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THE USE OF THE ROAD-TO-HEALTH BOOKLET DEVELOPMENTAL SCREENING IN THE DETECTION AND REFERRAL OF EARLY DEVELOPMENTAL DELAY IN THE PELONOMI HOSPITAL DRAINAGE AREA

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master in Science in Medicine in Child Development.

Johannesburg, 2016

DECLARATION

I, Bernice Naborn, declare that this research report is my own unaided work and that I have acknowledged all sources to the best of my knowledge. This research report is being submitted in partial fulfilment of the degree of Master of Science in Medicine (child development) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signature_____

_____ day of _____2016

ABSTRACT

Context: The use of the Road-to-health booklet (RTHB) developmental screening checklist may aid in the early detection of, referral and intervention for developmental delay in the primary care setting.

Objective: The aim of this study was to examine the use of the new Road-to-health booklet developmental screening checklist by the nursing staff of referring clinics at any visit before being admitted to hospital. This study aimed to compare the results of nurse-completed screening checklists with those completed by a paediatrician, and to compare the referral patterns of children with a suspected developmental delay by both the nursing staff and paediatrician. This study further aimed to establish whether there was an association between caregiver concern and the identification of a delay by using the RTHB checklist by the clinic staff or the paediatrician.

Design, setting and patients: A cross-sectional descriptive study of patients younger than six years of age referred to a hospital in Bloemfontein, South Africa, during May 2014 to October 2014.

Methods: Children referred to Pelonomi Hospital for admission were eligible for inclusion in the study. The use and results of the RTHB developmental screening checklist completed prior to admission by the referring clinics' nursing staff were documented. The caregivers

were questioned on the development of their child. The principal investigator, who is a paediatrician, repeated the same developmental screening checklist upon referral to the hospital. The outcome of the screening checklist completion and subsequent referral patterns of the clinics' nursing staff were compared to that of the paediatrician.

Results: The RTHB developmental screening checklist was completed by their clinic prior to referral in 45/113 (40%) of the study participants. In 6/45 (13%) of cases the clinic detected a possible delay. A developmental delay was suspected by 28/113 (25%) of the caregivers. The paediatrician detected a possible developmental delay in 32/113 (28%) of the cases. There was a statistically significant difference in the proportion of children with developmental delay detected by the paediatrician versus children with developmental delay detected by the clinic (14/45 [31%] vs 6/45 [13%]; $p < 0.0003$). Parental concern was associated with a higher rate of identifying delays as compared to the use of the RTHB by both the paediatrician ($p<0.0001$) and the clinic nursing staff ($p<0.0001$). There was no significant difference in the referral pattern of the clinic versus the paediatrician once a possible delay had been detected.

Conclusion: The RTHB developmental screening checklist is not used optimally to detect developmental delays at a primary care level.

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ABBREVIATIONS

GHS	General Household Survey
HIV	Human Immunodeficiency Virus
ICF	The International Classification of Functioning, Disability and Health
IQR	Interquartile range
M-CHAT	Modified Checklist for Autism in Toddlers
PEDS	Parents' Evaluation of Developmental Status
RTHB	Road-to-Health Booklet
SD	Standard deviation
TQQ	Ten Questions Questionnaire
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.1 Background

The term developmental delay refers to children under the age of five years who do not attain developmental milestones at the expected age.(1) There is considerable variation in the age at which children attain milestones and this should be taken into account. When a child does not reach a specific milestone at the latest expected age, the child is categorized as having a developmental delay.(2)

Developmental milestones are grouped according to developmental domains. These domains include motor, language, cognitive or adaptive, and personal and social development.(2) A delay can be present in one or more of these domains.

According to the Lancet's series on child development in developing countries, an estimated 200 million children under the age of five years do not reach their full developmental potential.(3) The global prevalence of developmental disability in children below 14 years of age is estimated to be 5.1%.(4)

The true prevalence of developmental disability in South Africa has not been established yet. There are only a few small studies published on the prevalence of disability in South

Africa.(5) Data from the General Household Survey (GHS) and Census 2001 show considerable variation in the prevalence of disability.(6) Census 2001 estimated that 5% of children younger than 19 years of age have a disability.(6)

Higher prevalence rates of disability seen in orphaned children and children with low parental education levels are in keeping with international data that shows poorer developmental outcomes associated with poverty, malnutrition and non-stimulating environments.(3)

The rationale for early identification of developmental delays is that children's brains demonstrate plasticity.(7,8) Plasticity allows the brain to adapt to circumstances and therefore creates a window of opportunity for early intervention to have maximal benefit.(9) Early intervention, when the brain is most plastic, has the greatest impact with the best possible outcome.

Early interventions such as correction of amblyopia, constraint induced therapy for hemiplegic infants and improvement of language stimulation are clinical examples of the brain's ability to alter its structure and function according to experience provided.(9-12) Numerous studies confirm the efficacy of early intervention for neuro-developmental disorders.(13)

Early identification of children with delays through developmental surveillance; screening and formal evaluation allows early intervention to take place. Developmental surveillance and screening should take place in the primary care setting and should form part of routine well-child visits. Caregivers and primary health care workers are integral to the implementation of this process.(14)

As the primary health care system in South Africa may be inadequately equipped to deal with the current patient load, the role of the caregiver in identifying delays is becoming more important.(15,16)

The Road-to-health booklet (RTHB) is a patient-held record that is used to document health, growth and development of children in South Africa. It also provides the well-child visit and immunization schedule. The development checklist in this booklet is basic and freely available to all caregivers and health care workers. It provides the platform to integrate developmental screening with routine well-child visits and it is intended to bridge the gap in early identification of developmental delay.

1.2 Problem statement

There has only been one previous study comparing the usefulness of the RTHB developmental screening checklist with a parent-reported screening tool.(17) No studies have been done to evaluate if the checklist is actually being used at a primary care level. It

would be of interest to investigate whether it is being used to correctly identify and refer children with a possible developmental delay. Results could be applied to plan, implement and monitor a feasible developmental surveillance program in South Africa.

1.3 Aim of study

The aim of this study was to examine the use of the new Road-to-health booklet developmental screening checklist by the nursing staff of referring clinics. This study further aimed to compare the results of nurse-completed screening checklists with those completed by a paediatrician, and to compare the referral patterns of children with a suspected developmental delay by both the nursing staff and paediatrician.

1.4 Study objectives

a) To estimate the proportion of completed vs. not completed developmental screening checklists in the Road-to-health booklet of children referred to Department of Paediatrics, Pelonomi Hospital.

b) In children whose developmental screening checklist was done by clinic nursing staff:

   - To estimate the proportion of children with a suspected developmental delay according to the clinic nursing staff.

- If a suspected developmental delay was present, to document in which domain (vision/adaptive, hearing and communication or motor development) the suspected delay had occurred and to establish whether a contributing aetiological factor could be identified.

- To document the referral pattern of the suspected developmental delay by the nursing staff.

c) To have the developmental screening checklist repeated by a paediatrician upon referral in order to:

- Calculate the proportion of children with a suspected developmental delay according to the paediatrician.

- If a suspected developmental delay was present, to document in which domain (vision/adaptive, hearing and communication or motor development) the suspected delay had occurred and to establish whether a contributing aetiological factor could be identified.

- To document whether and to whom the paediatrician referred a child with a suspected delay.

d) To compare the findings of the developmental screening checklist to that documented by the clinic nursing staff with the repeat assessment of a paediatrician.

e) To establish whether care-giver concern was associated with increased detection of delays by the clinic staff and the paediatrician.

CHAPTER 2

DEFINITIONS

2.1 Developmental delay

Developmental delay is a term used when referring to children, usually under the age of five years, that do not attain developmental milestones at the expected age.(1)

2.2 Developmental milestones

Developmental milestones are abilities, skills or behaviours that should be attained by a specific age. Milestones are achieved in a sequential manner and follow each other in order of complexity. (18)

2.3 Developmental domains

Developmental milestones are grouped together in streams or domains of development. (18)

2.4 Developmental screening

Developmental screening refers to the use of a standardized screening tool to identify those children at risk of a delay.(19)

2.5 Developmental surveillance

Developmental surveillance is the informal process of continuously monitoring the developmental trajectory of every child in order to recognize those children who may be at risk of a delay.(20)

2.6 Disability

Disability refers to impairment or inability to perform a certain task as would be expected within a social or physical context.(18)

2.7 Developmental disorder

Developmental disorder refers to a mental and/or physical impairment of childhood that result in an impairment or inability to perform activities of daily living. (19)

2.8 Global developmental delay

The term global developmental delay refers to children under the age of 5 years with delays evident in two or more developmental domains.(18)

2.9 Early childhood development

Early childhood development refers to the period of rapid cognitive, emotional and physical growth that happens during the first eight years of life.(21)

CHAPTER 3

LITERATURE REVIEW

3.1 Introduction

This chapter will discuss the definition of developmental delay and disability and the epidemiology of developmental delay in both the international and South African setting. The importance of early screening, diagnosis and intervention will be highlighted before reviewing developmental surveillance and screening recommendations. Current practice in South Africa will be reviewed and barriers to early diagnosis will be discussed.

Research referenced in this literature review was sourced from Pubmed and Science Direct. Keywords used included neurodevelopment, early intervention, developmental screening tools, developmental surveillance, patient-held records, parental concern, and South Africa.

3.2 The definition of developmental delay and disability

Developmental delay is a term used when referring to children, usually under the age of five years, that do not attain developmental milestones at the expected age.(1) The broad age variation in attaining milestones is taken into consideration. A delay is only present when a certain milestone is not reached by the latest age that a child is expected to do so.(2) Milestones are grouped according to developmental domains and a delay can be present in more than one domain. The term global developmental delay refers to children under the

age of 5 years with delays evident in two or more developmental domains.(18) The developmental domains are outlined below.

Motor development: this includes both gross and fine motor development. Gross motor development refers to the use of large muscle groups to maintain posture and ambulation. Gross motor milestones are attained in a sequential manner, meaning that a child will sit before they are able to walk, walk before they can run, and so forth. Fine motor development refers to the use of small muscle groups, especially those of the hands. Fine motor skill development allows manipulation of small objects for example, using the fingers to eat and holding a pen to draw.(2) Fine motor development is influenced by both visual and adaptive functions. The term motor delay refers to delays in gross motor control without delays in any of the other domains.(18)

Language development: this refers to the development of verbal and non-verbal communication skills. It includes all aspects of speech development from understanding speech (receptive speech) to speaking (expressive speech). Speech and language development is influenced by hearing. Speech development could be affected by other developmental domains, for example articulation disorders secondary to motor disorders. In autism spectrum disorder difficulties in understanding and interpreting language accompany the core problem of inadequate social development.(2) Cognitive or adaptive development: the ability to solve problems, reason, learn, retain and apply information is captured in this domain.(2)

Personal and social development: this includes responding to other people, building and maintaining relationships, as well as acquiring independence with skills such as eating, dressing and bathroom routine.(2)

For each domain there is a subset of developmental disorders that can be classified according to severity. For example, global developmental delay is classified as severe when the delay is more than 2 standard deviations below the mean for children of the same age according to standardised norm referenced testing.(22)

Some articles use the terms disability and delay synonymously. There is no single, universally accepted definition for disability. The International Classification of Functioning, Disability and Health (ICF) looks at three aspects of disability namely: the impairment itself e.g. limb amputation; the activity limitation e.g. inability to walk; and participation restriction e.g. cannot be part of the school soccer team. It contextualises the disability in terms of environmental and personal factors which will influence how the disability is perceived by the affected individual.(4)

3.3 Epidemiology of childhood developmental disability

According to the series on child development in developing countries published in the Lancet (2007), an estimated 200 million children under the age of five years do not reach their full developmental potential.(3) The global prevalence of developmental disability in children less than 14 years of age is estimated to be 5.1%.(4) Epidemiological studies on disability and mental health problems have shown both these conditions as having higher prevalence rates in resource limited countries.(20,23) The true prevalence of disability in South Africa is unclear. This is largely due to a lack of epidemiological studies. The prevalence of moderate to severe disability in children in South Africa is estimated to be at least 4-6%.(24)

As identified by Mclaren et al. there are only a few small studies published evaluating the prevalence of disability in South Africa.(5) Three separate South African surveys, conducted between 1992 and 2002, estimated the prevalence of disability to be between 1.1-6.3%.(5) Another more recent study found a total disability prevalence of 7% among children (aged 2-9 years) living in the Valley of a Thousand Hills, Kwa-Zulu Natal.(25) As these studies are very small their results cannot be generalised to estimate the prevalence of disability among all South African children.

In a situation analysis Statistics South Africa examined data from the National Census and the General Household Surveys to estimate the prevalence of disability. The General Household Survey (GHS) of 2009 estimated that 11.2% of South African children below the

age of 18 have a disability.(6) Census 2001 estimated that 5% of children younger than 19 years of age had a disability. There is significant variation between the results of the GHS compared to that of Census 2001, especially in the 0-4 year age group. The GHS estimated that 28% of children aged 0-4 years have a disability compared the Census 2001 which showed a 1.6% prevalence.(6)

The GHS used the Washington Group Short Set of Questions to determine the presence of disability. The questions asked covered seven domains of functioning including communication, self-care, concentration, walking, and hearing, seeing and talking. Difficulty in two or more of the domains, or inability to perform one of the domains, would result in an individual as being classified as having a disability.(6) These questions do not take age and developmental factors in to consideration and therefore could result in over estimation of the prevalence of disability. Census on the other hand asked whether an individual has any serious disability that prevents full participation in life activities such as education, work, or social life.(6)

It is argued that the data from the National Census is the most reliable when determining disability prevalence among South African children. The National Census includes all individuals living in private dwellings, as well as those in institutions, and is therefore representative of the entire population. Furthermore, the question asked to determine the presence of disability includes restriction in functional activities which is in line with the internationally preferred ICF framework. Using the Census data and taking population

growth in to consideration implies that there are at least 474 000 children in South Africa living with a severe disability.(6) Both these surveys only looked at severe disabilities and if mild and moderate disabilities are taken into account, the numbers would be higher.

Census 2001 showed that children living in the Free State Province, males, orphaned children and children with low parental education levels, were more likely to suffer from a severe disability. Although the location link is not clearly understood, it could be confounded by, for example, high poverty and food insecurity rates in the provinces that are most affected.(6)

This is in keeping with international data that shows poorer developmental outcomes associated with poverty, malnutrition, and non-stimulating environments.(3) In South Africa, 63% of the estimated 6 311 000 children under the age of six years live in poverty and almost a fifth of children under the age of five years are stunted.(26) This places South African children at increased risk for developmental adversity.(27)

3.4 The importance of early identification and intervention of developmental delay

The rationale for early identification is that children's brains demonstrate plasticity. Plasticity is achieved by selectively removing excessive neuronal connections through a process called pruning. The formation of new synapses and removal of excessive

connections are essential to form functional circuitry in the immature brain.(28) Plasticity gives the brain the ability to learn from experience.(7,8)

Experience refers to the sensory input perceived by the brain through stimulation. Early in life, new neuronal connections are formed at a rapid pace. These connections form the foundation for emotional and cognitive development later in life. The manner in which neuronal connections develop are largely due to genetic factors. The expression of the genetic code can however be altered by external factors such as experience. This phenomenon is called epigenetics. Research has shown that the brain's plasticity is optimal during these phases of rapid brain development.(9)

Although there are some brain regions that show plasticity later in life, most regions have a sensitive period during which they are most susceptible to experience-initiated change in structure and function.(9) The developmental trajectory of the individual can therefore be changed for the better or worse depending on the quality of experience that is provided from an early age.

Clinical examples of plasticity in practice include the improvement in vision with early correction of amblyopia. Visual input via the retina strengthens the neuronal connections of the visual system. With amblyopia there is under-stimulation of the visual cortex resulting in reduced strength and number of synapses formed. Correcting the amblyopia early and re-establishing visual input will allow neuronal connections to form thus leading to lifelong improvement in vision. This improvement is only seen in early correction and not later in life, thus confirming the sensitive period of the development of the visual system.(10)

Constraint induced therapy, for hemiplegic infants, is another example of neuroplasticity in action. Research has shown that in hemiplegic infants, improved motor function in the more severely affected limb is evident after restraining the unaffected limb. This improvement in function was accompanied by structural changes in the motor cortex in both the contra-lateral and ipsilateral hemispheres. Magnetic resonance imaging showed increased gray matter volume in the motor cortex after constraint induced therapy.(11)

The neuroplasticity model also holds true for early severe hearing loss, where identification and intervention before six months of age consistently leads to better outcomes. Reintroduction or improvement of auditory stimulation before the age of six months resulted in reorganisation and recruitment of auditory neurons with lifelong improvement in auditory function. The magnitude of improvement with early intervention is much greater than when intervention is instituted at a later stage in life.(12)

Intervention during sensitive periods, when the brain is most plastic, thus has the greatest impact with the best developmental outcome. Numerous studies confirm the efficacy of early intervention for neuro-developmental disorders.(29) One example is that early intensive behavioural intervention in children with autism spectrum disorder resulted in positive effects in adaptive behaviour, language and IQ.(30)

Not only has early intervention shown to be of help to children with actual disabilities, but it has also been shown to benefit children who are at risk of disabilities. Positive results seen in early interventional programs for very low birth weight premature infants, emphasises the need to identify those at high risk for neuro-developmental disorders.(13) Exposure to

toxic stress during childhood is another risk factor for developmental adversity in childhood. Scientific advances suggest that improvement of maternal mental health can buffer the brains of children against the detrimental developmental consequences of toxic stress.(31)

A Jamaican study showed that enhancing mother-child interaction through early stimulation had multiple benefits. This study evaluated the benefits of stimulation and nutritional supplementation in a group of stunted children. The study comprised of four arms – the control group, the stimulation intervention, in which weekly one hour visits focused on improving interaction between the caregiver and the child, the nutritional supplementation arm and a combined arm. The interesting fact was that the group who only received the stimulation did better than the group with food only supplementation.(32) Long-term cognitive benefits, improved psychosocial skills, reduced participation in crime, and increased school achievement, were among the proven benefits.(32)

The earnings of both groups were compared 20 years later. The results showed that the stunted group in the stimulation arm of the study earned enough to catch-up with the non-stunted study participants. This demonstrates that early childhood developmental intervention is a worthwhile economic investment with a favourable cost benefit ratio.(33)

Early detection of children at risk thus allows for intervention during the stage of brain development where brain plasticity is at its peak. Intervention during this period results in maximum benefit and better attainment of developmental potential.

3.5 Screening and diagnosis of developmental disorders

The main mechanisms used to identify children with delay are:

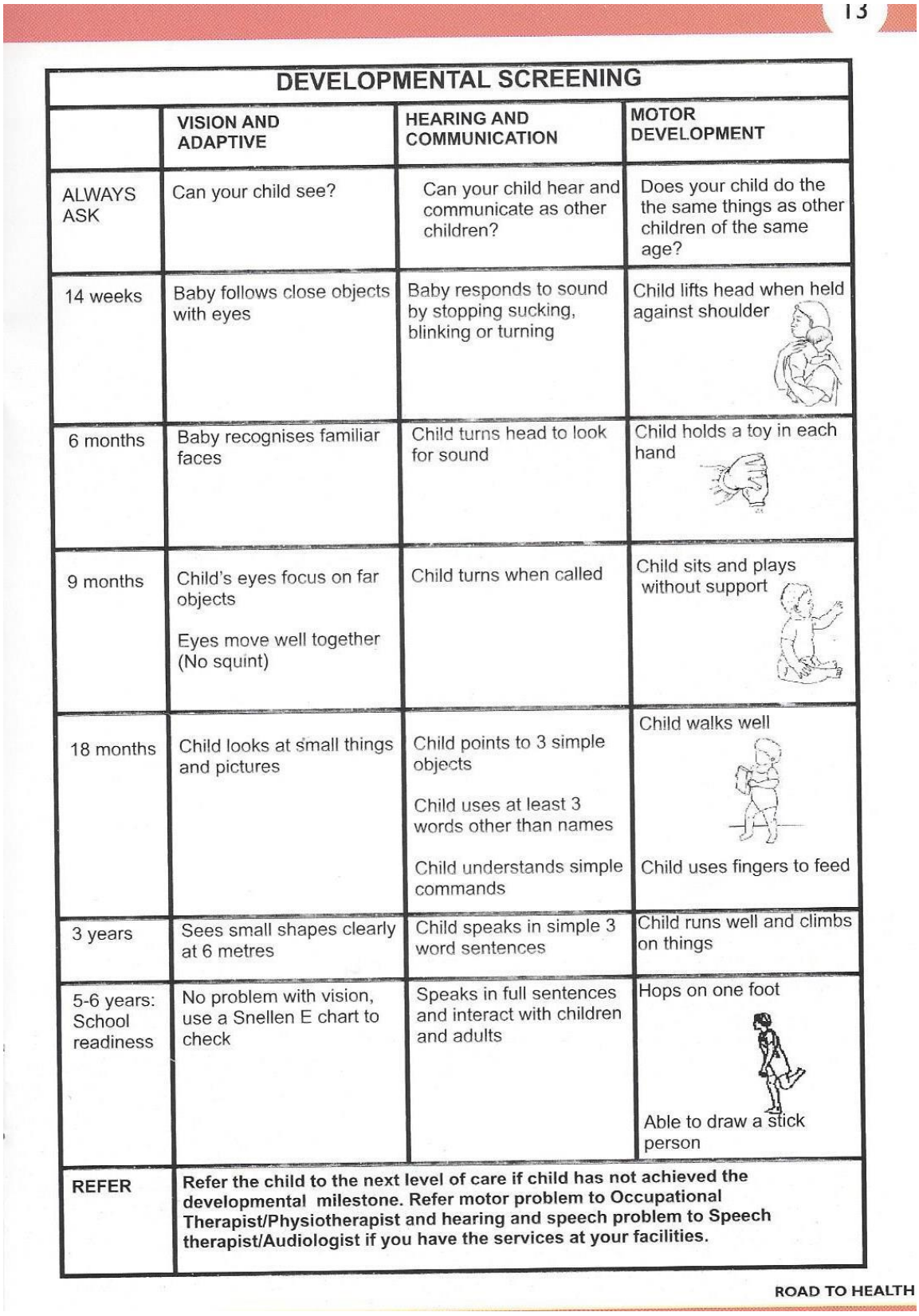
1. Developmental surveillance
2. Developmental screening
3. Formal evaluation with the aid of diagnostic tools.

Developmental surveillance is the informal process of continuously monitoring the developmental trajectory of every child. It implies monitoring when developmental milestones are reached, as well as noting both risk and protective factors for a developmental delay. Both health care workers and caregivers play an integral role in the implementation. It requires parental responsiveness and ongoing professional observation. Eliciting parental concerns, obtaining an up to date developmental history, observation during health care visits and using developmental check lists, are a few of the components that need to be attended to when conducting developmental surveillance.(20)

Developmental surveillance should be carried out in a primary health care setting and should form part of routine well-child visits. Primary health care workers are integral to the implementation of developmental surveillance as they have the most frequent contact with children during the crucial first two years of life. Any deviation from the normal trajectory of development should result in further evaluation by a skilled healthcare professional.(14)

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Figure 1.The RTHB developmental screening checklist



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DEVELOPMENTAL SCREENING

	VISION AND ADAPTIVE	HEARING AND COMMUNICATION	MOTOR DEVELOPMENT
ALWAYS ASK	Can your child see?	Can your child hear and communicate as other children?	Does your child do the the same things as other children of the same age?
14 weeks	Baby follows close objects with eyes	Baby responds to sound by stopping sucking, blinking or turning	Child lifts head when held against shoulder
6 months	Baby recognises familiar faces	Child turns head to look for sound	Child holds a toy in each hand
9 months	Child's eyes focus on far objects Eyes move well together (No squint)	Child turns when called	Child sits and plays without support
18 months	Child looks at small things and pictures	Child points to 3 simple objects Child uses at least 3 words other than names Child understands simple commands	Child walks well Child uses fingers to feed
3 years	Sees small shapes clearly at 6 metres	Child speaks in simple 3 word sentences	Child runs well and climbs on things
5-6 years: School readiness	No problem with vision, use a Snellen E chart to check	Speaks in full sentences and interact with children and adults	Hops on one foot Able to draw a stick person
REFER	**Refer the child to the next level of care if child has not achieved the developmental milestone. Refer motor problem to Occupational Therapist/Physiotherapist and hearing and speech problem to Speech therapist/Audiologist if you have the services at your facilities.**		

ROAD TO HEALTH

In October 2010 the South African Department of Health introduced the new Road-to-health booklet.(34) This booklet contains numerous health promotion messages. It urges the caregiver as well as the health care worker to document and monitor the general well-being, growth and development of every child. The developmental screening checklist (Figure 1) offered in the Road-to-health booklet was specifically developed for the South African setting.

The design of the developmental screening checklist is basic and easy to use. It depends on the caregiver recognizing abnormalities of vision, hearing/communication and motor development in their own child. Furthermore, it provides a list of a few simple actions or activities that a minimally skilled health worker could be expected to assess or identify in a child without any additional equipment. Alternatively the health worker can obtain confirmation of the absence or presence of these milestones by asking the parent or caregiver. The health care worker is prompted to refer any child in whom developmental delay is identified to a physiotherapist, occupational therapist, speech therapist or optometrist (as relevant) for confirmation of the problem and further action. Risk factors for neuro-developmental delay such as HIV exposure and infection, prematurity, low birth weight and malnutrition should be documented at each visit.

The developmental milestone checklist used in the Road-to-health booklet can be described as a developmental surveillance tool. It does not meet the specific criteria of a screening

tool as outlined below and the accuracy of this checklist to identify children with a developmental delay has not yet been established.(17)

Screening tools should meet the following criteria to be classified as such (32):

1. Have good validity and reliability
2. Acceptability to both administrator, 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

Criteria for developmental screening in South Africa were outlined by the National Workshop for Developmental Screening Group. They recommended that any developmental screening tool should only be used if there is an appropriate intervention available and it should directly be part of the management continuum and referral strategy. The caregiver should play an integral part in developmental screening.(35)

Developmental screening tests typically have a low positive predictive value.(36) This results in more children being referred for further investigation without having an actual

developmental disability. Despite this, research shows that children with false positive developmental screening tests are typically children that will benefit from help as they usually have multiple psychosocial risk factors.(37)

When considering the above mentioned criteria, the most appropriate screening tools in the already overburdened primary health care system of South African, would be parent-administered tools.

Examples of parent completed developmental screening tools are: the Ten Questions Questionnaire (TQQ), Modified Checklist for Autism in Toddlers (M-CHAT), Ages and Stages Questionnaire (ASQ), Childhood Developmental Inventory (CDI) and Parents' Evaluation of Developmental Status (PEDS).(2)

Of these screening tools, the ASQ and PEDS have a large body of research supporting their validity. None of these parent completed tools have however been validated for use in the South African setting.(17)

In a recent local study, the Road-to-health booklet developmental screening checklist was compared to the Parents' Evaluation of Developmental Status. Only a small convenience sample of children aged 6 to 12 months was included in the study. The results suggest that the RTHB checklist was inadequate to identify children at risk of developmental delays in this age group. (17)

An international gold standard for detecting developmental delays in children is the Bayley Scale of Infant Development. Although this standardised tool has been validated for use in South Africa, the version used is outdated.(38) It can also only be administered by a trained professional, it is time consuming and not feasible to administer in a primary health care setting.(39)

3.6 Missed opportunities and overcoming the barriers to early detection.

The American Academy of Pediatrics recommends that developmental surveillance should be carried out at every well-child visit from birth to 3 years of age. In addition, screening with a validated, standardised tool should be conducted at 9, 18 and 30 months of age. Autism screening should be conducted at 18 and 24 months of age.(40) What is happening in practice does not reflect the recommended guidelines. Even in resource rich countries health care systems are failing to adhere to these recommendations and as a result, children with developmental delays present late to health care facilities. (41)

On implementation of the Enhancing Developmentally Orientated Primary Care Program in the state of Illinois it was evident that less than 10% of children were screened for developmental delay. At least two thirds of paediatricians in Illinois admitted to inadequate screening practices, inadequate staff, training and reimbursement as the reasons cited for not incorporating screening into routine practice. (42)

In 1999 the Western Cape Province in South Africa adopted The Developmental Screening Program as formal policy which includes developmental screening at 0-6 weeks, 9 months

and 18 months of age. Upon evaluation of the implementation thereof in 2001, it came to light that only one in nine facilities were following the protocol for developmental screening. The barriers to the successful implementation of the policy are not unique to the South African setting and included inadequate training of nurses, unclear referral protocol, incorrect referral practice and lack of availability of intervention programs were. It was also evident that the results of the screening tests were poorly documented on the Road-to-health card.(35)

Improved child survival rates in South Africa have further increased the burden on the health care system. The population of children surviving prematurity and living with chronic diseases such as HIV has drastically increased the number of children at risk of developmental delays.(15,16) As the South African primary health care system may be inadequately equipped to deal with the current patient load, the role of the caregiver in identifying developmental delays is becoming more important.

Studies evaluating the role of parental concern in developmental surveillance emphasise the need to pay attention to these concerns, as most parents realise when something is wrong with their child.(43) Parental concern is directly associated with an increase in the detection of developmental delays and mental health risk later in life.(44) Furthermore, a strong parent-provider partnership decreases frustration and maternal guilt when an actual delay is diagnosed.(43) Research has shown that the sensitivity of parent-completed screening tools is approaching that of physician completed tools.(2) Parent-completed screening tools are preferred over directly administered tools when screening for a developmental delay in the primary care setting.(45)

Giving the care-giver ownership of their child's health is another strategy employed to improve service delivery in the primary health care system. Patient-held records, such as the RTHB has numerous advantages such as improved communication, defragmentation of care, and ownership.(46)

As the RTHB is also used to document immunisations and growth it provides the platform to integrate developmental screening with routine well-child visits. Integration of care is a strategy endorsed by the United Nations to provide cost-effective primary health services in resource-poor countries.(47) Research done in South Africa has shown that is feasible to combine hearing screening with immunisations. (48)

As the RTHB developmental screening checklist is the only tool that is freely available to all health care workers and caregivers in the South African setting, it is intended to bridge the gap in the early identification of developmental delays.

CHAPTER 4

METHODOLOGY

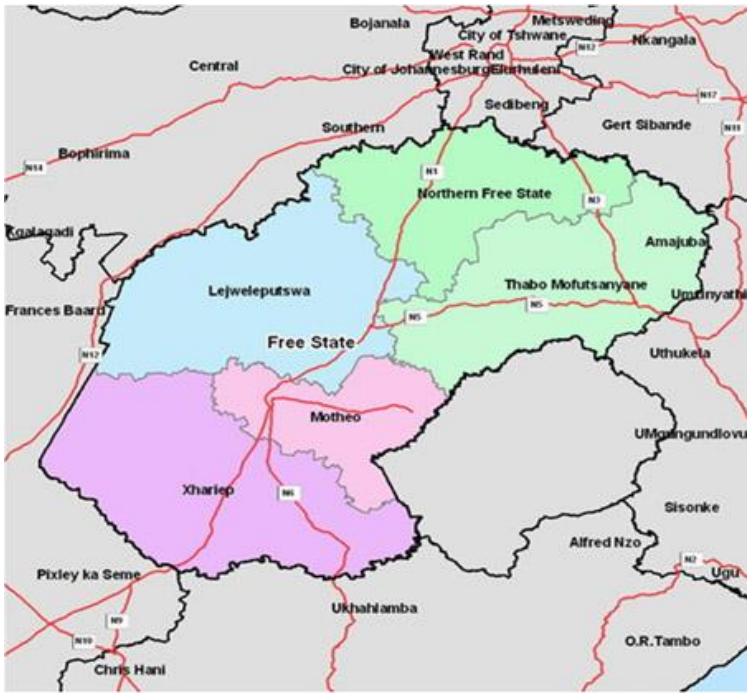
4.1 Research design

The study was designed as a prospective cross-sectional descriptive study, with analytical components.

4.2 Location of study

This study was conducted at Pelonomi Hospital. Pelonomi Hospital is situated in Bloemfontein and is a regional hospital for the southern Free State. It provides specialized secondary care and tertiary care for referred patients from the Motheo and Xhariep districts (Figure 2).

Figure 2. Map of the health districts of the Free State.



4.3 Study participants

The study population includes children referred for admission to Pelonomi Hospital from within the drainage area of the hospital. The study sample consisted of a convenience sample of 113 subjects who were admitted to Pelonomi Hospital during the months of May to October 2014.

4.3.1 Inclusion criteria

All children between the ages of 14 weeks and 6 years of age with a new road-to-health booklet and admitted the paediatric ward at Pelonomi Hospital were eligible for inclusion in the study.

Consent from the primary care-giver had to be obtained to be included in the study. The primary care-giver was regarded as the person taking care of the child most of the time.

Children with established disabilities prior to admission were included in the study.

4.3.2 Exclusion criteria

Children who were readmitted during the study period were only included once.

Children with old Road-to-health cards were not included.

Unavailability of the RTHB was an exclusion criterion.

Absence of the primary care-giver during admission was regarded as an exclusion criterion.

Prematurity was not regarded as an exclusion criterion and chronological age was used for assessment.

4.4 Outcome measures

4.4.1 The Road-to-health booklet developmental screening checklist

The RTHB developmental screening checklist is comprised of 21 questions (Figure 1). The questions are grouped together in three columns representing different developmental domains, namely: vision and adaptive; hearing and communication; and motor development. The first three questions should be asked of all children at every visit, followed by the questions tabulated adjacent to the various age groups. Specific questions are asked at 14 weeks; 6, 9, and 18 months; 3 years; and between 5 and 6 years of age. If the child is assessed as not having reached a milestone according to the questions asked, the child should be referred to Occupational Therapy, Physiotherapy, Speech Therapy or Audiology depending on the domain in which the delay is suspected.

4.4.2 Datasheet

A datasheet (Appendix A) was used to capture information for each study participant. The information captured included referral date, age and gender. The names of both the clinic that referred the child as well as the clinic where the child received well-child visits were documented. Information on the developmental status of the child was also captured. Firstly, the care-giver's understanding of the child's development was assessed. The care-

giver was asked whether they thought that their child was not developing normally at any time before admission. If they said yes they were asked to elaborate in order to establish which developmental domain was affected. They were also asked whether they could recall any risk factor or illness that preceded the abnormal development.

Secondly, the RTHB was inspected. If the checklist was completed at the clinic, the age at which it was filled in as well as the outcome of the checklist was documented. If there was any delay documented in the booklet, the domain in which it has occurred was noted as well as whether the child was referred. The date of referral, to whom the child was referred as well as whether the child was seen by the referral practitioner/therapist were recorded. Lastly, upon referral to Pelonomi Hospital, the checklist was re-administered by the paediatrician (principal investigator). Again, it was documented on the datasheet if a delay was suspected as well whether the child was referred for further evaluation or therapy.

4.5 Study procedure

The principal investigator obtained informed consent from each care-giver, interviewed the care-giver, inspected the RTHB development screening checklist and re-administered the checklist upon admission to Pelonomi Hospital. The RTHB checklist age category closest to current age of the child was used. The information was collected and captured on the datasheet (Appendix A, Section 2.3) by the principal investigator. A translator was used where the care-giver was not proficient in English or requested to answer in their home language.

4.6 Ethical considerations

Before the study was conducted ethical clearance was given by the Human Research Ethics Committee of the University of the Witwatersrand. Clearance certificate M140310. (Appendix B) Informed consent was signed by the care-giver of each study participant before proceeding with data collection. Consent to perform the study was obtained by the CEO of Pelonomi Hospital. If a delay was detected by the paediatrician the care-giver was counselled and the child was appropriately referred for further management.

4.7 Statistical Methods

Data was captured by the researcher in Microsoft Excel 2010 (Microsoft Inc.). Further analysis was carried out by a statistician using SAS Version 9.2 (SAS Institute Inc.). Descriptive statistics, namely frequencies and percentages, were calculated for categorical data. Means and standard deviations, or medians and percentiles were calculated for continuous data. Medians and interquartile ranges were used describe data with a skewed distribution. Analytical statistics, namely the Fisher's exact test, were used to investigate whether there were significant differences between the findings of the clinic and those of the investigator. A p value of < 0.05 was considered significant.

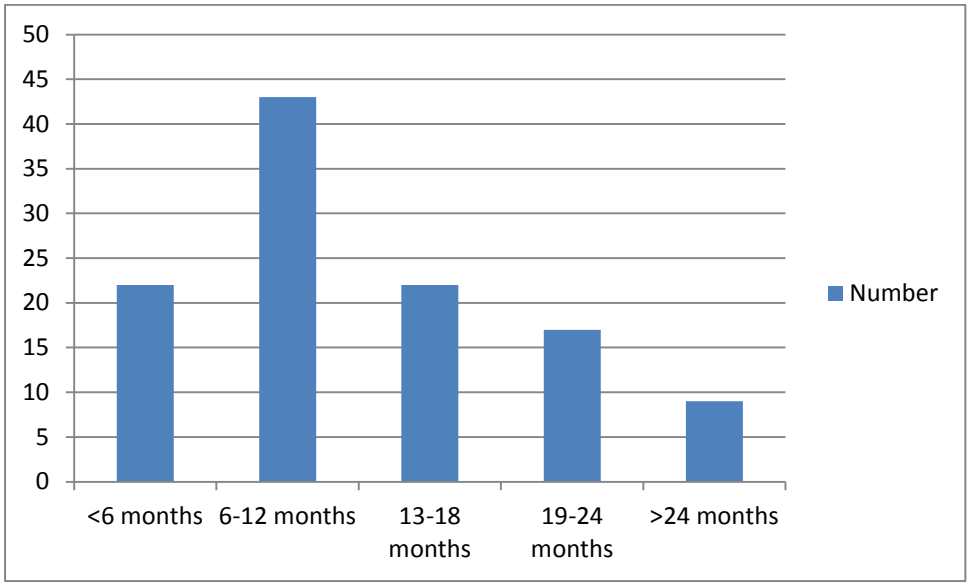
CHAPTER 5

RESULTS

5.1 Study population

A total of 113 children were enrolled in the study of these 14 children were excluded: four due to absence of the primary care-giver; one due to re-admission; five due to unavailability of the RTHB; and four due to age. The age distribution (figure 3) was skewed to the left with the majority of patients being of a younger age. The median age of the participants was 11 months (IQR 6-17 months). The cohort included 63 males (56%).

Figure 3. Age distribution of children according to number of children in different age categories



5.2 Primary care facility or clinic

All 113 children had attended a primary healthcare clinic at least once as part of their routine well-child visits. Children attending 41 different clinics were included in the study. Mangaung-University clinic partnership program (MUCPP), Heidedal and Freedom Square clinic were the most frequently named clinics – 20 (18%) patients were followed up by MUCPP, 16 (14%) by Heidedal clinic and 6 (5%) by Freedom Square clinic.

Just over a third (n=43, 38%) of the children had been referred to Pelonomi Hospital by their regular follow up clinic.

5.3 Developmental status

5.3.1 Developmental status according to the caregiver

Of the 113 participants 28 caregivers (25%) suspected that their child might have a developmental delay. Of the caregivers who suspected a delay (n=28), all suspected that their child might have a delay in motor development, seven (25%) in speech development and two (7%) children were suspected as having delayed visual development. Five of the children were suspected to have delays in both motor and speech development, while two were suspected to have delays in all three domains.

The median age of the children when parental concern was expressed was 7.5 months (IQR 5.5-12.5 months). The majority of caregivers noticed delays before one year of age (n=21, 75%), but of the 28 caregivers who suspected developmental delays 12 (43%) did so before their children were seven months old. All of the suspected delays were noticed by the

caregivers before their children were 24 months old. In almost half of the cases (13/28[46%]) the caregiver was able to recall a precipitating factor (Table 1) which occurred prior to the onset of the delay.

5.3.2 Developmental status according to the primary care facility/clinic

The developmental screening checklists of 45 (40%) of the 113 children were completed by a clinic at any visit prior to admission to Pelonomi Hospital and enrolled into the study. The median age of evaluation was nine months (IQR 3-18 months). Of the 45 checklists completed, developmental delay was suspected in six (13%) children. All six of the children had suspected delays in the motor domain, four had suspected speech delay, and one had suspected visual delay. One child had delays in all three domains, while three children had delays in both speech and motor development.

According to caregiver report, only 10 of the 28 children (36%) that had suspected delays were screened by their follow up clinic. All six of the children who had delays according to the clinic checklist (Figure 4) also had a suspected delay according to the caregiver.

All of the children with suspected developmental delays according to the clinic assessment had been referred to allied medical services. Three of the children were referred to the occupational therapist, one was referred to the physiotherapist, but no children were referred for speech therapy. Four children were referred by the clinic for further evaluation

by a general paediatrician. All of the children, except for one, had been seen by the discipline to which they were referred.

Table 1. Precipitating factor as reported by caregiver

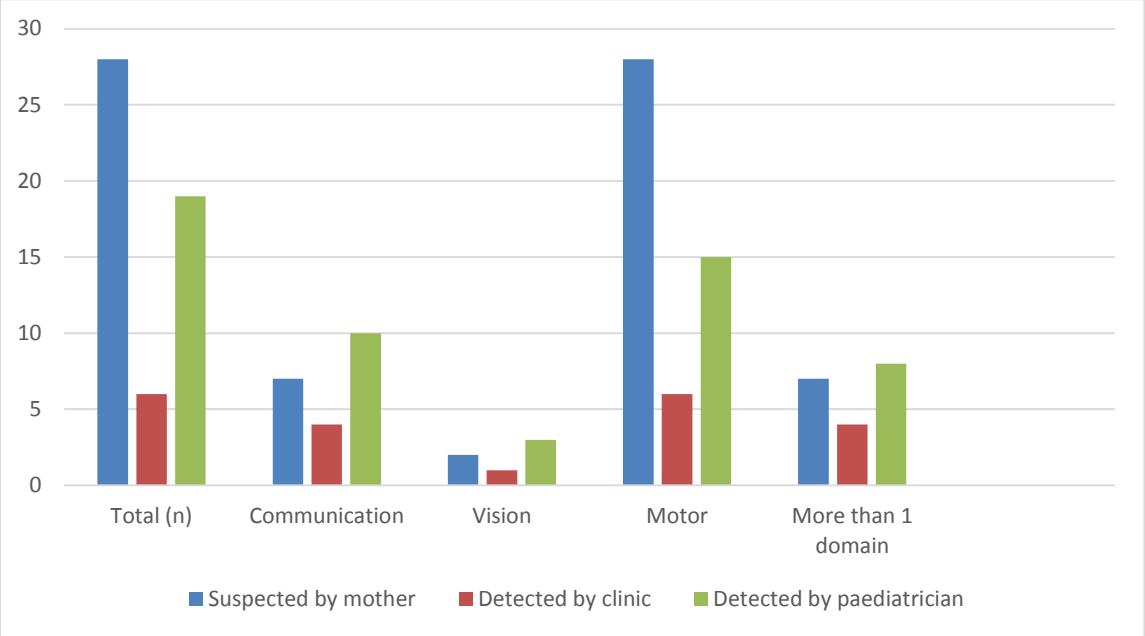
Factor	Frequency
Acute gastro-enteritis	2 (7%)
Alcohol abuse during pregnancy	1 (4%)
Down syndrome	1 (4%)
Epilepsy	1 (4%)
Malnutrition	4 (14%)
Illness not specified	3 (11%)
Prematurity	1 (4%)
No precipitating factor	15 (54%)

5.3.3 Developmental status according to the principal investigator (paediatrician)

The principal investigator repeated the RTHB developmental screening checklist for every study participant (n=113). A suspected developmental delay was detected in 32 (28%) of the children. From these, 14 (44%) had suspected speech delay, four (13%) had suspected visual

delay and 30 (94%) had suspected motor delay. Out of the 32 children with suspected delay 12 (38%) had delays in two or more domains. (Figure 5) Of the children with suspected delay according to the caregiver 19/28 (68%) also had suspected delay according to the paediatrician (Figure 4).

Figure 4. Comparison of the number of children with an identified developmental delay according to the person identifying the delay.



All of the children with a suspected developmental delay according to the paediatrician were referred except for one child who was already in therapy. 16 (50%) of the children with suspected delay were referred for both occupational and physiotherapy. 10 (31%) were referred for a combination of speech, occupational and physiotherapy. Three children were referred for assessment by a neurodevelopmental specialist (Table 2).

Figure 5. Flow diagram of delays detected by the paediatrician

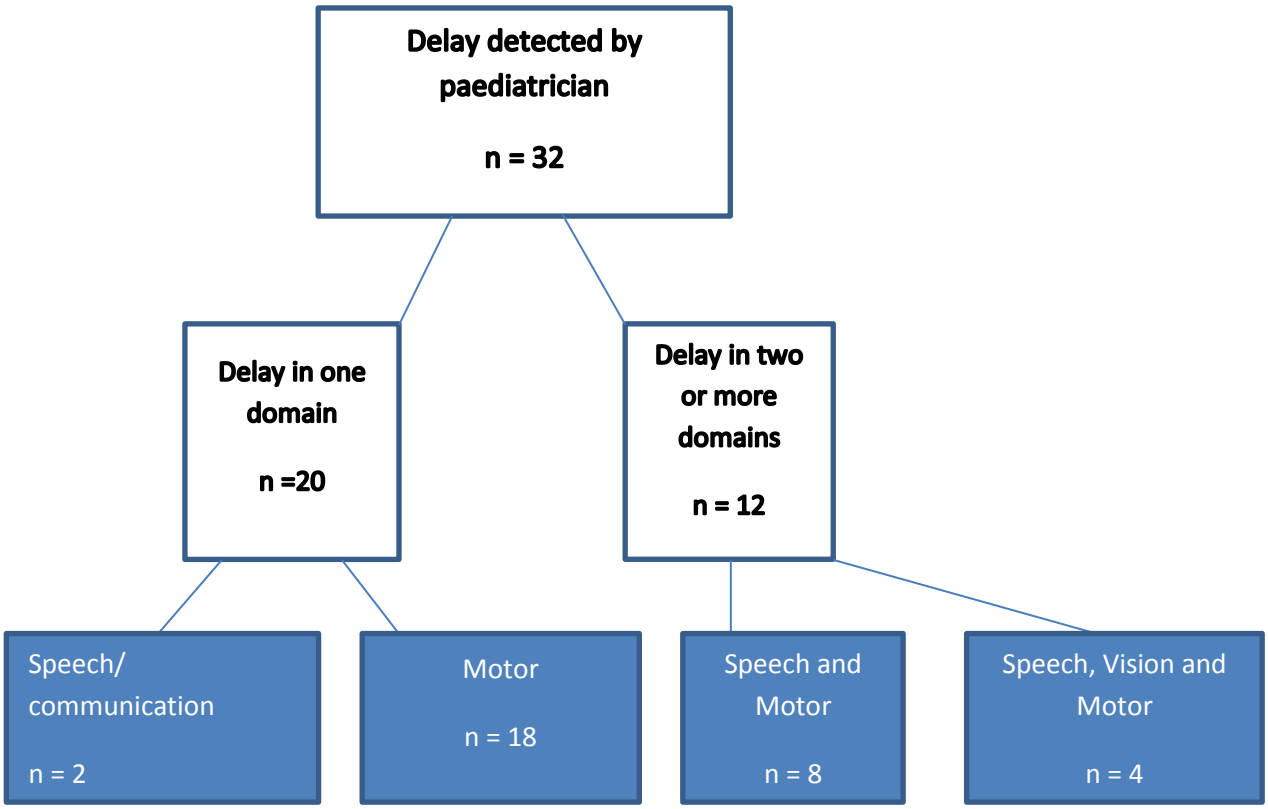


Table 2. Number of referrals to therapeutic disciplines

Referral discipline	Number of cases referred per discipline
Speech Therapy	14
Occupational Therapy	30
Physiotherapy	29
Specialist	3

5.3.4. Comparison of proportion of developmental delays detected and referral patterns

There was a statistically significant difference in the proportion of children with developmental delay detected by the paediatrician versus children with developmental delay detected by the clinic (14/45 [31%] vs 6/45 [13%]; $p < 0.0003$). Parental concern was associated with a higher rate of identifying delays by using the RTHB by both the paediatrician ($p<0.0001$) and the clinic nursing staff ($p<0.0001$).

There was no statistical significant difference in the referral pattern to occupational and physiotherapy of children with suspected delays detected by the clinic compared to that of suspected delays detected by the paediatrician. All of the children (6/6 [100%] and 32/32 [100%]) with an identified delay according to the RTHB checklist were referred.

CHAPTER 6

DISCUSSION

Results of this study, challenges and recommendations based on the results will be discussed in this chapter.

6.1 The use and usefulness of the RTHB developmental screening checklist in primary care

The primary health care platform is regarded as the most appropriate level to practice developmental surveillance. It is the most frequently accessed form of health care for many children. This is reflected in the results of this study as all participants attended a primary health care clinic at some point before being referred to Pelonomi Hospital. Well-child visits are intended to monitor health, growth and development of every child while providing essential services such as immunisations. The participants of this study were referred to a district hospital due to acute illness and not for developmental assessments per se.

The RTHB developmental screening checklist was poorly used at primary care level. The low screening rate for developmental delays at the clinics demonstrates that the RTHB is not being used effectively to promote the developmental health of children.

Lack of sensitivity of clinical judgement, limited time, infrequent health visits and inadequate training of health care providers are some of the factors that negatively impact the process of developmental surveillance and contribute to the delayed diagnosis and intervention of children with delayed development. (20)

Investigating the reasons for the poor utilization of the checklist was not an objective of this study. The results, however, prompt further discussion and investigation of the user-friendliness of the RTHB.

In South Africa, many of the above mentioned limitations are likely to play a significant role at the clinic level when it comes to the use of the RTHB developmental screening checklist. A recent South African study looked at perceptions and knowledge of nursing staff about the new RTHB growth charts. This study mainly focused on the nutritional aspects of the new RTHB. However, when nurses were asked about the user-friendliness of the new RTHB this study revealed that almost half of the participants felt that the booklet was difficult to understand and that they did not have sufficient knowledge to work with the new booklet. (34) As developmental screening and growth assessments are done during the same visit, not understanding the new RTHB format could easily impact on the utilization of the RTHB as a whole.

A lack of knowledge in the use of the developmental evaluation may be one of the reasons why there was a significant difference in the detection of suspected developmental delays by the clinic compared to the paediatrician as demonstrated in this study, but needs to be investigated further.

Many caregivers accessed different primary care facilities for health services and did not take their child to their regular follow up clinic when their child was ill. When presented with an acute illness the healthcare provider at the clinic would most likely have focused on

the acute problem at hand and not address all aspects covered in the RTHB. This would have resulted in fragmented care, and also impacted on the utilization of the RTHB.

6.2 The role of the caregiver in the neurodevelopmental health of their child

Caregivers should play an integral role in the process of developmental surveillance as well as screening.(35) Parental concern is regarded as one of the most reliable reasons for investigating a child for a possible delay, as it is associated with an increased detection of developmental delays.(44)

In this study, more caregivers were concerned that their child had a developmental delay than those who were actually identified by the RTHB checklist. Caregiver concern was associated with a higher rate of identifying a delay than by both the clinic and the paediatrician. Most of the caregivers expressed concern about the development of the child before the child had reached one year of age. Early detection of developmental delay creates a window of opportunity for early intervention if concerns are timeously and appropriately investigated. The fact that only a few of the children where the caregiver raised concern were identified during screening by the clinic is alarming. This poses the question as to whether, and at what time point, the caregivers had alerted the primary health care system to their concerns, and if alerted what action was taken by the clinic.

6.3 Neurodevelopmental delay

The majority of children with suspected developmental delay had delays in the motor domain as detected by the clinic as well as the paediatrician. There was a significant difference in the proportion of suspected developmental delays identified by the paediatrician compared to the clinic. The paediatrician detected more delays by using the same surveillance tool.

This may be explained by the following, but needs to be investigated further:

- As the children referred to Pelonomi Hospital were referred for acute illness, they are not representative of the general healthy paediatric community. Their acute illness may impact on the outcome of the checklist. The motor domain is most likely to be affected as children with acute illnesses such as pneumonia or gastro-enteritis may for various reasons show some regression during the acute phase with recovery after treatment.
- The time spent on completing the developmental screening checklist with the caregiver may have impacted the yield of delays. Nurses in the primary care setting may have limited time to spend on completing the checklist with the caregiver. This may have influenced the answers given by the caregiver and also the interpretation there of by the clinic staff. The paediatrician spent enough time to make sure that the question asked and the answer given was understood by both parties.
- The use of a translator may have influenced the answers given by caregivers.
- The paediatricians' knowledge of the development of children may have influenced the results.

6.4 Referral and intervention for neurodevelopmental delay

There was no significant difference in the referral pattern of the clinic compared to the paediatrician. Most of the children that needed referral required multidisciplinary referrals. The nursing staff at the clinics referred all the children that they identified with a delay by using the RTHB. The clinic did not refer children to speech therapy although they identified children with a speech delay. This is unexpected as they referred to other disciplines. The availability and accessibility of speech therapists might be accountable for this but needs to be investigated further. Raising awareness of value of the RTHB could result in more referrals.

6.5 Limitations encountered while conducting the study

The following limitations were encountered:

- The detection of developmental delay may have been influenced by the fact that the children were ill when assessed. As explained above they may show regression during the acute phase of any illness, with the motor domain being the most likely to be affected. As the checklist was administered on admission it might have been useful to repeat it on discharge.
- The paediatrician was involved in overseeing the in-hospital management of some of the participants included in the study. Knowing the detailed history and examination done on admission to the ward may have influenced the assessment.
- An appropriate formal developmental screening tool was not used to establish validity of the checklist used in the RTHB. It could have been useful to compare the

results of the paediatrician and that of the clinic with a standardized tool. This approach was not used because of time constraints and training required to use the Bayley scales of infant development.

- Another limitation to this study was that there was a time lapse between the completion of the checklist at the clinic and that of the paediatrician upon admission to the hospital.

6.6 Recommendations based on findings

6.6.1 Clinical recommendations

- The RTHB developmental screening checklist should be used as part of developmental surveillance at every well-child visit.
- Clinic staff should be encouraged to elicit any caregiver concern and should use the RTHB checklist to confirm the delay and refer appropriately.
- Any failure to attain a milestone as listed on the checklist should lead to prompt referral for further investigation and intervention.
- Training of all healthcare workers on to disseminate knowledge of developmental surveillance and screening.
- Training of healthcare workers on techniques to interview and talk to caregivers about the development of their child.

- Training of healthcare workers on the importance of developmental assessment and early intervention as part of the Integrated Management of Childhood Illness program in South Africa.

6.6.2 Research recommendations

We recommend that larger multi-center studies should be conducted to evaluate:

- The usage of the Road-to-health booklet by primary health care in South Africa.
- The knowledge and perceptions of nursing staff on the use of the developmental screening checklist in order to plan training and address the gaps.
- Factors influencing the use of the road-to-health booklet in order to implement new strategies to ensure optimal use of this valuable booklet.
- The knowledge and perceptions of caregivers of child development and the use of the road-to-health booklet.
- The knowledge and perceptions of caregivers about the importance of early intervention and stimulation.
- The availability of trained professionals to whom children with a detected developmental delay can be referred to.

CHAPTER 7

CONCLUSIONS

The aim of this study was to investigate the use of the new Road-to-health booklet developmental screening checklist by nursing staff of primary health care clinics. Furthermore, this study aimed to compare the results of the primary health care clinic nurse-completed developmental assessments with those completed by a paediatrician, and to compare the referral patterns of children with a suspected developmental delay by the nursing staff and a paediatrician. Information was gathered by reviewing the developmental screening checklist in each participant's Road-to-health booklet. A basic interview was held with the caregiver where after the developmental screening checklist was re-administered by the principal investigator (paediatrician).

In summary, the study found that:

1. The RTHB developmental screening checklist is poorly used by primary healthcare clinics.
2. There was a significant difference in detection of suspected developmental delays by the paediatrician as compared to the clinic. The paediatrician detected more delays by using the same surveillance tool.
3. The majority of suspected developmental delays were in the motor domain as detected by the clinic as well as by the paediatrician.

4. Parental concern regarding development was associated with a higher rate of identification of developmental delays by both the clinic and the paediatrician.
5. There was no statistical significant difference in the referral pattern of the clinic compared to the paediatrician. The fact that the clinic did not refer any children for speech therapy was however of clinical importance.
6. Most of the children that needed referral required multidisciplinary referrals.

Our findings show that the RTHB developmental screening checklist is not being utilized optimally to promote the developmental health of a population at risk. When completed at each well-child visit the RTHB checklist can be used to identify children at risk of a developmental delay. We must continue to evaluate the accuracy and validity of this checklist in the South African population.

CHAPTER 8

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APPENDICES

Appendix A Datasheet

Road to Health booklet developmental screening - Pelonomi

Subject nr ☐☐☐ 1-3

1. Demographic information

1.1 Date of referral: _____/_____/_____ (dd mm/ yyyy) ☐☐☐☐☐☐☐☐ 4-11

1.2 Date of Birth: _____/_____/_____ (dd mm/ yyyy) ☐☐☐☐☐☐☐☐ 12-19

1.3 Gender: [1] Male [2] Female ☐ 20

1.4 Age in months: _____ ☐☐ 21-22

1.5 Regular follow-up clinic: _____ ☐ 23

1.6 Referral institution: _____ ☐ 24

2. Developmental screening

2.1 Does the care-giver suspect any delay?
"Do you think that your child is not developing normally?"
[1] Yes
[2] No ☐ #

If Yes, specify in what domain?
"Tell me more: Is it speech/communication, vision or the movement of your child that is affected?"
[1] Speech/communication
[2] Vision
[3] Motor ☐ #

If yes, when did she first notice the delay?
Age in months:_____ ☐☐ 27-28

If the suspected delay is of recent onset, can the mother recall any precipitating factor?

[1] Yes
[2] No ☐ 29

If yes, specify: _____ ☐ 30

2.2 Was the developmental screening done at last visit to the clinic?

[1] Yes
[2] No ☐ 31

If yes, age of child at last visit in months: _____ ☐☐ 32-33

If done, was any delay detected

[1] Yes
[2] No ☐ #

If Yes, specify in what domain?

1	Speech/communication	
2	Vision	35
3	Motor	

If Yes, was the child referred?

1	Yes	
2	No	36

Date of referral: _____/_____/_____ | 37-44

dd mm yyyy

Referred to:

1	Speech therapy	
2	Occupational therapy	45
3	Physio therapy	
4	General practitioner	
5	Specialist clinic	

Was the child seen at the referral site? | 46

1	Yes	
2	No	

If yes:

Date seen: _____/_____/_____ | 47-55

dd mm yyyy

2.3 Was the developmental screening done/repeated at time of referral? | 56

1	Yes	
2	No	

If done, was any delay detected

1	Yes	
2	No	57

If Yes, specify in what domain?

1	Speech/communication	
2	Vision	58
3	Motor	

If Yes, was the child referred?

1	Yes	
2	No	59

Referred to:

1	Speech therapy	
2	Occupational therapy	60
3	Physio therapy	
4	Specialist clinic	

Appendix B Ethics approval certificate

R14/49 Dr Bernice Naborn

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140310

NAME: (Principal Investigator)	Dr Bernice Naborn
DEPARTMENT:	Paediatrics Pelonomi Hospital, Bloemfontein
PROJECT TITLE:	The Use of the Road to Health Booklet Developmental Screening in the Detection and Referral of Early Development Delay in the Pelonomi Hospital Drainage Area
DATE CONSIDERED:	28/03/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof L Jacklin
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	30/04/2014

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

DECLARATION OF INVESTIGATORS

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

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES