of screening developmental delays?	There has been a reduction in the number of nurses and the demands experienced by nurses in rural areas are profound (23). A study conducted in 2008 found that the emotional and physical strain experienced by nurses in rural PHC facilities became barriers to effective provision of high quality care and created tension between the nurses and their clients (23). This study also revealed that newly qualified nurses were forced to run facilities independently without the necessary years of experience (23) Concerns such as these, provide reasons why nurses in PHC settings in rural areas could not be prioritising the early identification of developmental delays.	Key informant highlighted the need to train PHC nurses on how to use the screening tool in the RTH booklet. Currently, the focus is on health (weight –malnutrition) and not on development. Health education to pregnant mothers during ANC visit. Community sensitization. "Developmental delays are not a national priority." KI1 "PHC nurses don't get adequate assistance. They need training.." KI3 "Ensuring that nurses are trained to do screening." KI2
Please share your experiences with parental involvement regarding detecting developmental delays.	It is important to consider embracing the family or community in early identification, cultural influences and differences and the	There was consensus on role of families in early identification of developmental delays they mentioned families play a big role in identify children with developmental delays in their homes and neighbourhoods

	co-ordination between all key role players from policymakers to family members(129).	becoming referral source within the community however they mentioned that this should be enhanced through educating them. “The RTHB is not user friendly to parents and there is not enough empowering going around parents getting to use it.” KI1 “Educating parents during pre-natal services that's before the child is born. KI2 “Their role is very critical. But most people do not know the basics about child development.”KI3
How would you view community involvement to support parents to detect developmental delays?		They all mentioned that the community plays a big role. They act as a referral source as they come and report children with developmental delays. They are in the area where the children are look after which is a big opportunity if they are aware, the community can act as a referral source. “Community has a big role to play. Community look after children in both formal and informal ways.” KI1 “Communities play an important role.” KI2 “Every child who is not developing as his or her peers should be identified and the caretakers or the mothers or the parents then are urged by the community to go for help....” KI3

In your experience how does stigma prevent mothers/caregivers from bringing their children to the clinic for screening?		Nothing was noted around stigma.
Please describe the roles the CHW's play in early detection of developmental delays in the community.	The Ten Question Disability Screen Tool (TQS) is an alternative developmental screening tool specifically geared toward LMICs(15). Considering the challenges South Africa is facing with limited and overburdened nursing staff, this tool offers the advantage that it can be administered by people who have no background in disabilities(42).	The KI have very limited interaction with CHW but have heard about their involvement in community health activities. However, if they are on board, they need to be equipped on how to identify developmental delays – "As for CHW, I haven't interacted with any of them at my level of service delivery.." KI2 "Health education to mothers and training CHWs." KI1
What do you think is your main role as a Registered Nurse is when it comes to detection of developmental delays at a clinic level?	However, there has been a reduction in the number of nurses and the demands experienced by nurses in rural areas are profound(16). A study conducted in 2008 found that the emotional and physical strain experienced by nurses in rural PHC facilities became barriers to effective provision of high quality care and created tension between the nurses and their clients(23). Primary Healthcare facilities in South Africa can be an enabler to early identification. This system consists of initial medical consultations at Primary Healthcare Clinics, which are mainly nurse-driven(11).	Although they are the primary contact of the population with the health system, other health professionals should get on board at the PHC level as far as detection of developmental delays is concern. It should be the responsibility of a trans disciplinary team of health professionals not only at the clinic level but also at every contact of a child with a service provider be it health or education. "Revision of the RTHB, counselling, and including developmental delays as part of the national priority so that health professionals can take part in child development."KI1

		"Early identification of developmental should be looked at within a system of care for children and families. KI2 "It should be a focus of a whole society and medical services and social development." KI3

After the evidence was used to shape the interview guide, the researcher collected the following data from the study participants, as summarised below in the three main areas, themes and sub-themes. The findings obtained are presented in the sub-sections below.

Table 6: Summary of three main areas, their themes and sub-themes

	Area 1 **Detection of developmental delays**	**Area 2** **Co-ordination of the Health System**	**Area 3** **Factors contributing to the detection of developmental delays**
Theme 1	**Surveillance**	**Infrastructural and Organizational issues**	**Service delivery issues**
Sub-Themes	**3.1.1.1 Observation of the child**	**3.2.1.1 Allocated spaces to monitor a child's skills**	**3.3.1.1 Limited time to do screening due to high patient load**
	3.1.1.2 Mother's concern about the child's development	**3.2.1.2 Human Resources**	
		3.2.1.3 Availability of Specialist in the area	
Theme 2	**Screening**	**Re-engineering of PHC**	**Attitude of Parents**
Sub-Themes	**3.1.2.1 Road to Health Booklet developmental screening tool**	**3.2.2.1 Implementation of a Community-based approach**	**3.3.2.1 ignorance**
	3.1.2.2 General assessment during every visit to health facility	**3.2.2.2 Assistance from CHWs**	**3.3.2.2 Irresponsibility**
			3.3.2.3 Stigma
Theme 3	**Reported information**	**Integration of services at PHC facilities**	**Inaccessibility**
Sub-Themes	**3.1.3.1 CHW- reported information**	**3.2.3.1 Perceived shared responsibility of RN**	**3.3.3.1 Financial constraints**
	3.1.3.2 Community member reported information	**3.2.3.2 Perceived responsibilities' linked to Developmental Screening**	**3.3.3.2 Lack of transport**

		3.2.3.3 Referral Routes	
Theme 4	Knowledge on developmental delays	Protocols to guide PHC nurses	
Sub-Themes	3.1.4.1 Understanding of developmental delays	3.2.4.1 Protocol guidelines	
	3.1.4.2 Knowledge on risk factors		
	3.1.4.3 Experiences		
Theme 5		Fragmentation of services among the different levels of health care facilities	
Sub-Themes		3.2.5.1 Reporting systems between PHC level and referral facilities	

3.1 Detecting developmental delays

Four major themes were derived from the RN responses as methods currently used for early identification of developmental delays in children (Figure 4).

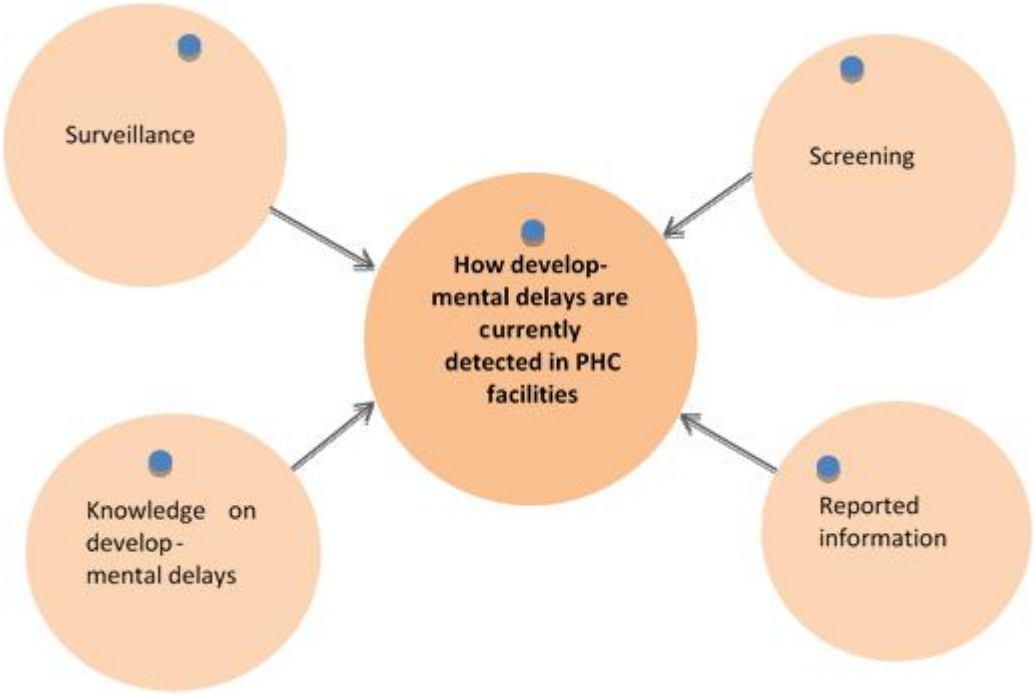


Figure 4: Methods currently used to detect developing delays in PHC facilities.

Illustrated in Figure 4 is the major themes derived from RN on how developmental delays are currently detected in PHC facilities.

The methods include surveillance, screening, reported information, and knowledge on developmental milestones. The specific sub-themes for each main theme are presented on Table 7.

Table 7: Specific measures currently used to detect developing delays in PHC facilities

	Themes	**Sub-themes**
3.1.1	**Surveillance**	3.1.1.1 Observation of the child
		3.1.1.2 Mother's concern about the child's development
3.1.2	**Screening**	3.1.2.1 Road to Health Booklet developmental screening tool
		3.1.2.2 General assessment during every visit to health facility
3.1.3	**Reported information**	3.1.3.1 CHW- reported information
		3.1.3.2 Community member reported information
3.1.4	**Knowledge on developmental delays**	3.1.4.1 Understanding of developmental delays
		3.1.4.2 Knowledge on risk factors
		3.1.4.3 Experiences

As presented on **Table 7**, four major themes and 9 sub-themes were derived from the nurses as the current methods used to detect childhood disabilities. These methods are discussed below.

3.1.1 Theme 1: Surveillance

3.1.1.1 Sub-theme 1: Observation of the child

The RN stated that observation of the child is one of the methods used to detect developmental delays in children. This is supported by the following responses.

"It is very easy to identify what is wrong with a child just by observing their physical features like eyes (slightly closed), head (small)". (RUS1)

Nurse RUS1 further shared, that it is her responsibility whenever doing immunisation to tell the doctor her observations.

Nurse RUS3 highlighted that *"We use the eye chart. Moving simple object across the child's face and examining if the child moves the eyes in the direction of the object. Drop something to assess response."*

"They come every month for scale and Immunization, so we observe through a year. First Year we observe that then it comes with the Immunization again after a year but normally every month."(RUS2)

RUS5 shared that if babies can't speak or hear she uses observation techniques to investigate these.

"Its part of history taking and observation because we can see if err we enquire about age if the child before and then during err consultation we observe the child what she can do and we can that what there are any challenges we enquire from the mother and then we examine and refer." RUS4

MOS4 response to observation was as follows, *" Yes, but if the child is not (crawling,etc) we just ask them. Sometimes we check the neck and head circumference. If a child is not meeting requirements we refer to the hospital. And then doctor can do something or whatever."*

"uhm... when it comes to children that I see every day. Isn't it that we should be checking the children even if we don't do this checking we just assist the children as we see the children and then to start with we are taking weight every time they come to the clinic." MOS2 in response to observations.

Nurse MOS5 and MOS3 responses towards observation referred to the screening rather than observation that is done by a doctor or another nurse.

MOS3, " Most of the time it's done by the Nurse who will be doing child welfare because of most of the children she saw most of the children even those who are not sick because myself in the consulting room i'll be seeing sick patients but when immunisation she is seeing each and every child under 5. So she's the one who will always be seeing them."

3.1.1.2 Sub-theme 2: Mother's concern about the child's development

The nurses also noted that the mother plays a key role. Information reported by the mothers also helps in the identification of developmental delays in children.

MOS2 said *"last year I had a baby whose mom came in for Immunisation and then she got in here and then she asked me about the head of the baby it is growing bigger and bigger everyday…..So that is why I am saying that Moms are very alert about development of their babies"*

One nurse said some parents are aware about the milestones especially those who have at least one child because they compare with the first child. *"What actually assist them in the development is because it will not be their first child so she will be comparing the child with the first one, then she will quickly see the difference and come and ask."* (MOS3)

"*Parents do report to the clinic. My child is like this and my child is like that. Mothers do compare their children with each other at the clinic. They ask each other is your child doing this now or is he doing that. They do report if the child is not like the other children."* (MOS4)

RUS2 said "*….moms are clever and they will come to you and say to you that this one isn't walking, what is happening? From experience we get much information from the mother then compare with our examination….The mothers do understand this development of the child. If she sees that the child is so many months and then she's not or his not crawling or his not talking or his not acting like the child in that age the mothers will report this to the sisters saying but this child is not doing this and that and this and he is so many months."*

Other mothers out there when they come in they just tell me Sister this child is not doing what and what So, we just put the child there (points to open area on the floor) and examine whether the legs are the same size, the legs don't have a problem in the legs maybe. It's called club feet or maybe, even the mother is not aware of that. We also examine the knees". (RUS3).

RUS1 , however , stated, " Then I ask her how was the child born was it normal delivery, was it facilitated delivery, was it a caesarean section and then I just want to find out from the Mom if she can see if there is something wrong. Because in most cases the mothers they don't see.umm."

3.1.2 Theme 2: Screening

3.1.2.1 Sub-theme 1: Road to Health Booklet developmental screening tool

All the nurses noted they use the developmental screening chart in the RtHB, however, there were no specific tools or specific equipment used to screen for developmental delays.

"*No challenges, the Road to health booklet just simple and self-explanatory*." (MOS3)

"*We give the RTH booklets. But the occupational therapist and the physio do come here*". (MOS5)

"*During immunization. We scale them and also check speech, sitting, standing, head circumference every month through the first year and then after a year. We use their card then we refer if there is something that we suspect, it is the only thing that we use to screen*(referring to the RtHB). (RUS2)

RUS2, further added, *" Umm as professional nurse I think to work with that Road to health chart is much easier and I think it is easy way to use it because it has everything under the nose, ear, speech, walking and all reflexes."*

"So I won't say we are that much privileged about the tools we use we only depend on this Road to health chart and the assessment during visitation.... "*Yes, we do because we nurse children according to the child booklet and whatever that is included in there we do." (*RUS4)

RUS3 shared *" Uh..uh..we are just referring to this,,er,,er,,this card (RN shows the researcher the RtHB.) When you do the , the immunisation you are going to the page then, you are going what the er..er.. child road card tells you...then you re going to sue it for checking the baby."*

MOS2 responded as follows, *" and this road to health what what, as I've eh ehe, indicated at first."*

"We usually use the Road to Health Booklet." MOS4.

3.1.2.2 Sub-theme 2: General assessment during every visit to health facility

The RN also noted that conducting a general assessment during every encounter at the health facility assists them in identifying children with developmental delays. The

child's medical history from time of delivery is also documented. Majority noted that the other method used involved asking the mother about the baby, as they screen for developmental delays. In addition, they highlighted the use of other tools such as head circumference tape, growth charts and weighing machine.

"*We check weight and compare with road to health card and milestone checking. We measure the head circumference, mid upper arm circumference and eyes to at teething and also to look at it".* (MOS2)

"We use the pen to test the eyes but for motor abilities, we ask from the mothers". (MOS4)

"Screen children during every contact with the health facility. Screening depends on the age of the child. For a three days old child, reflexes are checked; head circumference and length are measured and recorded. Through these, you can identify if something is wrong". (RUS1)

"During immunization, we scale them and also check speech, sitting, standing, head circumference every month through the first year and then after a year. We use cards to screen then refer if something is wrong". (RUS2)

"We have other method we use like asking the mother is the child crawling or not, she is going to tell me". (RUS3)

This sub-theme gives more clarity on how the RtHB screening is completed. It appears that a variety of methods are being used. There was no standardised way that emerged. The only common factor is the RtHB developmental screening tool which everyone uses as a guide. However, this will be addressed more in the next Chapter.

3.1.3 Theme 3: Reported Information

3.1.3.1 Sub-theme 1: CHW reported information

According to the respondents, CHW reported information also assist in the early identification of developmental delays in children.

"*They do door to door visit. They really help us in so many issues even in developmental, they report that a child is one year six months but looks like a nine months old"*. (MOS3)

"*CHW do. They report if they identify a delay of any kind and tell the mothers to come to the clinic. They use their referral forms to encourage the parents to come to the clinic*". (MOS4)

"*CHW play a role in picking up those development problems. And also when we pick them in the clinics, we send them to go the houses to look for the patients and come to the clinic with them*". (MOS5)

"*CHW report whatever they discover in the community*". (RUS4)

"*CHW find the patients at home and refer to the clinics"*. (RUS3)

Nurse RUS5 shared that "*most of the CHW's bring the children they find with delayed milestones to the clinic and to the baby wellness clinic. If they can't bring the mother in they take their telephone numbers and bring it to the sister at the clinic to ensure follow up and if the mother doesn't come they do make follow up's".*

3.1.3.2 Sub-theme 2: Community members reported information

Registered Healthcare nurses are of the view that community members do support parents to detect developmental delays. A majority said the community participate in a number of ways which include community members seeing a child with a delay, reporting it to the facility, picking up the child and taking him/her to the clinic.

One nurse said that *"teachers' are also part of the Community members so they also report and also indirectly the community puts the parents with a delayed child under pressure as they ask a lot of questions about the child that makes them bring the child to the clinic." (*RUS1)

"Yes, the community is involvement to support parents to like pick up if their child has a developmental delay but it's through health education." (MOS3)

"The community is involved in picking up problems where there are like delays in development. No, they come to us and tell us at house number there's a child who is having this problem and then we send those health workers there, Even the schools the teachers when they find that child they call us and then" (MOS5)

"*Yes, when a community member sees that there is something wrong with the child what is wrong with the child? The child is not like other child?' You see so I think they*

put is pressure on the parent with parents with kids with a disability. I think it is pressure that the community put on the parent because everybody will be saying but this child is not like my child, and my child is not doing this, mine is doing this. So, this what they normally say to them and they come but it is not nice". (RUS1)

One of the nurses (RUS5) shared that at the clinic they give health education to the community members who encourage the mothers to come to the clinic if they see something is wrong with their child.

Another nurse (MOS2) remained neutral on the matter, " *UUmm... I don't know what to say about community support and the mom's support. I don't want to lie."*

3.1.4 Theme 4: Knowledge on developmental delays

3.1.4.1 Sub-theme 1: Understanding of developmental delays

All nine study participants had an understanding of what developmental delays are, even though they did not use medical terminology to describe it. According to their responses, developmental delays centres around aspects such as expected milestones, failure to reach expected milestones, and normal growth and development. The following were their responses.

"I think its most of the people that has developmental delays due to HIV, children from HIV Mothers they are the one that got that problem up to so far." (MOS3)

"…….milestones in the development……." (MOS4)

MOS2 described it as follows, *"You start with the weight we see if the, the weight is coordinating with the percentile that in this Road to Health card and then if there is something below or its above you see there is something wrong with the baby."*

"*Ok what I can say is, is when the child is not like a growing well according to the milestones. Like you know a child is supposed to sit at six months, crawl at eight months, something like that and then the child is not developing according to the way he should. Then it looks like the child is having a delay, delayed milestones*." (RUS1)

If the child does not pick up after a month you refer to the hospital, then its malnutrition Those type of stages…. We assess it, especially the Speech. We assess also the speech of the children that are communicating…Arre..and then there is a portion at the back of our card ….There is a portion that says you must assess the speech, you

*must assess the touch, and the familiar of the person… I mean err… what can I put…Arre…these children are living with the parents and the discipline maybe some family members….. The child must move ok, how to assess them…… Then normally from three months the child must be able to move and roll and wrap…" (*RUS2) The Researcher understood the participants' description as a description of movement relevant to a three month old.

RUS3, *"I can say developmental delay is when the child is born, this child we expected to go through milestones. Then when you are in child welfare you are supposed to be thoroughly examined this baby the time it reaches in the in the in the clinic, then you do that thing, to see that the child is maybe when call is it reacting or she is doing some sounds".*

"Umm I believe it's when the a child does not err…achieve doing the achieving, is not achieving the milestones that he is supposed to be achieving at a particular age that he is supposed to achieve at….." (RUS4) The researcher interpreted this as a child not achieving their specific age-related developmental milestones.

3.1.4.2 Sub-theme 2: Knowledge on risk factors

Knowledge on risk factors for developmental delays also assisted in detecting childhood disabilities. A few of the nurses from rural noted that developmental delays are common in the exposed babies than the unexposed babies.

"*Developmental delays are due to HIV that children from HIV Mothers they are the one that get it. Most the babies she sees with developmental delays are the ones with the moms that are HIV positive."* she added *"I would say 1 percent of people with negative status have poor developmental status." (*MOS3)

"*Some developmental delays are due to malnutrition and then those who are affected by this HIV, then…yes…"* (MOS5)

RUS4 shared, *" Ummm.... and then there are cases like malnutrition , cases like err, HIV infection like being infected without being prevented during pregnancy because they become pregnant there, they stay there, they deliver at home and these is such cases. So , so it's only their being err, err being attended to when they come to the clinics. Maybe sometimes you find that she's already five, she's missed all the*

immunisations, she can do this, she cannot do this, it's a case of malnutrition , it's then that you start referring to social workers or to the hospital."

3.1.4.3 Sub-theme 3: Experiences

A majority of the RN have had experience in identifying children with developmental delays.

"We do it every time a child comes but refer to the hospital there is nothing that we do here at the clinic we refer the child to the hospital where they go the specialist at the hospital." (MOS2)

"Yes, I had experience like that the one last year. Then, the problem of that child she was, the child was one years old mastered....According to assessments it looks like the six months old. The the mother didn't prospect the child because of the newly accepted one, so that one was suffering because milk was given to the child, no food, was given only water and bush tea and that that the bush tea is for young kids" (MOS5)

When referring to experiences RUS1, shared *"ummm actually after identifying them, then we refer to the doctor and then the doctor is the one who actually refer to another level so that they can get the proper care that they need and then there are some investigations done."*

RUS2 referring to experience shared, "Normally we get that the children be slow into care especially from two years due to TV...arrh... most of the children and watching tv..... Language delays..."

"Experience...in this clinic I to see, cause when we see the child with this problem we usually refer her to speech therapist maybe and the mother and the mother is also going to be interviewed, is the child er...crying or doing bubbles or do you see that the child is not responding when you are trying to play with the child."RUS3

RUS5 shared her experience as an example of a five year old who can't talk but can walk. She shared how the mother stayed at home with the baby and didn't bring the bay to the clinic. She also shared how she refers these children to the doctor.

Only MOS3, shared that her experiences were limited because she did not deal with children under 5 daily. Her account is as follows, *" Most , most of the time it's done by the Nurse who will be doing child welfare because most of the children she saw..."*

In summary, methods used by RN in detecting developmental delays include surveillance, screening, reported information, and knowledge on developmental milestones. Specific measures include observation of the child, mother's concern about the child development, RtHB developmental chart, general assessment during every visit to health facility, CHW- reported information, community member reported information, understanding of developmental milestones, knowledge on risk factors, and experiences. However, how these are inter-related and the complexities thereof will be discussed in the next chapter.

3.2 Health System factors affecting the early identification of developmental delays in children aged 0-5 years

Five major themes were derived from the nurses responses as health system factors affecting the early detection of developmental delays in children (Figure 5).

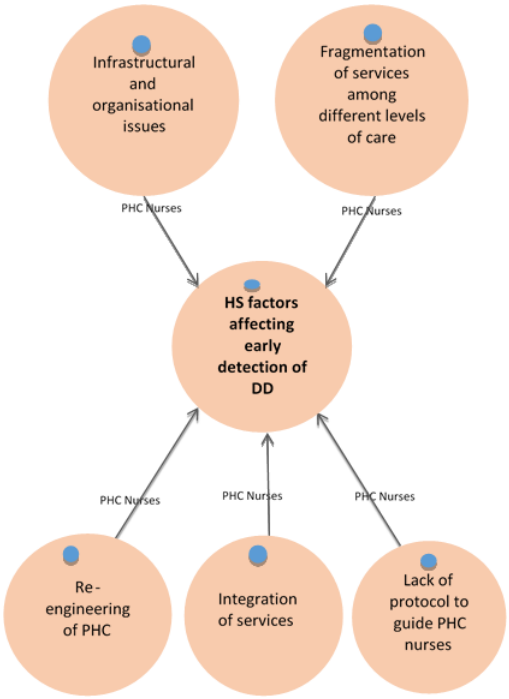


Figure 5: Health system factors affecting early identification of developmental delays.

Illustrated on Figure 5 are the major themes derived from nurses on health system factors affecting early detection of developmental delays.

The factors include infrastructural and organizational issues, re-engineering of PHC, integration of services, lack of protocol to guide PHC nurses, and fragmentation of

services among the different levels of health care. The specific sub-themes for each main theme are presented on Table 8.

Table 8: Health system factors affecting early identification of developmental delays

	Themes	**Sub-themes**
3.2.1	**Infrastructural and Organizational issues**	3.2.1.1 Allocated spaces to monitor a child's skills
		3.2.1.2 Human Resources
		3.2.1.3 Availability of Specialist in the area
3.2.2	**Re-engineering of PHC**	3.2.2.1 Implementation of a Community-based approach
		3.2.2.2 Assistance from CHWs
3.2.3	**Integration of services at PHC facilities**	3.2.3.1 Perceived shared Responsibility
		3.2.3.2 Perceived responsibilities linked to Developmental screening
		3.2.3.3 Referral Routes
3.2.4	**Protocols to guide PHC nurses**	3.2.4.1 Protocol guidelines
3.2.5	**Fragmentation of services among the different levels of health care facilities**	3.2.5.1 Reporting systems between PHC level and referral facilities

As presented on **Table 8**, five major themes and 10 sub-themes were derived from the nurses as health system factors affecting early detection of developmental delays. These factors are discussed below.

3.2.1 Theme 1: Infrastructural and Organizational Issues

Registered Healthcare nurses' assert that infrastructural and organizational issues negatively contribute to the detection of developmental delays in children.

3.2.1.1 Sub-theme 1: Allocated space to monitor a child's skills

Two of the urban respondents noted that infrastructural issues such as unavailability of consultation rooms and well child service rooms made it challenging to conduct screenings optimally.

RUS4 , *“ Because our facilities are very small clinic.”*

RUS3, *“ The challenges is in our clinic is the space. There is no space. Even if you can be helped by that er... instrument or some other thing to use...the er...space in our clinic.... Only we are using the consulting that side... It is used to do er...er... Child Welfare. It is a small consulting room. Even you cannot put something there to use for, tracing, examining the baby...”*

Even though a minority of RN shared this it should be noted and will be further discussed in the next chapter.

3.2.1.2 Sub-theme 2: Human Resources

A few respondents, from the rural and urban PHC setting explained that staff shortages were some of the reasons that influence identification of developmental delays.

“As you can see we are only two sisters in this big clinic So that affects me because as a sister, working with children the first thing I have to weigh the children, I’ve got to do the interruption, do the head circumferences, the MUAC, after that I should assess the patient, the child and I should come and vaccinate the child being one sister. That is affecting me. So, I am going to miss some of the things that I could have seen in the last time I was with the baby.” (MOS2)

MOS4: *“We have many challenges. There are staff shortages”*

MOS5: *“we are so busy, it’s a problem to us here we are worse having one sister. It’s too much”*

RUS4, *“ There is no specific person because most of the time we are short staffed, so whoever, we make it a point who ever consults that child, we examine everything, developmental stages, nutrition, err, information about there they are staying if they tare receiving grants whatever from the mother or the guardian which is bringing the child to the clinic.”*

3.2.1.3 Sub-theme 3: Availability of Specialist in the area

A respondent from the urban area and another respondent from a rural PHC setting explained that there is a general lack of specific specialist in the district. This at times

make it difficult to refer a child identified with a specific developmental delay. On the other hand children identified with developmental delays have to wait for a month or two for the rotating specialist to visit the facility.

"*We wait for the occupational therapist who comes twice a month. We book patients for her.*" (MOS5)

"*The Challenges it will be you say the child must go and see speech therapist. So, the challenges we are having is due to referral. When you refer you will find that person is not there or this person we don't have him or her in our district. So, it's a challenge that we get." (*RUS2)

3.2.2 Theme 2: Re-engineering of PHC

3.2.2.1 Sub-theme 1: Implementation of a community-based approach

Two urban based nurses noted that the re-engineering of PHC by adding WBOT serves as a positive step towards early identification of developmental delays in children. The rural based nurses did not specifically talk about WBOT and re-engineering of the PHC system but in the next sub-theme they contributed more specifically.

"*…..but there are other healthcare workers who go to the ...they called re-engineering nurses, who visit the clients. They go there visiting the the the community. So they also pick up things, when they go there. They have a nurse working with them..Err"* (RUS3)

Another nurse noted a challenge that they see only those children who come to the facilities *"The challenge us we see those children only when they come to the clinic because we haven't been doing its only now that the past two to three years that they introduce this uh re-engineering that they follow clients to their residential places but mainly previously we depended on the client coming to the clinic." (*RUS4).

3.2.2.2 Sub-theme 2: Assistance from CHWs

The majority of nurses described that CHWs play a very important role doing door to door visits. During these visits they check whether the children are vaccinated, screened for developmental delays, educate the mothers about the status of their

babies, refer the mother and the child to the clinic and also report back to the clinic. Sometimes they come with the cases.

One of the nurses mentioned that they do not necessarily focus on developmental delays but rather on health risks or health problems at large.

MOS2 *"They get into the village, they when they get to the village they ask for this, to check if the baby is well, is the baby vaccinated and they also check as you say the baby and ask the Moms any questions ask they see in the baby. And then they will come back and report back to the clinic and then would tell the, the, the, mom there they should go to the clinic, if you get this baby to the clinic the reason being one, two, three, four, five. Then the mother will come and report at the clinic and say the Community health workers did say, they said I should come to the clinic. You being the sister at the clinic, the community health worker would report to you saying I am sending number, with this reason and when the Mom comes in here, I already know the problem is this, this, this, this"*

MOS3 *"They really help us, they really help us because they are doing door to door visits and some of them, they group themselves. Each group has an area that they visit on monthly basis. When there is a new born they will, only check the new-born at three days and then at ten days they went there to check the baby then they are trained to check the baby and frequently after three months"*

A minority of the nurses said they have never heard from the CHW's regarding early detection of developmental delays in the community. *"No. Actually I have never heard from them about, them identifying those kids, actually haven't been given a report about that." (*RUS1)

*"Yes we are having the CHW's that we working with so they are the one who help us in the community to assess then to refer to the clinic....I think they know everything because they are working with there is a Sister they are working with. I think they know everything about it. Sister trains them and guides them." (*RUS2)

RUS5 shared that most of the CHW's brought the children they found with developmental delays to the clinic and the baby wellness clinic. She further expanded

that if the CHW's could not bring the mother in to the clinic they would bring her number to the sister at the clinic to ensure that a follow up occurs.

MOS4 shared that CHW's do get involved and that they are a great help. If a concern is addressed to the Community Health workers and they go out and see the family. MOS4 further added that the CHW's go into the villages and come and report problems.

It appears that there is a distinct link between this theme , Re-engineering of PHC and its two sub-theme's above and the theme 3.1.3 Reported Information and it's sub-theme, 3.1.3.1 CHW-reported information. The Re-engineering of PHC in both the rural and urban areas appear to have had a positive impact on how information is being reported to the RN, how follow up visits are administered and also how children with challenges are being detected. This manner of gaining information appears to assist the RN who are already working in a very demanding environment.

3.2.3 Theme 3: Integration of services at PHC facilities

The integration of service in the PHC clinics was emphasized by the participants as one of the positive contributions of the health system in the detection of developmental delays in children.

3.2.3.1 Sub-theme 1: Perceived shared responsibility of Developmental Screening

Developmental screening forms part of the nurses job description and they often do it every time a child comes to the facility but usually when a child comes for Immunization. Regarding who is responsible for early detection of developmental delays at their clinics, a majority of the nurses said its' everyone's responsibility

"We are all responsible for that because children are not just coming to the welfare clinic but also coming to the general ward when they are sick. So, the sister attending to that child can really see that this is not correct." (MOS2)

MOS3 *"Everybody is responsible if you see something that is not right you, you come to the other one then we are to, we phone the Paediatrician at the hospital and then she says send them on such and such a date."*

"*There is no specific person because most of the time we are short staffed, so we make it a point who ever consults that child, we examine for everything, developmental stages, nutrition, information about where they are staying if they are receiving grants whatever from the mother or the guardian who is bringing the child to the clinic."* RUS4

While another nurse said it was due to rotation. "*Nothing challenges us because we are rotating so if you see something you just tell your colleagues Fridays you saw one, two, three four can you please assess again."* (RUS2)

3.2.3.2 Sub-theme 2: Perceived responsibilities linked to Developmental screening

A majority of the nurses added that their responsibilities include promoting development of the baby using the RthB, to support the parents, to give counselling to the mothers' who have a babies presenting with developmental delays and educating the mothers' especially pregnant females.

"*I support the parent and to give counselling just reassure the parent that the child will get the best care even if the child maybe at a later stage can go to a special school or something, like the child is going to get the proper care but the stakeholders should buy equipment's in the clinics.*" (RUS1)

"..Examine, to see and to refer and to make sure that the person has got the has been helping, has been getting the help and further management. I must ensure that As a Nurse. I must make sure that I have examined thoroughly, I have referred to the correct level…And then follow-up that that child is being helped." (RUS3)

*"Pick up those kids at the villages yes after finding those kids? Then we order some foods from the social workers then they send us some food for those kids then there is some porridge, some food parcels for those kids, so for those who are not breastfeeding some milk maybe are given to them." (*MOS5)

From the responses of other participants, it could be drawn that health education on healthy living and development are required and provided to parents.

"*Supervise and emphasize health education to the client, about developmental and that must be done during ANC and during Immunization because in Antenatal that is*

where you start every day about the child. If the person can ask during ANC then after delivery she will still remember." (MOS3)

3.2.3.3 Sub-theme 3: Referral Routes

Once a delayed developmental milestone is detected, a majority of nurses highlighted a number of activities that follows which included; taking a history from the mother (asking some questions about the baby), educating the mother on feeding the baby, then informing her that the baby had a delayed developmental milestone and lastly filling in the referral form and referring the baby to an internal facility based Doctor who later refers to the specialist / Occupational Therapist or the nurse refers directly to the Occupational Therapist at the hospital for further management. A minority of the nurses go ahead and phone the hospital and make an appointment with the Occupational Therapists.

*"I talk to the mother and ask for what she feeds the baby, and then I start educating her about how she can feed the baby and how to mix the food. Then tell the mother that this baby is malnourished therefore the baby should get to the hospital, to be treated with good, healthy food and when the mother agrees. Fill the referral form and refer." (*MOS2)

MOS3 ,"*We are not the ones who refer to the Occupational Therapist we refer to the doctors and the doctor in turn at the health centre refers to the Physio, or the Occupational Therapist or Speech Therapist".*

*"We wait for the occupational therapist who comes twice a month. We book patients for her." (*MOS5)

RUS1, *"I take the history from the Mom. Explain to the mother as the problem then refer to the hospital to the paediatrician."*

"*Yes because always when something, we refer or the social worker if there is something or physiotherapist or to our doctor in the clinic. Always we refer to the doctor to make sure that what we are really doing, examining is the true picture of the child. The doctor is here in the clinic is also helping us. If the doctor is not in, we refer the child to Paeds OPD for further management and the mother is going to go with the*

referral form to Paeds OPD for consultation to the paeds doctor who comes weekly every Wednesday's." (RUS3)

"Because our facilities are very small clinic, we detect a case we explain the mother what is happening to the child and why it is happening. So, we usually write a referral form to take to the clinic then they do go for referrals and they come back for follow-up because we need to monitor the child." (RUS4)

For nurses (RUS5 and RUS2), they take the baby directly to the doctor at the clinic. If the doctor is not at the clinic they phone the hospital directly to get an appointment date for the mother.

3.2.4 Theme 4: Protocols to guide Registered Healthcare nurses

3.2.4.1 Sub-theme 1: Protocol Guidelines

The majority of the nurses said there was no particular protocol that guides them to screen for developmental delays at their facilities but they only use the RtHB.

"We don't have a specific protocol we are just referring to the road to health booklet" (RUS3)

RUS5 stated that they do have guidelines in the form of the Road to health booklet.

RUS4 *when discussing available protocols responded, "We don't have a particular screening tool, honestly we don't*."

MOS 3 stated, *"No protocol."*

*"Uh, the guide for screening we don't have, the guide for we are having uh, for Immunization programme." (*MOS2)

MOS 5 *"We don't have protocols."*

The various referral routes RNs are using in the sub-theme 3.2.3.3 , Referral Routes, link to this sub-theme of Protocol Guidelines where the RN highlighted that there is no protocol guiding them. With no clear protocol to follow it appears that every RN use what they feel is best for their environment, thus leading to a mixture of referral routes and in addition a variety of screening methods used to obtain information for the RtHB ,as described in the sub-theme, 3.1.2.2 General assessment during every visit to health facility.

3.2.5 Theme 5: Fragmentation of services among the different levels of health care facilities

A majority of the participants in addition highlighted that fragmentation of care services between the PHC facility and referral facilities contributes negatively to the detection of developmental delays.

3.2.5.1 Sub-theme 1: Reporting systems between PHC level and referral facilities

Lack of a proper reporting system between the PHC facilities and the referral facilities pose challenges and reporting appears to be done in an informal manner by the RN at the PHC facilities.

*"No feedback on treatment from hospital." (*MOS2)
*"We get feedbacks from the parents and a discharge letter or an acknowledgement that the child has been seen. But not all the patients do so, some we have to ask when we meet them." (*MOS4)

A few participants also noted that they did not receive feedback directly from the facilities they referred their patients to, as is alluded to in the following statements;

MOS3 problem is *"Primary Healthcare don't keep the patients, weigh and then we give supplements or refer only some will come back, some will not come back".*

Another nurse (RUS5) shared that they ask the mothers to give feedback or reports from the doctor on whether the child is improving or not.

"…….but the only problem that you are having is that when we have referred people to the hospital we don't receive feedback from the parents." (MOS2)

"*Moms are the ones who comes back and explains to me that, you remember when you sent me to the hospital that date, so they did one, two, three, four. They are saying thus and that and normally they come with a letter." (*RUS1)

"*Hospital takes over with management after referral, no feedback is given to us. Child only continues with routine immunization*." (RUS3)

In summary, health system factors contributed both negatively and positively on the detection of developmental delays in children. Negative contributions include infrastructural and organizational issues, lack of protocol to guide RN, and fragmentation of services among the different levels of health care facilities. In detail,

insufficient space to monitor a child's skills, staff shortages, lack of specialists in the area, no guidelines, discontinuity of care on referrals, and lack of a proper reporting systems between PHC level and referral facilities were health system factors that contributed negatively to the detection of developmental delays in children.

Positively, the health system is re-oriented through re-engineering of PHC and the integration of services to facilitate detection of developmental delays in children. Positives measures include implementation of a community-based approach, assistance from CHWs, perceived shared responsibility amongst RN, and referral routes.

3.3 Challenges faced in early identification of developmental delays in children

About the challenges the nurses encountered when using these screening tools, all the nurses highlighted no challenges specifically with the RtHB. However, a majority of nurses noted service delivery issues, parental issues, inaccessibility, and communication as some of the challenges faced in detection of developmental delays in children (Figure 6).

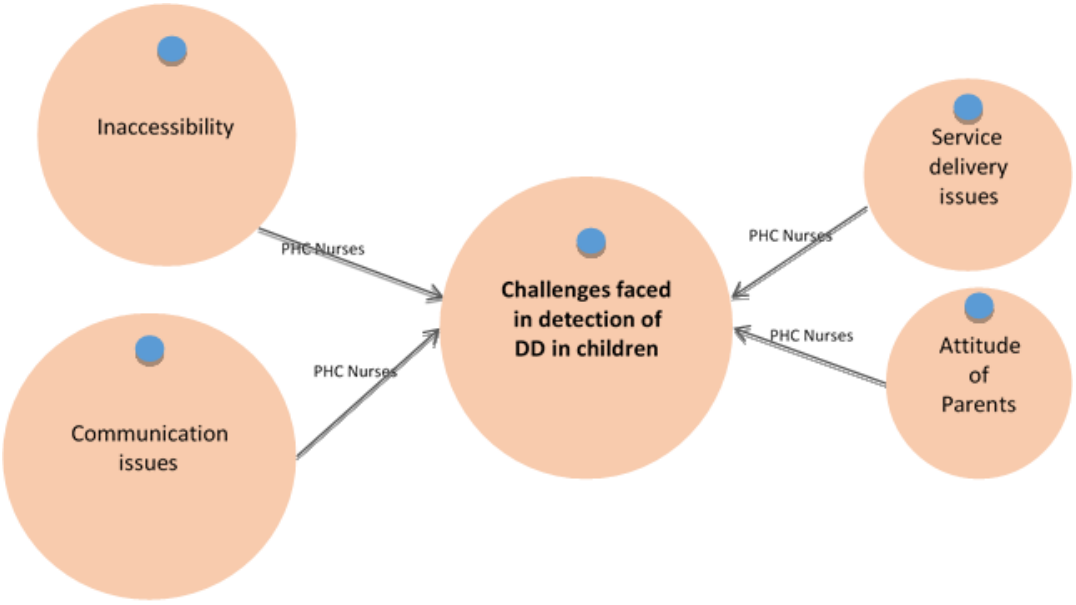


Figure 6: Challenges faced in the early detection of developmental delays.

Illustrated on Figure 6 is the major themes derived from nurses as challenges faced in early detection of developmental delays in children.

The challenges include service delivery issues, parental issues, inaccessibility, and communication. The specific sub-themes for each main theme are presented on Table 9.

Table 9: Challenges faced in early detection of developmental delays

	Themes	**Sub-themes**
3.3.1	**Service delivery issues**	3.3.1.1 Limited time to do screening due to high patient load
3.3.2	**Attitude of Parents**	3.3.2.1 Ignorance
		3.3.2.2 Irresponsibility
		3.3.2.3 Stigma
3.3.3	**Inaccessibility**	3.3.3.1 Financial constraints
		3.3.3.2 Lack of transport

As presented on Table 9, three major themes and seven sub-themes were derived from the nurses as the challenges faced in detection of developmental delays in children. These challenges are discussed below.

3.3.1 Theme 1: Service delivery issues

The nurses highlighted that screening takes a lot of time amidst the busy schedules and in addition, there are always long queues of patients waiting to be attended to.

3.3.1.1 Sub-theme 1: Limited time to do screening due to high patient load

Three participants' shared their concern about the time taken to complete the RtHB screening tool due to high patient load.

MOS 2 *" So that affects me because as a sister, ehh, working with children the first thing I have to weigh the children, I've got to do the, I got to do the head circumference, the mwak, After that I should assess the patient, the child and I should come and vaccinate the child being one sister. That is going to affect me. The development of the baby, let me say at times I am not going to do that. I'm just going to vaccinate the baby and say this I will do the other time. So I am going to miss some of the things that I could have see in the last time I was with the baby."*

RUS2, "Its the honest truth because it's not only immunization, its immunization, and then the three days that are delivered from the hospital and then the newborns, ne.

Those who are sick, emergencies, like maybe a child fell from where ever, drank paraffin this and that. So I also do that... So it, it's a challenge because it's not just immunization because immunization then that's supposed to do screening...And screening it takes a lot of time...You don't just say bring all the kids here and inject them and go. No it's like individual you stay with one parent, one baby..."

MOS2 further shared,*"Cause it's, there are too many when they are coming, ke, ke, to the clinic."*

RUS1, "Umm...cause normally our clinics are full every day."

In addition, the sub-theme 3.2.1.3 Human resources and this sub-theme appear to be connected. Staff shortages at PHC facilities means a higher patient load for each RN on duty and less time spent to do thorough assessments or screening, as is shared in this sub-theme by a few RN.

3.3.2 Theme 2: Attitude of parents

Although some nurses shared that, parental attitudes could negatively affect health seeking behaviour of parents', the majority asserted that this does not prevent mothers from bringing kids to the clinic.

However, other parental attitudes such as ignorance, irresponsibility, and stigma contribute negatively to the detection of developmental delays in children.

3.3.2.1 Sub-theme 1: Ignorance

Parent are interested in quantity and not quality. Most often they are not interested in health education and assessments.

"Parents are ignorant." (MOS3)

"*Then I ask her how was the child born was it normal delivery, was it a facilitated delivery, was it a caesarean section and then I just want to find out from the Mom if she can see if there is something wrong. Because in most cases the mothers they don't see."* (RUS1)

RUS3, "*they are not educated so maybe if they notice they don't have it in mind that I have to take this child to the clinic. So, others they just sit there, then they bring the child when it's late….Very few parents detect and report delays because they are not well educated, they can't see something is wrong, and others don't know*."

RUS5,"*Some mothers can see a delay while others don't see anything wrong. But a majority do not see that their babies are showing delayed milestones. They only bring the babies in the clinic when they are sick and then the Nurses pick up the delay*."

"Moms are very alert about the development of their babies. Some come with questions about the development of their children, some give feedback once referred. However some don't know and are also in denial even when they are told the child has a delay." (MOS2)

RUS4, " *So they just stay at home with the kids and then at some other time they bring the child to the clinic only when they are sick. They don't see delay in developmental milestones as being a problem so they usually don't consult those kids and we discover them by ourselves. They never bring the child themselves saying this one is supposed to be sitting by now but she is not, they only come when the child is sick. No, this child is sick and this, this, this and then we discover ok that the delay is due to malnutrition and other stuff"*

3.3.2.2. Sub-theme 2: Irresponsibility

The RN shared their concerns regarding parental involvement and parents apparent lack of responsibility towards their children's' health.

"*Challenges we have is with the mothers. They don't seek medical assistance early for the children with disabilities." (*MOS4)

"*Mothers are less interested. They allow the CHW to deal with it during home visits*." (MOS5)

"*The challenges that I can sight is that the, the responsibility of the parent. I don't know if it is due to culture or what because most of the time we discover this children late when they are brought to the clinics because the main challenge is teenage pregnancy and they are not the one's taking care of the children, ne. They are left with the grandmothers and sometimes they just relocate the mothers they are leaving the children with the Gogo's and then we only discover and usually because they are old, they only take it, it is normal for the children who are born with disabilities they don't mind they don't take it as a child with a disability should get help. Mothers are less concern."* (RUS4)

3.3.2.3 Sub-theme 3: Stigma

Some nurses said there is stigma among the mother/caregivers and that some bring their children in the late evening.

*"Yes, some will bring her child in the afternoon when everybody is off because they are afraid when they come as a group the other children are real big and vibrant and bubbly and so late in the afternoon when everybody is exhausted." (*MOS3)

RUS1, *"Cause most parents if they see that there is something wrong with the child they like isolate the child they don't want the child to be seen by other community members. Ja, they don't know as much to support because as I am saying the parents they normally isolate the child. You will see like they just keep the child at home and then they don't want the child to go to other places like maybe crèches or where they just keep their child at home*."

RUS4 responding to stigma*,"I do believe that because er, you will find err, err, most of the kids that have had disabilities they don't bring them much and you even , even, er, patients with epilepsy, they usually don't accompany them to the clinics."*

However, others shared that they don't think stigma keeps mothers/ caregivers away.

"I don't think the moms have any stigma about their baby, they really don't have because we see different, babies with different, problems." (MOS2)

"No, they don't stay away because of stigma." (MOS4)

*"None. The mothers do come because of the support from the caregivers and from us." (*RUS2)

"Yes, there's some stigma, yes, yes..." (MOS5)

Other participants did not have anything to share on the matter. It is clear that every RN has a different perception of stigma in their communities and also that each community could vary in how they are dealing with children living with disabilities and their families. This could explain why we see the in congruencies in the data collected.

It also appears that despite the perceived stigma in certain communities in this theme it appears that it does not hinder community members from reporting information to the RN as is shared in the sub-theme 3.1.3.2. Community member reported information.

3.3.3 Theme 3: Inaccessibility

Some of the participants affirm that inaccessibility are caused by; financial constraints on the side of the patients and lack of transport on the side of the specialists these are some of the challenges around detection of developmental delays in children.

3.3.3.1 Sub-theme 1: Financial constraints

Financial constraints experienced by parents were identified as a possible challenge as is shared by two rural participants.

RUS5: *"Some parents come, others don't come and some have financial problems to come to the clinic."*

"But it's not even far. It's a distance of 5km's. It's only about R8 to go there but usually if they say they don't have I do give them money to go there to make sure that they come back." (RUS4)

3.3.3.2 Sub-theme 2: Lack of transport

Lack of transport for allied health workers to attend the PHC facilities was recognised as a challenge by two of the participants from both the urban and rural settings.

MOS5 *"We got a challenge because the Occupational therapist take some times to come this side, they can phone and then I'm coming then you know what just cancel I won't be able because there is no transport to come this side, so we some challenges."*

"But our social worker that side is very active it's just that she is also having these challenges about transport because even she is supposed to comes, she usually comes on Thursdays and then sometimes she doesn't come due to transport problems." (RUS4)

In summary challenges faced in early identification of developmental delays in children include service delivery issues, parental issues and inaccessibility. Specific challenges

were, limited time to do screening due to high patient loads, ignorance, irresponsibility, stigma, financial constraints and lack of transport for Allied Health professionals.

Conclusion

The RN appear to share the responsibility of developmental screening, they create their own referral systems, they actively use the CHW's and the community to assist them in early detection of developmental delays and despite the perceived ignorance of parents they still depend on mothers' to raise concerns regarding the children's wellbeing.

Both urban and rural participants equally shared the same experiences in most themes. However, rural participants highlighted their patient's financial constraints and the re-engineering of the PHC more than urban participants. Urban participants on the other hand seemed more aware of risk factors, such as HIV, that affect developmental delays than their urban counterparts. The rural participants also highlighted the human resource challenges more than their urban colleagues.

Rural and urban participants seemed to contradict themselves when it came to how they perceive the involvement of the mothers or caregivers. They all shared that mothers were very forthcoming with identifying early delays and at the same time they said that parents appeared ignorant and irresponsible. This poses an interesting contradiction that will be discussed further in Chapter 4. The relationship between the healthcare provider and the caregiver.

Another contradiction related to parental and community involvement surfaced under the sub-theme of Stigma. Rural participants shared that stigma is not a challenge in their communities. Whereas, urban participants clearly stated that it is. These interesting contradictions will be further discussed in the next chapter.

From these results we see a picture of RN that are using the RtHB despite challenges they face. They use methods of observation, parental concerns, CHW , community involvement and general assessments to detect developmental delays in children aged 0-5 years. There is no standard way in which any of them assess except that the RtHB is a common factor. They have a general understanding of developmental

delays and experiences are vast. However, the health system appears to challenge their already vulnerable screening and surveillance methods.

The health system appears challenged despite the introduction of the re-engineering of the PHC. It appears in need of a protocol guide to ensure effective early detection of developmental delays and a uniform referral system that ensures effective feedback to referring facilities. In addition, the need for more human resources and specialists are also contributing factors in the need for early identification of developmental delays. However, the presence of CHW's and the perceived shared responsibilities shows how these RN have adapted to their challenges.

Other factors of importance are service delivery issues, parental ignorance and irresponsibility and inaccessibility of both the caregivers and the allied health professionals.

From these results the RN, who despite a lack of protocol , understaffing and accessibility challenges experienced by allied health professionals to reach their clinics, still make their best attempts at ensuring that the early detection of developmental delays occur at their clinics using the RtHB developmental delay screening tool. However, it is clear that with limited time available to screen , it is not a high priority , especially when specialist are not available and there is a poor return of feedback after referrals have been sent.

These factors will be discussed in depth in Chapter 4.

CHAPTER FOUR

DISCUSSION

4.1 Introduction

The main aim of this present study is to explore Registered Healthcare Nurses perceived factors currently affecting the early identification of developmental delays in children aged 0-5 years in selected facilities in Bojanala District. In this chapter the findings from the study will be discussed in the light of the study objectives. The discussion focuses on themes and sub-themes derived from the study data, and references made to relevant literature.

4.2 Detection of developmental delays in PHC facilities by Registered Healthcare Nurses

Basically, only informal measures are used by RN in detecting developmental delays in children. This is reflected by the results of this study as participants highlighted measures including observation of the child, mother's concern about the child's development, the RtHB developmental chart , general assessment during every visit to health facility, CHW- reported information, community member reported information, understanding of developmental delays, RN knowledge on risk factors and RN experiences. Developmental delays are detected through surveillance, screening, reported information, and knowledge on developmental milestones.

With the exception of the eye chart other formal diagnostic techniques are not utilized by RN to identify developmental delays in children. Reasons why these diagnostic tools are not being used will be discussed in Section 4.3.

A recent study conducted in South Africa confirms that mainly informal techniques such as surveillance (observation and screening using RtHB), are used for early identification of developmental delays at PHC levels(130). However, a low screening rate for developmental delays using the RtHB was documented, and the screening checklist was poorly used, thus eliciting a failure in promoting effective developmental health of children(130).

In addition, an erstwhile study had documented the lack of availability of developmental screening tools and their implementation in public hospitals in South Africa(130).

4.2.1 Theme 1: Surveillance

The current PHC system in South Africa is invaluable as a potential environment for developmental surveillance and screening(43). In addition, the well-child clinics provide a platform for periodic evaluation of a child's development (88). The findings in this study correlate with the study conducted by Guralnick regarding the importance of parental involvement and concerns, and using observation as a measure to detect developmental delays(100).

The RN in this study use observation as a tool to detect developmental delays. Studies conducted by Aly, Taj & Ibrahim, as well as Pizur-Barnekow, et al. confirm that developmental surveillance can be done using observation as part of the process (7, 26). Thus the findings regarding surveillance is in congruence with the aforementioned studies.

Part of the reason for relying on observation could be related to the lack of resource tools available at these clinics. This will be discussed later in this chapter under the theme Infrastructure within the section co-ordination of health systems.

Furthermore, according to Guralnick, infants receiving early identification services make greater progress following early detection by means of developmental screening and/or surveillance as first point of access when the whole family is involved (100). The findings in this study reveal that RN use mothers' concerns regarding their children's development as a good resource when conducting their screening tests. This finding is congruent with Glascoe & Robertshaw who shared that Healthcare providers consider parents as a good resource when conducting screening tests because they are usually the first to identify their children's' developmental difficulties (46).

However, parents or caregivers may face challenges in accessing services, and this will be discussed later in this chapter under the challenges faced in early identification of developmental delays.

Most parents realise when something is wrong with their child, and studies evaluating the role of parental concern in developmental surveillance emphasise the need to pay attention to these concerns(29). The RN in this study reflect this practice at their clinics.

In this study, the majority of RN shared that they use probes to elicit developmental information from the mothers or caregivers. Probing parents is a method used in developmental surveillance and can be administered by various well-trained health care services providers (7, 26). However, it needs reactive and proactive healthcare workers and caregivers in order for it to be effective(7).

However, at the same time the RN in this study also contradicted themselves regarding parental concerns, as most of them perceived parents as ignorant and lacking responsibility thus parents are being viewed as deterrents in the early detection of developmental delays. Thus one could assume that the RN probing leads mothers to raise their concerns regarding developmental delays, rather than mothers naturally sharing this information as reported by the RN.

The role of the caregiver in identifying delays is becoming more important, especially as the PHC system in South Africa may be inadequately equipped to deal with the current patient load(27, 28). This will be explored more under the section co-ordination of health systems.

4.2.2 Theme 2: Screening

Over the last few decades many developmental screening tools have been developed and validated internationally(36). The challenge in early identification of developmental disabilities is using the correct tools that respond to local differences, such as, cultural perceptions in the meaning of disability and being able to use it in different countries(42). The important role of tools is acknowledged in identifying children with developmental delays.

There is limited research available for LMIC including South Africa on the improvement of early detection of developmental delays amongst infants and young children through the use of or implementation of developmental surveillance and screening tools(49-51).

Since 2010, the DoH has been using the RtHB as a national assessment and monitoring tool for child health (16, 56). In this study, all the RN use the RtHB as a

monitoring tool and refer to the developmental screening tool in the RtHB as the only tool they use for early identification of developmental delays. The KI shared that the RtHB developmental screening tool is the only tool being used and at the same time anything can be used. The RN in the study only used the RtHB.

A study conducted in 2014, revealed that the RtHB developmental screening tool needed to be adapted or replaced, as it failed to identify more than half of infants at risk for developmental delays or disabilities within the PHC setting(43). This information is vital when exploring the factors affecting the early detection of developmental delays or disorders and could partially explain the poor reporting of disabilities in children under the age of five years(43).

The KI, however, highlighted that there are challenges around using the RtHB developmental screening tool because of experiences of very few health charts of referred children with developmental delays being filled in at PHC level. The KI shared that RN need to be trained on how to use the RtHB developmental screening tool, as emphasis currently is being placed in health (weight-malnutrition) and not on development.

This study did not focus on the reliability and validity of the tool but rather whether RN are aware and using it in their clinics. This has been confirmed by this study. However, this finding can be influenced by a study limitation which will be discussed in this chapter later.

The important role of tools is acknowledged in identifying children with developmental delays. However, the wisdom needed to apply these in settings where specialized training is not widely available and contacts with health services are limited is highly questionable(42). The findings of this study highlight the availability of the RtHB developmental screening tool, as well as the lack of conformity between the various RN when conducting the RtHB developmental screening tool. Thus even though the RtHB developmental screening tool is available to everyone there is no standard methods used to conduct the screening. This finding directly relates to the lack of protocol guidelines that will be discussed later in this chapter.

Early identification of developmental delays is a complex system which requires high quality assessments by trained professionals(25, 70). Developmental assessments are currently not being routinely carried out at PHC level(25).

The findings in this study reveal that RN use general assessments during every encounter at the health facility to help them identify developmental delays. In addition they document the child's medical history. These general assessments, however, are not only specific to the developmental screening tool in the RtHB but also related to the head circumference, growth charts and child's weight.

This is an indication that the RN are taking their initiative to gain general information of the child's wellbeing and developmental status. This links up with the general lack of policy guidelines for the early detection of developmental delays and appropriate referral routes and lack of additional training for the RN.

4.2.3 Theme 3: Reported Information

The findings of this study suggest that CHW reported information to the RN assisted in detecting children with developmental delays in the community. The CHW either reported it to the RN at the clinics or in one account they brought the children to the clinic. The importance of the role the CHW plays in the early detection of developmental delays will be further explored under the section co-ordination of health systems. However, this study revealed that RN recognized that the CHW reporting contribute positively to assisting them in early detection of developmental delays.

This study reveals that the community plays a pivotal role in assisting the RN to detect developmental delays in the community. The study further reveals that community members reported information directly to the clinics or taking the child directly to the clinics. This study found that parental, community and CHW involvement contributed positively towards assisting RN to collect information regarding children's' developmental milestones. The KI shared that families play a major role in identifying children with developmental delays in their homes and neighbourhoods. Considering the challenges South Africa is facing with limited and overburdened nursing staff this can be explored more to see how using the parents, community and CHW more effectively to assist in surveillance and screening.

The Ten Question Disability Screen Tool (TQS) is an alternative developmental screening tool specifically geared toward LMICs(15). It consists of 10 questions administered in the form of an interview, and it engages the caregiver to provide the information. Research has also shown that the TQS can effectively identify children that should be referred for further assessment(42). This tool offers the advantage that it can be administered by people who have no background in disabilities(42).

In view of these findings a tool like TQS could be beneficial for the RN in these sub-districts. However, this is a matter for national level because it would counter the use of the developmental screening tool in the RtHB.

4.2.4 Theme 4: Knowledge on developmental delays

Nurses basic training should equip them to recognise typical or delayed growth and development in infants in order to make the necessary referrals, support the infants and their parents during intervention(59).This study found that the RN have a basic understanding of the term developmental delay. The KI agreed that there was no consensus on the term developmental delays or how it can be best described. The participants basic understanding of the term developmental delay can be seen as an indication that the SAQA Qualification for Further Education and Training Certificate: Nursing (NQF Level 4), includes a core component for the growth and development of a child and adolescent (61). However, this can only be confirmed through research.

However, according to Van der Linde, Kritzinger & Redelinghuys, South Africa faces challenges in this area, as PHC personnel lack both the knowledge and resources to identify developmental delays and disorders in infants and young children(58). Nurses working in the community need a strong foundation of knowledge and skills regarding normal growth and development to be able to guide parents in the promotion of the normal development of infants, as well, as the early identification of developmental delays and appropriate referrals for further examination(41).

This finding can support future studies to further explore the depth of knowledge that can enhance early identification of developmental delays in PHC settings by RN.

In South Africa and other LMIC, HIV/AIDS, infant mortality and Tuberculosis receive higher priority than early identification(14). These are the same conditions that can cause secondary developmental delays and disorders in young children(24, 25). This

study reveals that a minority of the RN were knowledgeable that a relationship exists between these conditions and developmental delays. However, it was more evident with the rural participants that the urban participants. This finding can be further explored as it will enhance the scope of practice for the RN within the area of early identification of developmental delays.

The diversity of roles played by the nurse in South Africa within the PHC setting causes the duty of screening for disability within a paediatric setting to be facilitated by the nurse(60). This study revealed that the RN had experience ranging between two years up to 32 years in the PHC setting. Experienced, RN, were thus more common than expected. However, human resources will be discussed in further detail under the section co-ordination of health systems. In addition, an experienced RN shared that early identification of developmental delays became second nature to them because of their years of experience. This is a factor to consider when recruiting RN to rural areas as more experienced RN could be more of an asset because of their years of clinical experience.

4.3 Co-ordination of health systems in the early identification of developmental delays

A functional healthcare system should be supported by appropriate policies, guidelines, monitoring and evaluation tools, and a well-trained and equipped staff. A well-coordinated health system is very important in the process of early detection and management of childhood disabilities (Study KI). The lack of policies on child development directly impacts on early detection of disability in children among health personnel (Study KI).

The findings of the present study indicate that, the South African health system is not well coordinated to promote effective detection of developmental delays. The RN pointed out both positive and negative contributions of the health system. Positive contributions include the re-engineering of PHC services through implementation of a community-based approach, assistance from CHWs, perceived shared responsibility and referral routes. Expert knowledge support that community-based approach including CHWs, integration of well child services, collaboration among health personnel and proper referral systems would facilitate detection of developmental delays (Study KI).

Negative contributions include insufficient space to monitor a Childs' developmental milestones, staff shortages, lack of a specialist in the area, inadequate resource (lack of diagnostic tools to facilitate formal evaluation), no protocol guidelines and lack of a proper reporting system between PHC level and referral facilities.

A recent study conducted in South Africa reported the existence of these negative aspects within the health system and how they inhibited the promotion of developmental health of children(107, 131).

4.3.1 Theme 1: Infrastructural and organizational issues

Although there is an international agreement regarding the importance of developmental surveillance, agreement has not been reached on how monitoring should be performed, what form it should take and what tools should be used(33, 34). The findings in this study are reflective of the lack of agreement and co-ordination of services in the area of early detection of developmental delays.

The lack of allocated spaces to monitor a child's skills was observed in all the clinics visited by the researcher. However, a minimum of participants shared their frustration with regard to this. In addition, it was the urban participants who highlighted this and none of the rural participants. A study conducted in South Africa found that healthcare workers movement was also influenced by high stress levels and low work satisfaction of which, infrastructural support was noted(89).

Health worker density has increased steadily since 2000 in South Africa and already meet the WHO targets, a minority of doctors, nurses and midwives are working in PHC and rural areas experience the greatest shortages of qualified staff(72, 73). There has been a reduction in the number of nurses and the demands experienced by nurses in rural areas are profound(23). The findings in this study identify with the findings in these studies as most of the rural participants shared that staff shortages influenced the identification of developmental delays.

In addition this study found both rural and urban participants shared that the general lack of specialists in their areas make it more difficult to identify more specific developmental delays and influences the time range for a specialist to attend to their clients.

Currently, rehabilitation services are few and not available at over 70% of public health facilities in South Africa(25, 90). In addition, the capacity for evaluating neurodevelopment of children in many LMIC's, including South Africa, is poor due to a limited number of specialist healthcare professionals especially in rural area(77). Thus shortages of appropriately skilled staff and resources to conduct assessments and provide follow up care are further challenges' experienced(25). This study is congruent with these findings.

4.3.2 Theme 2: Re-engineering of PHC

The findings in this study confirm that re-engineering of the PHC is positively affecting service delivery. This is highlighted by the community involvement and the support offered by the CHW to the RN. The North West Province(NWP) was one of the earliest to implement the WBOT strategy and is regarded as one of the provinces that made the most systematic and sustained progress in implementing PHC outreach teams(82).

In 2015 the NWP had a coverage of 72.6% of wards with at least one WBOT team(83). A number of evaluations have been conducted to document the unfolding implementation of the WBOT's in the NWP(82, 84-87).The NWP recorded improvements in a number of PHC coverage indicators, such as early antenatal booking and vitamin A coverage possibly influenced by the WBOT's(78).

The PHC re-engineering strategy entailed each municipal electoral ward to deploy WBOT's with an average of one team per 1500 households(78).The WBOT's roles are to strengthen health prevention and promotion and secondly, to identify and support vulnerable individuals and families(78). Each team should consist of a Professional Nurse, five to six Community Health Workers (CHW's), as well as a health promoter and an environmental health practitioner(78).

This study found that the majority of RN found the CHW assistance invaluable. Despite the CHW not receiving any formal training regarding early identification of developmental delays they are proactively identifying children who are displaying delayed milestones. The DoH decided to formalise the training of CHW's to ensure that all are similarly trained and have a clear and standardised scope of work ensuring

that they integrate into the district health system(78, 80). However, there is no mention of screening as part of the CHW's responsibilities(25).

4.3.3 Theme 3: Integration of services at PHC facilities

All infants in South Africa must be immunised four times in their first year of life, this ensures that they attend the Well Baby clinics. Monthly well baby visits, for services such as, growth monitoring, oral health and developmental screening, are encouraged and sick child visits may also occur(25). During these visits the caregiver needs to bring the RtHB along.

This study highlights the positive contribution this service play ensuring that children are seen regularly and that it provides an opportunity for the RN to do follow ups on developmental milestones.

According to Scherzer, all levels of specialities of health care workers who provide treatment for children in South Africa should be aware of children's development and behaviour by means of regular developmental surveillance and timely referrals to allied healthcare professionals when delays in development are detected(54). This study highlights the need to further investigate this as RN take most of the responsibility for early identification.

The KI mentioned that, although everyone can be involved, no one is currently taking full responsibility. The findings are that RN know that they are responsible, however, they are not supported extensively due to lack of specialists available in their areas. The findings of this study further suggests that RN rotate the responsibility of developmental screening at their respective clinics and they do not perceive other health professions to be responsible for early detection of developmental delays. Thus, no specific person is responsible. This could impact on continuity of care within the clinics. The KI shared that other health professionals should also come on board at the PHC level. They shared that it should be a trans-disciplinary team approach. However, exploring this was not within the scope of this study.

The National Workshop for the developmental screening group outlined criteria for developmental screening in South Africa(33). This group recommended that any developmental screening tool should only be used if there are appropriate interventions, management continuums and clear referral strategies(33). No clear

referral criterion has been specified for use with the RtHB developmental screening tool(57). Thus, there are few guidelines to assist the RN who need to make decisions regarding who should be referred, when they should refer children and whom they should refer children too. The KI' views highlighted that the referral route process differs from being non-existent to being very specific. They all shared that there is no formal referral route available for the RN at PHC level.

Despite this the RN in this study all developed a clear, individualised referral route according to the needs of their facility and the availability of specialists in their areas.

The KI highlighted that there is no formal way of doing referrals and feedback. Thus this study highlights that despite lack of protocol guidelines and formal referral routes RN are developing referral routes that work best for them in their areas. The findings in this study also highlight that the RN know who they need to refer specific cases to.

4.3.4 Theme 4: Protocol to guide PHC nurses

According to the WHO most low and middle income countries (LMICs) do not have a model for the I) promotion and monitoring of the development of children, II) prevention and early identification of risk factors associated with developmental difficulties or disabilities, and iii) early interventions(14).

Early identification of childhood disabilities in South Africa is straddled across the following three Government departments: DoH, DoE and DSD (67).The *White Paper on* INDS recognizes that there are outstanding policies in a number of areas, particularly in the area of identification of disabilities(68). The INDS explains that policies aimed at prevention of disabilities do not have clearly demarcated links to identification and early intervention policies(68). This study reflects the INDS in that no policy or protocol guidelines are available for the RN.

4.3.5 Theme 5: Fragmentation of services among the different levels of health care facilities

The findings of this study show that there is a fragmentation of services between PHC facilities and referral facilities. Early identification of developmental delays is a complex system which requires high quality assessments by trained professionals; effective

information sharing and collaboration by practitioners, working with parents to develop joint action plans; locating needed services within and outside the clinic or hospital, arranging successful referrals and conducting on-going monitoring and evaluation of intervention(25, 70).

Access to early intervention services in either public or private sector can be through various channels, such as, self-referral, referral from other organisations, other health or education professionals or through existing intervention programmes usually based at tertiary level health facilities(70).

The findings in this study displayed the lack of feedback once a child has been referred to the next level of intervention. The RN shared that there was a general lack of feedback from the hospitals once a child has been referred. Thus there appears to be poor on-going monitoring and evaluation and this needs to be further explored in the future. Tertiary facilities can take over care and not inform the PHC facilities. This can make things difficult for the RN at PHC level as was noted by participants in this study.

Early identification of developmental delays is a complex system which includes arranging successful referrals and conducting on-going monitoring and evaluation of intervention(25, 70). This study highlights the lack of feedback from the tertiary facilities to the PHC after a child has been referred. This makes it difficult for the RN to do follow up's when a mother brings her child to the clinic. The follow up's depend on how much the mother knows what the specialist attended to at the hospital. This is an area needs to be further explored to ensure continuity of care for the child.

4.4 Factors contributing to early identification of developmental delays in children

Even though the RN are perceived to have no challenge in using the RtHB, limited time to do screening, long queue of patients, ignorance of caregivers/parents, financial constraints and lack of transport for Allied healthcare professionals contribute negatively to the detection of developmental delays in children by PHC nurses.

Previous studies conducted in South Africa highlighted that limited time and infrequent health visit (7, 130); and long queue of patients, irresponsibility, stigma, and ignorance(131), promote delayed diagnosis and intervention of children with developmental delays.

4.4.1 Theme 1: Service delivery issues

Rural areas in South Africa still tend to be the most under-served and historically neglected(101). Almost 40% of the South African population live in rural areas(102). Findings of this study are that RN felt that the screening takes a lot of their time and that there were always long queues of patients waiting to be attended too. This finding was evident in both the urban and rural PHC settings.

Studies conducted by Rising, Baron & Averill and Babes & Sarma reported that health practitioners may shorten their service time (in some cases without being aware) when there are many patients waiting to be attended to (97, 98). Concerns such as these, provide reasons why nurses in PHC settings in rural areas could not be prioritising the early identification of developmental delays. What this study found was that RN felt that the screening took up too much time when they had to attend to long queues of patients irrespective of whether they were in urban or rural settings.

4.4.2 Theme 2: Attitude of parents

The findings in this study are that the attitude parents are negatively impacting the early detection of developmental delays. The number of visits to the clinics Guralnick highlighted the lack of focus on assessment of stressors affecting parents , such as, information needs, interpersonal and family distress, resource needs, and confidence threats(70, 106).

The study findings reveal that the majority of RN perceive parents as irresponsible, by not taking responsibility, not seeking medical advice and being less interested or concerned. Environmental conditions such as poverty, HIV/AIDS and risks associated with childhood disability provide a favourable environment for the development of stressors which may impact family patterns of interaction(106). So what can be perceived by the RN as irresponsible behaviour could be behaviour related to stressors experienced by parents. The number of visits to the clinics Guralnick highlighted the lack of focus on assessment of stressors affecting parents , such as, information needs, interpersonal and family distress, resource needs, and confidence threats(70, 106).

Furthermore, communities across Africa view people with disabilities negatively because they believe that it is a punishment from God and is of a spiritual nature(104,

105). Perceptions like these can prohibit families from accessing healthcare services or seeking help when they become aware of developmental difficulties. This study found that RN in urban areas observed that some parents do have issues around stigma and they display this by either avoiding normal clinic hours or keeping their children at home.

The majority of rural RN in the study, however, shared that stigma was not a concern of the parents. The findings in this study are incongruent to other studies where cultural belief systems are noted as influencing the decisions of people using health care services (93, 103). There is no evidence in this study linking cultural belief systems or stigma to lack of attendance. This could be related to study limitations or these communities can be exceptions to the norm. However, this needs to be further explored.

4.4.3 Theme 3: Inaccessibility

Despite South Africa being relatively well off, compared to neighbouring countries, poverty is still a big challenge for a large majority of the population and universal , equitable access to health care is still out of reach(93).

In rural parts of South Africa access to required specialists are even more difficult where families may travel for two days or more to get to a clinic and where chances are that the required specialist might not be available on the day of their arrival (70, 71). The findings in this study support these studies.

According to Peters et al. people in poor countries have less access to healthcare services than those in richer countries, and within these poor countries, people have less access to healthcare services than better-off citizens(92, 93). This study reveals that financial constraints have been identified as a factor to why parents could not be accessing services in these sub-districts.

Furthermore, the absence of clear protocols, the low priority status of child development with nursing and medical professionals, as well as the variations in families access to health services due to financial, geographical, transport and other constraints, make it difficult to ensure that children’s development is monitored effectively(70).

A sub-theme that emerged from this study was the lack of transport available for the specialist to access clinics. This resulted in patients coming for their appointments but not being seen because the allied health professional did not have transport to access the clinic.

In conclusion this Chapter explored the main study objectives and concluded that all RN in this study had a basic knowledge of developmental delays and they all used the RtHB as a guide for detection of developmental delays. They rely heavily on observation of the child during clinic consultations and use the mothers concerns raised as surveillance measures. They do not use any formal assessment techniques to complete the RtHB developmental screening tool. Community and CHW reported information also positively contributed to the early detection of developmental delays.

Despite the re-engineering of the PHC the RN highlighted that staff shortages, lack of allocated space to perform developmental screening and the lack of availability of specialist in the area affected the early detection of developmental delays. The RN display innovation and flexibility in a health system where there is no protocol guidelines and proper referral routes. With limited time to do developmental screening and long patient queues early detection of developmental delays is not a high priority.

In addition, the parents' perceived irresponsibility and stigma experienced more specifically in urban areas further exacerbate the problems faced by RN in Bojanala District to detect developmental delays early.

4.5 Limitations of the Study

4.5.1 Generalisation of the study

The aim of the study was to explore the early identification of developmental delays in children aged 0-5 years by RN in the Bojanala District. Even though the sample size was limited to 10 participants the use of an in-depth interview for data collection provided rich data. Another limiting factor is the uniqueness of each of the sub-districts that the research was conducted in. Consequently, the findings of this study cannot be generalised to other districts in the Northwest Province or other provinces in South Africa. However, since data was derived from experts in the field and also from RN working in PHC facilities, it is convincing enough to mention that, the findings could reflects what is happening in the country as a whole.

This affirmation is drawn from the truth that the study participants do not function as individuals but are simply servants, who are guided by policies and implementation measures set by the country. And these policies and measures are often similar across the provinces. In the case of developmental delays, the measure set by the country is the RtHB.

4.5.2 Complete team perspective

The KI did not include a RN because KI were sought within the disability field. The views of the RN would have created a broader picture of the factors affecting the early identification of developmental delays in children aged 0-5 years by RN in the Bojanala District. Despite this limitation the three KI were from three different healthcare disciplines which provided a good overview for the researcher to work with.

4.5.3 Bias

The KI did not include anyone specific that had worked in the Northwest Province. However, all the KI had a variety of experiences in most provinces in South Africa. Another bias is that the primary researcher is working with children with disability and as such had prior knowledge about the topic from her interactions with the children and their parents or custodians. Nevertheless, all prior information about this topic were kept aside and the only findings presented were those revealed from the data.

4.5.4 Objectivity

The researcher at times sensed that some of the RN answered according to what they felt the researcher was expecting and not according to their own truth. Thus despite the researcher trying to be as objective as possible, it was possible that this phenomenon occurred.

4.5.5 Variety of study participants

Widening the study to include the mothers, community members, and referral facilities could provide more insight into the challenges faced by RN in the PHC setting. Notwithstanding, purposively selecting the study participants and using in-depth interview provided all the answers for the study objectives.

In addition, data saturation or similarity was observed from the selected study participants. Therefore, this study provides a good baseline for further research to be conducted to compliment the present findings.

4.5.6 Time Stressors

Most of the RN despite having set times for the interviews were mostly stressed during the interviews because of the long queues of patients waiting to be attended to. So even though the interview ran the full course and the RN were welcoming in their approach there was a sense of urgency that could also have led to the factors shared under objectivity. All the RN were offered to have the interviews done after hours but they all requested to meet during work hours. Fortunately, the interviews did not exceed 30 minutes per participant. And within this time frame, in-depth interviews were carried out and information was obtained for all the questions highlighted on interview guide.

CHAPTER FIVE

RECOMMENDATIONS AND CONCLUSION

5.1 Recommendations

Based on the findings from the present study, the following recommendations are made:

5.1.1 Detection of developmental delays in PHC facilities by Registered Healthcare Nurses

- The district should consider providing workshops on the RtHB developmental screening tool.
- The district should consider providing workshops on the relationship between HIV/AIDS, TB, malnutrition and developmental delays in children aged 0-5years.

5.1.2 Co-ordination of health systems in the early identification of developmental delays

- The district should allocate and make provision for specific spaces at PHC facilities for developmental screening to take place.
- Protocol guidelines for the early detection of developmental delays at PHC facilities need to be developed at a national level.
- The provincial DoH should consider investigating methods of recruitment and retention of staff in order to improve the shortage of staff in these sub-districts.
- A referral route and protocol guideline should be developed for RN and introduced by the district to support the RN at PHC facilities in the absence of a national guideline.
- The district should consider providing workshops for the CHW to further empowerment regarding developmental delays and childhood disabilities.

5.1.3 Factors contributing to early identification of developmental delays in children

- The district should consider running capacity building and skills training on detection of childhood disabilities for RN.
- New techniques for the early detection of developmental delay should be introduced and integrated from a National level.

- The district should consider providing workshops for parents/caregivers on the importance of early identification of delayed milestones and where to find help.

5.2 Conclusion

The present study explored RN perceived factors affecting early identification of developmental delays in PHC facilities in Bojanala District. Information was collected by one-on-one interview sessions with RN. The main findings include the use of informal measures without diagnostic instruments to identify developmental delays, lack of sufficient support from the health system, and limited collaboration between different governmental sectors in detection of childhood disabilities.

In summary, there are both positive and negative factors affecting the early identification of developmental delays by RN in the Bojanala District. These factors range from CHW assistance, availability of the RtHB to inaccessibility and lack of protocol guidelines, to name a few. The positive and negative factors were equally spread across the rural and urban sub-districts. There is a need for support from the national health sector and collaboration among governmental and non-governmental sectors.

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APPENDIX 1: Plagiarism Declaration



I, **Andrea Abrahams**, Student number **881094** am a student registered for the degree of Master of Public Health in the academic year 2018.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature: _____ Date: _____

APPENDIX 2: Key Informant Interview Guide

Background Information

Interview No. :

Profession:

Early Identification

- Please share how would you define the term Developmental delay?
- What is the current norm in South Africa to detect children with developmental delays at a Primary Health Care Level?
- Can you share what you understand by the term developmental surveillance?
- According to your experience what assists or challenges PHC Nurses from ensuring that developmental surveillance occur at PHC Clinic level?
- Please share which tools are currently being used in PHC Clinics to screen development?
- According to your experience can you please share when and where these tools used within a PHC Clinic setting?

Co-ordination of the health system in South Africa

- Besides nursing staff who else is assisting with developmental screening at PHC settings in South Africa?
- What is your opinion regarding assistance with developmental screening at PHC settings in South Africa?
- What policies are guiding PHC Nurses at PHC settings to ensure the efficient detection of developmental delays?
- How often according to policies or guidelines should a child be screened?
- Can you please describe the process that follows once a delayed developmental milestone is detected at a PHC clinic?
- In your experience how are referrals followed up by Registered Nurses in PHC Facilities?
- What should the ideal clinic be doing to ensure that early detection of developmental delays occur at PHC level?

Factors contributing to the detection of developmental delays

- Please share what in your opinion is the role of families in early identification of developmental delays in a South African context?
- Please share what in your opinion is the role of the community in early identification of developmental delays in South Africa?
- What are your hopes for early identification of developmental delays in the South Africa?

APPENDIX 3: Registered Nurses Interview Guide

Interview No:

Years in Primary Healthcare setting:

Year of graduation:

Qualifications:

Additional Training:

Early Identification

- Please share your understanding of developmental delays?
- What has your experience in providing care for child/ren with a developmental delay/s been like?
- Do you view developmental screening as part of your job description?

(If yes, how often do you do it?) (If, No please share the reason/s)

- Please describe the tools or methods you use for screening developmental delays at your clinic?
- Please describe the challenges you experience using these screening tools?

Co-ordination of the health system

- Tell me about the particular protocol guide you use to screen the developmental delays at your clinic?
- Please tell me who is responsible for early detection of developmental delays at your clinic?
- Please Describe the process that follows once a delayed developmental milestone is detected at your clinic?

Factors contributing to the detection of developmental delays

- Please share specific context or situations that typically influence or affect your experiences of screening developmental delays?
- Please share your experiences with parental involvement regarding detecting developmental delays.
- How would you view community involvement to support parents to detect developmental delays?
- In your experience how does stigma prevent mothers/caregivers from bringing their children to the clinic for screening?
- Please describe the role CHW's play in early detection of developmental delays in the community.
- What do you think your main role as a Registered PHC Nurse is when it comes to detection of developmental delays at a clinic level?

APPENDIX 4: Provisional Ethical Approval Certificate WITS

Human Research Ethics Committee (Medical)

Research Office Secretariat: Senate House Room SH 10004, 10th floor. Tel +27 (0)11-717-1252
Medical School Secretariat: Phillip Tobias Building, 2nd Floor Tel +27 (0)11-717-2700
Private Bag 3, Wits 2050, www.wits.ac.za Fax +27 (0)11-717-1265

20 May 2016

To Whom It May Concern

SUBJECT: CONFIRMATION OF RECEIPT OF ETHICS APPLICATION

Protocol Ref No: M160423

Protocol Title: Exploring the Factors Affecting the Early Identification of Development Delays in Children Aged 0-5 year by Registered Healthcare Nurses in Bojanala District

Principal Investigator Miss Andrea Abrahams

Department: School of Public Health

This letter serves to confirm that the Human Research Ethics Committee (Medical) has received an application for clearance of research for the abovementioned study. In order for a clearance certificate to be issued, the researcher is required to submit written approval to conduct the study in your district/institution.

The researcher has been informed that this letter is not a clearance certificate and that the study cannot commence without your approval and receipt of a clearance certificate from the HREC (Medical).

Should you have any queries, you may contact me at tel: 011 717 1252/1234/2700 or by email zanele.ndlovu@wits.ac.za

Yours Faithfully,

.....

Ms Zanele Ndlovu
Administrative Officer
Human Research Ethics Committee (Medical)

UNIVERSITY OF THE WITWATERSRAND
OFFICE OF THE DEPUTY VICE CHANCELLOR RESEARCH
20 MAY 2016
RESEARCH OFFICE HREC (Medical)
JOHANNESBURG

APPENDIX 5: Letter of Request to the North West Provincial Department of Health

University of Witwatersrand

Private Bag

Johannesburg

30th May 2016

North West Provincial Department of Health

Private Bag X2068

Mmabatho

2735

Dear Sir/ Madam

Re: Permission to conduct research in the Bojanala Platinum Health District

My name is Andrea Abrahams and I am a third year Masters in Public Health student at the University of Witwatersrand. My supervisors are Dr. Richard Cooke and Jacqui Couper from the WITS Centre for Rural Health.

I am writing to you to request permission to conduct research in the Bojanala Platinum Health District. The aim of this research is to explore factors currently affecting the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in selected facilities in Bojanala District. The Objectives of the study are:

1. To describe how developmental delays are currently detected in Primary Health Care (PHC) facilities by Registered Healthcare Nurses in the Bojanala District.

2. To understand how the co-ordination of the health system in Bojanala District currently affects the early detection of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Primary Healthcare Facilities.

3. To explore the factors currently contributing to the detection of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Primary Health Care facilities in Bojanala District.

4. To make recommendations to enhance the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Primary Health Care facilities in Bojanala District.

Undertaking this research in your Province will include interviewing 10 Registered Healthcare Nurses at 10 selected clinics in the Bojanala District. The Sub-districts of Moses Kotane and Rustenburg have been identified because of their rural and urban differences for the study. Madibeng sub-district has been identified as a pre-test site. Anonymity of participants will be ensured at all times and participation is voluntary (all instruments and consent forms are attached).

This data will be analysed and findings will be gladly shared with your department. To assist you in reaching a decision, I have attached to this letter:

(a) A copy of the Confirmation of receipt of ethics application letter by the University of Witwatersrand Human Research Ethics Committee.
(b) A copy of the research instruments which I intend using in my research.
(c) A copy of the research proposal.

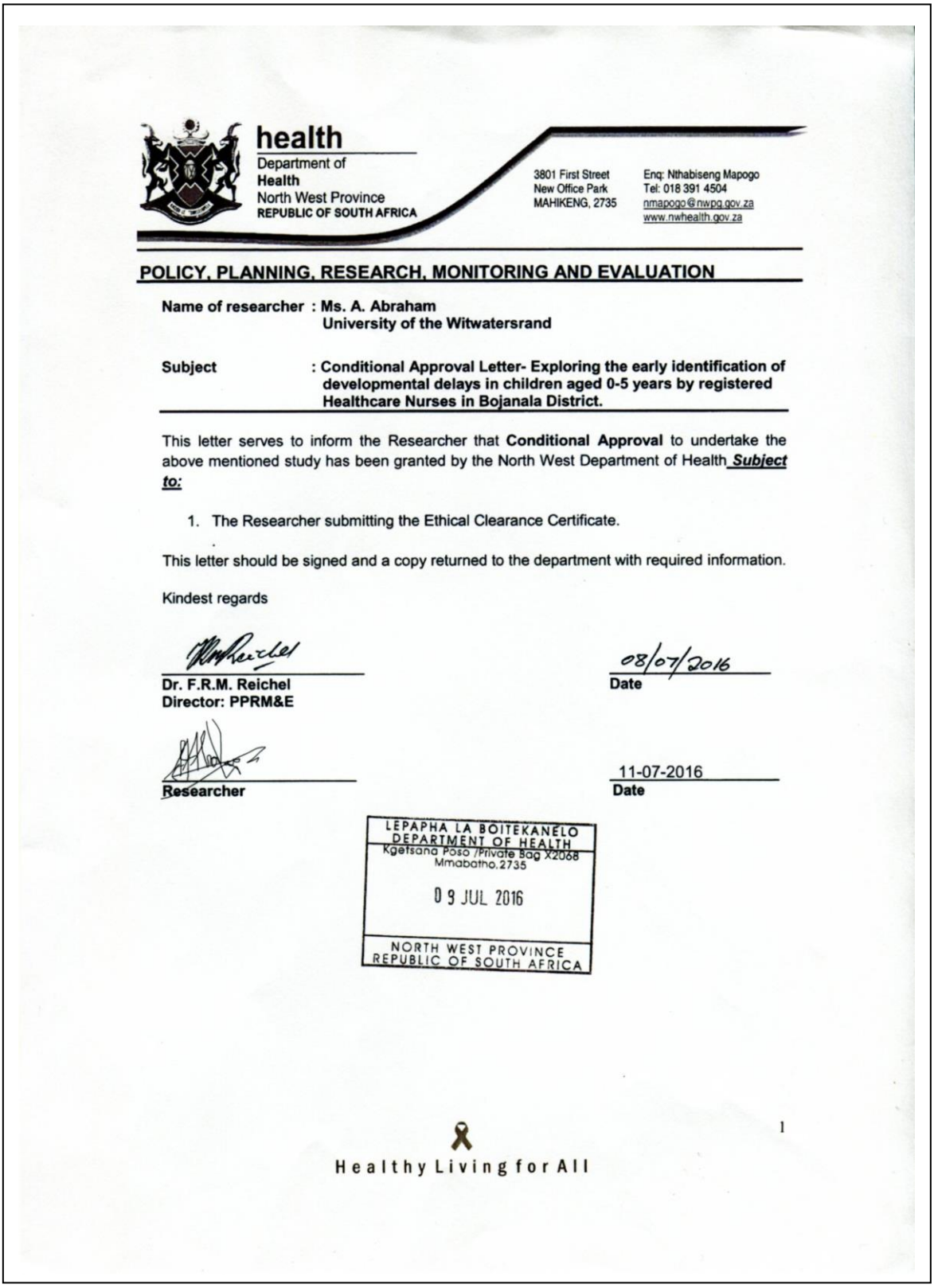
We will endeavour to implement this research project with the utmost integrity at all times.

We are looking forward to your input and kindly request that you consider this application for approval from your department. Should you have any additional queries, which have not been dealt with in the attached protocol and supporting documentation, please contact me, as I am the primary investigator (details listed below).

We look forward to hearing from you.

Kind Regards
Andrea Abrahams
BSc (OT) UCT
074 660 9820
abrahams.andrea@googlemail.com

APPENDIX 6: Provisional Ethics Clearance Certificate from North West Provincial Department of Health



health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

3801 First Street
New Office Park
MAHIKENG, 2735

Enq: Nthabiseng Mapogo
Tel: 018 391 4504
nmapogo@nwpg.gov.za
www.nwhealth.gov.za

POLICY, PLANNING, RESEARCH, MONITORING AND EVALUATION

Name of researcher : Ms. A. Abraham
University of the Witwatersrand

Subject : Conditional Approval Letter- Exploring the early identification of developmental delays in children aged 0-5 years by registered Healthcare Nurses in Bojanala District.

This letter serves to inform the Researcher that **Conditional Approval** to undertake the above mentioned study has been granted by the North West Department of Health ***Subject to:***

1. The Researcher submitting the Ethical Clearance Certificate.

This letter should be signed and a copy returned to the department with required information.

Kindest regards

Dr. F.R.M. Reichel
Director: PPRM&E

08/07/2016
Date

Researcher

11-07-2016
Date

LEPAPHA LA BOITEKANELO
DEPARTMENT OF HEALTH
Kgetsana Poso /Private Bag X2068
Mmabatho, 2735
09 JUL 2016
NORTH WEST PROVINCE
REPUBLIC OF SOUTH AFRICA

Healthy Living for All

1

APPENDIX 7: Ethics Clearance Certificate WITS

R14/49 Miss Andrea Abrahams

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160423

NAME: (Principal Investigator)	Miss Andrea Abrahams
DEPARTMENT:	School of Public Health Bojanala Platinum Health District Primary Health Care Facilities
PROJECT TITLE:	Exploring the Factors Affecting the Early Identification of Development Delays in Children Aged 0-5 year by Registered Healthcare Nurses in Bojanala District
DATE CONSIDERED:	06/05/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Richard Cooke
APPROVED BY:	Professor P. Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	25/07/2016

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 10004,10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the the conditions under which I am/we are authorised 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 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 review in April and will therefore be due in the month April each year.

Principal Investigator Signature Date 15-08-2016

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 8: Ethics Clearance Certificate North West Department of Health



health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

3801 First Street
New Office Park
MAHIKENG, 2735

Enq: Nthabiseng Mapogo
Tel: 018 391 4504
nmapogo@nwpg.gov.za
www.nwhealth.gov.za

POLICY, PLANNING, RESEARCH, MONITORING AND EVALUATION

Name of researcher : Ms. A. Abraham
University of the Witwatersrand

Physical Address
(Work/ Institution) _____

Subject : Research Approval Letter – Exploring the early identification of developmental delays in children aged 0-5 years by registered Healthcare Nurses in Bojanala District.

This letter serves to inform the Researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The Researcher is expected to arrange in advance with the chosen facilities, and issue this letter as proof that permission has been granted by the Provincial office.

This letter of permission should be signed and a copy returned to the department. By signing, the Researcher agrees, binds him/herself and undertakes to furnish the Department with an electronic copy of the final research report. Alternatively, the Researcher can also provide the Department with electronic summary highlighting recommendations that will assist the department in its planning to improve some of its services where possible. Through this the Researcher will not only contribute to the academic body of knowledge but also contributes towards the bettering of health care services and thus the overall health of citizens in the North West Province.

Kindest regards

Dr. F.R.M. Reichel
Director: PPRM&E

10/08/2016
Date

LEPAPHA LA BOITEKANELO
DEPARTMENT OF HEALTH
Kgetsana Poso /Private Bag X2068
Mmabatho,2735
11 AUG 2016
NORTH WEST PROVINCE
REPUBLIC OF SOUTH AFRICA

Researcher

15-08-2016
Date

Healthy Living for All

APPENDIX 9: Information Sheet for the KI

Good Day,

My name is **Andrea Abrahams**, currently a student doing my Masters in Public Health at the University of Witwatersrand. To fulfil the requirements for a Master degree I am required to undertake a research component. The research topic is as follows:

"Exploring the factors affecting the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Bojanala District"

The purpose of this correspondence is to invite you to participate in this research study. I would be most grateful if you would agree to participate in this study.

What is the aim of this study?

The aim of this study is to explore factors affecting the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in selected facilities in Bojanala District, currently. It is hoped that the results of the study will have input into the development of early identification of developmental delays at PHC clinics.

What is expected from you as a participant?

If you agree to participate after I explain the purpose of this research, you will be required to undergo a one-on-one in depth interview with the researcher where you will be asked a series of questions related to the topic. The interview will last between 45 minutes to one hour.

Where and when will the study be conducted?

The study will be conducted during the month of August 2016 during a telephonic or Skype call. A suitable room that is quiet and confidential will be used during the call. The study will be conducted during the week and times will be confirmed in advance.

Are there benefits to the participant?

No. There are no direct benefits to you, but your participation in this research and the findings may help improve the knowledge on early identification of developmental delays in Primary Healthcare clinics.

What about confidentiality?

Confidentiality will be maintained at all times. No names are required at any stage during the research. At the top of the interview , which only the researcher and supervisor will have access to, will be a study number to help order and identify the interview but this will not be linked back to you as the participant. These and the tape recorder will be kept in the researcher's safe that will be locked at all times.

The tapes will be stored for 2 years after publication or for 6 years without publication, thereafter it will be destroyed. In addition, the findings will be reported and published as group and not individual results, in order to protect any identifying information.

May I withdraw from the study?

Certainly, you may do this at any time without having to give a reason. Your participation in this study is entirely voluntary. Your responses will be confidential and you will not be victimized in any way by not participating or by withdrawing from the study.

Your participation in the study will be highly appreciated as it will aid the researcher to understand the factors affecting the early identification of developmental delays in children aged 0-5 years in this district and to make recommendations to improve this area of work.

If you are unhappy about anything that takes place or would like more information please do not hesitate to contact the research supervisor. Alternatively, you can contact the chairperson of the Human Research Ethics Committee (medical) at the University of Witwatersrand.

Principal Researcher:

Andrea Abrahams BSc(OT)

Email : abrahams.andrea@googlemail.com

Cell: 074 660 9820

Supervisor:

Dr.Richard Cooke BSc Finance, MBChB, MMed (Family Medicine)

Email: Richard.Cooke@wits.ac.za

Human Research Ethics Committee (Medical)

University of Witwatersrand

Medical School Secretariat PV Tobias Building

Tel: 011-717 1252/2700

Should you wish to participate, please read and sign the attached consent form.

Thank you.

APPENDIX 10: Consent Form to participate in the study

STATEMENT CONCERNING PARTICIPATION IN A RESEARCH PROJECT

Name of project: Exploring the factors affecting the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Bojanala District

- I understand that I have been invited to participate in the above research project. The aims and objectives of the proposed study have been explained to me.
- I was provided with the opportunity to ask questions and have been given adequate time to think about the project. The aim of the study is sufficiently clear to me.
- I have not been pressurized in any way. I understand that participation in this project is completely voluntary and that I may withdraw from it at any time and without supplying reasons.
- I understand that identifying information will be kept to a minimum and separate from the record of the interview (audio recorded and written) and written submission.
- I am fully aware that the results of this project will be used for scientific and educational purposes and may be published. I agree to this provided my privacy is guaranteed.

Name of participant: ……

I hereby consent to participate in the interview Signature: ……

Place: …… Date: ……/2016

Statement by the researcher:

I provided verbal and written information regarding this project. I agree to answer any future question concerning the project as best I am able. I will adhere to the approved protocol.

Name of researcher: …… Signature: ……

Place: …… Date: ……

Principal Researcher:

Andrea Abrahams BSc (OT)

Email: abrahams.andrea@googlemail.com

Cell: 074 660 9820

Supervisor:

Dr.Richard Cooke BSc Finance, MBChB, MMed (Family Medicine)

Email : Richard.Cooke@wits.ac.za

Human Research Ethics Committee (Medical)

University of Witwatersrand

Medical School Secretariat PV Tobias Building

Tel: 011-717 1252/2700

APPENDIX 11: Consent Form to be audio recorded and transcribed

Dear Sir/ Madam,

"Exploring the factors affecting the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Bojanala District"

The research study mentioned above involves the audio recording of your interview with the researcher. Neither your name nor any other identifying information will be associated with the audio or audio recording or the transcript. Only the research team will be able to listen to the recordings.

The tapes will be transcribed by the researcher and erased once the transcriptions are checked for accuracy. Transcripts of your interview may be reproduced in whole or in part for use in presentations or written products that result from this study. Neither your name nor any other identifying information (such as your voice or picture) will be used in presentations or in written products resulting from the study.

By signing this form, I am agreeing to the following:

1) The Researcher can audio record me in an interview as part of her research.
2) I know that the researcher will present her findings and publish the results of this research and that my name will not be used in any of these.
3) Audio recording during interviews is voluntary and I may request the researcher to stop recording during the interview or to erase a portion of the recording.
4) The interviewer will write down my responses I understand that should I not agree to the audio recording of the interview, but consent to the interview nonetheless.

Name of participant: _____

Participant's Signature: _____

Date: _____

APPENDIX 12: Information Sheet for Registered Healthcare Nurses

Good Day,

My name is **Andrea Abrahams**, currently a student doing my Masters in Public Health at the University of Witwatersrand. To fulfil the requirements for a Master degree I am required to undertake a research component. The research topic is as follows:

"Exploring the factors affecting the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in Bojanala District"

The purpose of this correspondence is to invite you to participate in this research study. I would be most grateful if you would agree to participate in this study.

What is the aim of this study?

The aim of this study is to explore factors affecting the early identification of developmental delays in children aged 0-5 years by Registered Healthcare Nurses in selected facilities in Bojanala District, currently. It is hoped that the results of the study will have input into the development of early identification of developmental delays at PHC clinics.

What is expected from you as a participant?

If you agree to participate after I explain the purpose of this research, you will be required to undergo a one-on-one in depth interview with the researcher where you will be asked a series of questions related to the topic. The interview will last between 45 minutes to one hour.

Where and when will the study be conducted?

The study will be conducted during the month of April 2016 at the Primary Healthcare Clinic where you are currently employed. A suitable room that is quiet and confidential will be used at your clinic. The study will be conducted during the week and times will be confirmed in advance.

Are there benefits to the participant?

No. There are no direct benefits to you, but your participation in this research and the findings may help improve the knowledge on early identification of developmental delays in Primary Healthcare clinics.

What about confidentiality?

Confidentiality will be maintained at all times. No names are required at any stage during the research. At the top of the interview , which only the researcher and supervisor will have access to, will be a study number to help order and identify the interview but this will not be linked back to you as the participant.

These and the tape recorder will be kept in the researcher's safe that will be locked at all times. The tapes will be stored for 2 years after publication or for 6 years without publication, thereafter it will be destroyed. In addition, the findings will be reported and published as group and not individual results, in order to protect any identifying information.

May I withdraw from the study?

Certainly, you may do this at any time without having to give a reason. Your participation in this study is entirely voluntary. Your responses will be confidential and you will not be victimized in any way by not participating or by withdrawing from the study.

Your participation in the study will be highly appreciated as it will aid the researcher to understand the factors affecting the early identification of developmental delays in children aged 0-5 years in this district and to make recommendations to improve this area of work.

If you are unhappy about anything that takes place or would like more information please do not hesitate to contact the research supervisor. Alternatively, you can contact the chairperson of the Human Research Ethics Committee (medical) at the University of Witwatersrand.

Principal Researcher:

Andrea Abrahams BSc (OT)

Email: abrahams.andrea@googlemail.com

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Dr. Richard Cooke BSc Finance, MBChB, MMed (Family Medicine)

Email: Richard.Cooke@wits.ac.za

Human Research Ethics Committee (Medical)

University of Witwatersrand

Medical School Secretariat PV Tobias Building

Tel: 011-717 1252/2700

Should you wish to participate, please read and sign the attached consent form.

Thank you.