LANGUAGE AND COMMUNICATION DEVELOPMENT IN PRESCHOOL CHILDREN WITH VISUAL IMPAIRMENT: A SYSTEMATIC REVIEW

by

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Dissertation submitted in fulfilment of the requirements for the degree MCommunication Pathology in the Department of Speech-Language Pathology and Audiology at the UNIVERSITY OF PRETORIA FACULTY OF HUMANITIES

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March 2015

ACKNOWLEDGMENTS

- Professor Alta Kritzinger; you deserve a great deal of thanks for your constant support and knowledgeable guidance these last years. The time you spent with me considering our role as speech-language therapists in the complex field of visual impairment were invaluable. You were encouraging through the difficult times and always made me feel like it was tricky but possible. I have enjoyed working with you very much and look forward to many more years of collaboration.

- Mrs Jeannie van der Linde; I am so grateful for your keen sense of analysis and synthesis that guided me so well. Your enthusiasm towards our research was a great motivation. Thank you all your input.

- To my family who provided me with synonyms, proof reading, critical reviewing but most of all love, understanding and support, thank you with all my heart.

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Title of thesis/dissertation/mini-dissertation: LANGUAGE AND COMMUNICATION DEVELOPMENT IN PRESCHOOL CHILDREN WITH VISUAL IMPAIRMENT: A SYSTEMATIC REVIEW

I declare that this dissertation is my own original work. Where secondary material is used, this has been carefully acknowledged and referenced in accordance with university requirements.

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_____ 10-7-2015

SIGNATURE **DATE**

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LIST OF ABBREVIATIONS

ASD: Autism Spectrum Disorder

ASHA: American Speech–Language–Hearing Association

ECI: Early communication intervention

FASD: Fetal Alcohol Spectrum Disorder

HIV/AIDS: Human immunodeficiency virus infection and acquired immune deficiency syndrome

ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th Revision

ONH: Optic Nerve Hypoplasia

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PVI: profound visual impairment

ROP: Retinopathy of Prematurity

SCRR: social, communication and/or restrictive or repetitive behaviour,

SOD: Septo optic dysplasia

SVI: severe visual impairment

UNAIDS: Joint United Nations Programme on HIV/AIDS

VI: Visual impairment

VISS: Visual Impairment and Social Communication Schedule

WHO: World Health Organization

FORMATTING

The APA referencing style was used in this dissertation

Abstract

Language and communication difficulties of young children with visual impairment (VI) may be ascribed to intellectual disability, multiple disabilities and autism spectrum disorder (ASD) rather than sensory impairment. As a result, the impact of VI on communication development has been underestimated and undertreated. Speech-language therapists should be included on the early intervention team for children with VI. There is a need to review and critically appraise recent peer reviewed research to examine the strength of the evidence and to describe the language and communication developmental characteristics in young children with VI. A literature review regarding the developmental characteristics of children with VI was compiled as a foundation of information. A systematic search of recent literature (2003-2013) was then completed using the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses). Primary and secondary search phrases were used in three databases and 1661 articles pertaining to language and communication developmental characteristics were identified. Once the inclusion criteria were applied, the level of evidence of the nine remaining publications was determined. Thematic analysis was used to describe the early language and communication characteristics of children with VI. All the studies were from developed countries and participants from seven of the nine articles had congenital VI. Five studies received an evidence level rating of III while four articles were rated as IIb. Two main themes emerged from the studies, 1) early intervention and 2) multiple disabilities and ASD. Language and communication development is affected by VI especially in the early stages of development and speech-language therapists should therefore be included in early intervention for children with VI. Recent evidence on the early language and communication difficulties of children with VI is stronger than in the past where studies were mostly on evidence level IV, i.e. descriptive research and expert opinion. Language and communication difficulties are missed or not prioritized in children with VI due to the co-occurrence of multiple difficulties such as intellectual disability, ASD and multiple disabilities. Six articles attempt to address this problem. The impact of VI itself on communication remains unclear because the effect of VI on language and communication development cannot yet be separated from the primary conditions. Children with VI are a hidden population for speech-language therapists. This systematic review motivated the need for speech-language therapists to become involved in early intervention for children with VI from the perspective of prevention

of further delay, intervention for existing delays and advocating for the awareness of the possible communication problems. Children with VI, specifically those in developing countries within Sub-Saharan Africa with acquired VI, need to receive greater focus not only within research but also in clinical practice. The identified language and communication developmental characteristics and early intervention guidelines by ASHA (2008) provide the framework for improved service provision by speech-language therapists to young children with VI.

Keywords: visual impairment, language, communication, development, characteristics, preschool, young children, systematic review, early intervention, Autism Spectrum Disorder, multiple disabilities.

CHAPTER 1: INTRODUCTION

"Problems caused by nature can be modified by nurture." (Peltzer-Karpf, 2012, p. 70).

Chapter Aim:

The aim of the chapter is to provide background on visual impairment (VI) in young children and highlight the need for a systematic review of recent literature as there appears to be a lack of knowledge about the language and communication development of infants and young children with the condition. It is argued that speech-language therapists working in early intervention may not have sufficient knowledge to identify, assess and treat young children with VI. The chapter ends with a rationale and a research question.

1.1. Background

1.1.1 Early communication intervention in South Africa

It is widely recognised that early communication intervention (ECI) is considered best practice for young children at risk and their families, as it results in improved outcomes for the child (Alliston, 2007). In recent years South African speech-language therapists have been progressively more involved in ECI (SASLHA, 2011).

The populations that early communication interventionists serve are often both culturally and linguistically diverse and have multiple disabilities (Coleman, 2009). ECI aims to treat all young children of all cultures, languages and disabilities that are at risk of or have a communication disorder (Coleman, 2009). In South Africa, early communication interventionists deal with many challenges, such as lack of resources (Strasheim, 2009) and parents who are often illiterate and poor, and who, as everywhere else, may not understand the conditions their children face. Samuels, Slemming and Balton (2012) point out that for most children in South Africa early intervention often starts too late and ends too early. It is within this context of many challenges that early communication intervention must be provided to infants and young children with VI.

1.1.2. The impact of visual impairment on communication development

Young children with VI have not typically been identified as being at risk of a communication disorder (James & Stojanovik, 2006). The impact of VI on the communication development in young children has been underestimated and undertreated (House & Davidson, 2000; James & Stojanovik, 2006).

VI may affect the play, motor, cognitive, social and language skills of young children (Chen, 2001). Developmental difficulties in these domains and what is known about the neurological development of the visual system, highlight the need for intervention starting within the first 12 months of life (Davidson & Harrison, 1997). Early intervention is recommended to help maximise children's development and improve long-term functional outcomes for both the child and family (Dale & Salt, 2007).

The visual system is the most complex sensory system, but also the least mature at birth (Glass, 2002). In contrast to the processing capacities of the auditory system already evidenced in the newborn's preference for the maternal voice (Owens, 2012); the visual system only starts to function at birth. Since early communication intervention typically applies to children from birth to three years of age (Rossetti, 2001) it coincides with the period that visual maturation is achieved (Glass, 2002). Communication development that takes place in the first three years of life is the foundation for later language and literacy development (Rossetti, 2001).

Object permanence develops between six to twelve months and the understanding that a picture is a symbol of a real object emerges. During this period non-verbal communication develops as mutual gaze progresses and infants begin to demonstrate referential gaze to indicate the desire for attention, a person or an object. Progress in non-verbal communication links to early language development as adults label what the infant is looking at. Children also begin to respond to another person's facial expressions (Glass, 2002). These features highlight the early links between the visual system and communication development. The different components of the visual system serve as a reminder of the complexity of vision.

1.1.3. The visual system

According to Roorda (2002) the sensory organ of vision involves the interaction of the brain and the eye via pathways. For vision to take place the eye must receive an image and then transmit the image to the visual cortex of the brain for interpretation. The eye is a complex system used to capture images and is made up of the eyelids, cornea, iris, pupil, lens and retina. The cornea is a film that covers the eye while the iris is the circle of colour around the pupil. The pupil controls the amount of light admitted into the eye and the lens focuses the image. An important part of the eye is the retina as it contains photoreceptors which allow for day and night vision and the perception of colour, movement and high- and low-contrast forms. It is in the retina that the light is converted into nerve impulses and transmitted to the visual cortex via the optic nerve. The brain then interprets the impulses so as to produce an image and provide information regarding placement, motion and orientation in space thereby allowing the person to identify and *see* the image (Roorda, 2002).

Vision improves as the visual cortex and visual system matures. As maturation takes place, the ability to interpret and comprehend images improves (Roorda, 2002). The development of the visual system encompasses both physiological and neurological maturation.

1.1.4. Essential knowledge of visual functioning for speech-language therapists

The term most often used to denote normal vision, ‘20/20’, refers to visual acuity. Visual acuity refers to the ability to discriminate detail (New York State Department of Health, 2007). The first number in the fraction denotes the distance from the image, i.e. 20 feet. The second number indicates the distance someone with ‘normal’ vision would need to stand from the image in order to see it clearly. For example, a person with 20/200 vision can see at 20 feet what a person with normal vision can see at 200 feet (Coylar, 2015).

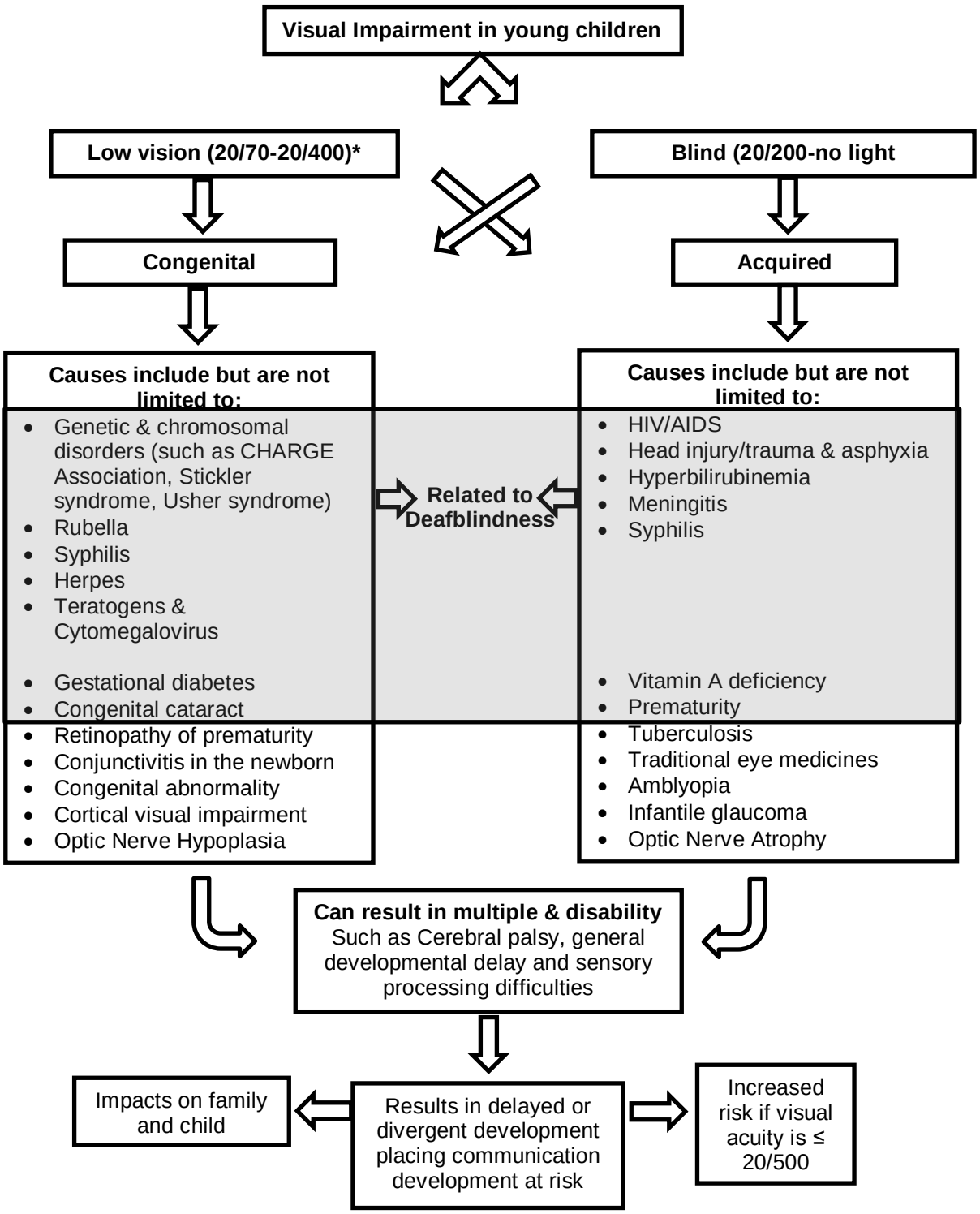
The visual system consists of many other visual functions that act in combination with visual acuity. The combination of functions is similar to the relation between auditory processing and hearing ability. According to The New York State Department of Health (2007), these functions include visual field, colour perception, contrast sensitivity, depth perception, dark adaptation and binocularity. Visual field refers to the area that can be seen when the eye is

in a fixed position, while colour perception is the ability to perceive colours and contrast sensitivity discriminates between lightness and darkness. Depth perception is the judgement of the distance of objects relative to each other in space and the ability to orientate one's position in relation to objects. The adjustments the eye makes in low light is known as dark adaptation. In order to achieve normal visual acuity the visual system must be functioning adequately which includes the eye's structure, all visual functions and the neural components involved in vision (New York State Department of Health, 2007).

The intricacy of the visual system is clear when discussing the visual functions. VI is defined as the loss of any aspect of vision that diminishes the ability to see (New York State Department of Health, 2007). It is imperative that speech-language therapists receive information regarding the visual functions of children with VI from professionals such as ophthalmologists. With knowledge of the visual functions speech-language therapists can attempt to reduce the impact visual difficulties may have on successful early communication assessment and intervention.

Speech-language therapists are not traditionally familiar with the development of vision and VI. Speech-language therapists must be able to understand the aetiology of the child's impairments, consider the implications of the impairments and understand the relation between the impairments. As indicated in Figure 1 the overview of VI includes low vision to total blindness, in two etiological categories, i.e. congenital and acquired, without and with associated disabilities or multiple disabilities, which can also be linked to dual sensory impairment.

VI is a condition with diverse causes and severity, and, depending on the primary condition, can pose a significant risk for dual sensory impairment. Dual sensory loss or deafblindness may develop due to various conditions that are established risks for communication development including Down syndrome, Cerebral palsy, Fetal Alcohol Spectrum Disorder (FASD) and cytomegalovirus (Rossetti, 2001). The presence of dual sensory loss complicates assessment and treatment considerably.



* Normal vision is equal to or better than 20/70.

Figure 1: Causes of visual impairment and resulting disability

1.1.5. Causes of visual impairment

VI may present due to problems in either the visual nervous system, the eye itself or due to problems in both areas. Decreased vision may occur due to problems with allowing light into the eye, focusing the light on the retina, the reaction of photoreceptors of the retina, transmitting the visual information via the optic nerve and visual pathways or the visual cortex interpreting the information (New York State Department of Health, 2007). VI may also result from problems with integrating the information and supplying the correct feedback to the eye and the extra-ocular muscles enabling maintained fixation on a target (Bishop, 1996). Due to the complexity of the visual system the causes and effects of VI are numerous and intricate (Holte *et al.,* 2006a). Consequently children with VI are a heterogeneous population that require much understanding (Parker, Grimmett & Summers, 2008).

The International Classification of Diseases-10 [ICD-10] (Update and Revision, 2006) identifies the following ranges of vision; normal (equal to or better than 20/70), moderate (20/70-20/200) and severe VI (20/200-20/400). Moderate and severe VI are grouped as low vision. Blindness is categorised over three ranges, blind (20/200-20/1200), blind with light perception and blind with no light perception (WHO, 2012).

Childhood blindness is caused mainly by vitamin A deficiency, rubella, newborn conjunctivitis, congenital cataract, and retinopathy of prematurity [ROP] (WHO, 2004). The economic status of the country that the child resides in and the availability of resources for management of the VI, may contribute to the causes of VI.

In developed countries the predominant causes of VI include cortical VI, ROP, teratogens and cataracts. These conditions occur globally in infants that have experienced stressful pregnancies or births, but due to the increased availability of resources in developed countries these children are more likely to survive (Carden & Good, 2006). In middle-income countries retinal conditions, mainly due to hereditary retinal dystrophies and retinopathy of prematurity, are the predominate causes of VI (Kello & Gilbert, 2003).

In developing countries, such as South Africa, the main causes of VI are related to acquired conditions due to a lack of resources and stressful environments (Gilbert & Foster, 2001). These include corneal scarring due to measles, vitamin A deficiency, damage due to traditional eye medicines, rubella cataracts and ophthalmia neonatorum, a bacterial conjunctivitis contracted during delivery (Kello & Gilbert, 2003; WHO, 2011). Traditional healers make use of acidic substances, fungi and urine, and may apply boiled or boiling hot substances or objects, such as spoons to the eye. These treatments may result in chemical injury, thermal and mechanical damage or infection, resulting in dense corneal scarring (Foster & Johnson, 1994).

The aetiologies of VI and communication disorders may be from singular causes or may result from conditions causing multiple disabilities (Somefun, Lesi, Danfulani & Olusanya, 2006). Conditions that may result in visual and/or communication impairment in young children can occur at different times, i.e. prenatally, perinatally, postnatally or later in childhood.

Genetic and chromosomal causes

Prenatal causes of VIs may present due to various genetic causes such as Usher Syndrome, and chromosomal abnormalities such as Down syndrome (Blumsack, 2009). Usher syndrome is an autosomal recessive disease characterised by hearing impairment and degeneration of the retina, resulting in a loss of visual field (Blumsack, 2009). Most children affected by Usher syndrome present with a congenital hearing loss, however, hearing loss can occur later in childhood. VI typically occurs later in childhood or adulthood due to retinal degeneration. Visual loss may be rapid or progressive. Vestibular function has also been known to be affected. Approximately 50% of people with dual-sensory loss present with Usher syndrome (Blumsack, 2009). Early communication interventionists must therefore utilise the child's vision to develop communication before visual acuity deteriorates. Speech-language therapists must be prepared to provide training on compensatory communication strategies to the child and family as VI progresses.

There are currently in the excess of 80 known genetic and chromosomal syndromes that may result in deaf-blindness (Holte *et al.,* 2006a). Dual sensory loss results in substantially greater disability than a single disability such as deafness or blindness (Tedder, Warden & Sikka, 1993) and appears to be under-recognized and reported (Blumsack, 2009). The Joint Commission on Infant Hearing therefore endorses the ophthalmological assessment of all infants with confirmed hearing loss (Blumsack, 2009).

Down syndrome is one of the most common syndromes as it affects one in 1000 children born (WHO, 2011). Impairments of hearing, vision and mental ability are typical of the syndrome (Blumsack, 2009; Finn & Fewell, 1994). Visual problems common to children with Down syndrome include strabismus, hyperopia, myopia, lid abnormalities, iris nodules, nystagmus, refractive errors and cataracts (Tsiaras, Pueschel, Keller, Curran & Giesswein, 1999). The identification of VI in children with Down syndrome is considerably delayed due to underreporting (Evenhuis & Nagzaam, 1998). Speech-language therapists with knowledge of the VIs common to children with Down syndrome are well placed to assist with early identification of VI through referral. ECI is crucial for children with Down syndrome as the developmental domain most affected by the syndrome is communication (Roberts, Price & Malkin, 2007).

Prenatal causes

Prenatal causes of VI may include, but not limited to, fetal exposure to alcohol and intrauterine infections such as cytomegalovirus. These conditions affect visual development in utero and impact on communication development and other developmental domains from birth onwards (Blumsack, 2009; Kello & Gilbert, 2003).

FASD is characterised by numerous disabilities including VI and neurodevelopmental difficulties such as communication disorders (de Beer, Kritzinger & Zsilavecz, 2010). FASD can affect all parts of the eye, resulting in moderate to severe VI. Anomalies may include microcornea (the radius of curvature of the cornea is smaller than normal and corneal diameter is decreased), microphthalmus (one or both eyes are abnormally small), cataracts (clouding of the crystalline lens of the eye obstructing the passage of light), coloboma of the iris and choroid (an opening in one of the structures of the eye), and retinal dysplasia (folds or

rosettes of retinal tissue). The most commonly reported anomalies are optic nerve hypoplasia (the underdevelopment of the optic nerve) and tortuosity of the retinal vessels (coiling of retinal vessels). Strabismus and refractive errors are also often identified in children with FASD. Due to the high frequency of ocular abnormalities in children with FASD, an ophthalmological evaluation is often recommended to assist with diagnosis of the disorder (Strömland, 2004).

Cytomegalovirus infection may be contracted prenatally or perinatally. Cytomegalovirus is the most common congenital viral infection and neonates may present symptomatically or asymptomatically. Of the surviving infants 70-90% develop neurological impairments including hearing loss, VI and mental disability (Caserta, 2013) and is an established risk for communication delay (Rossetti, 2001). The majority of VIs resulting from cytomegalovirus occur in symptomatic individuals. These impairments include optic nerve atrophy, macular scars, cortical VI and strabismus. Individuals with asymptomatic cytomegalovirus may present with mild impairments due to macular scaring and strabismus (Coats, Demmler, Paysse, Du, & Libby, 2000). Cytomegalovirus retinitis, which is associated with HIV/AIDS, will be discussed later

Perinatal causes of VI

VI can be caused perinatally due to conditions such as retinopathy of prematurity and cortical VI (Kello & Gilbert, 2003; Mohammadzadeh, Derakhshan, Ahmadshah, Amiri, & Esmaeli, 2009).

Retinopathy of prematurity occurs in preterm infants because retinal blood vessels do not fully develop until the ninth month of gestation and can lead to permanent VI. The degree of VI depends on the severity of retinopathy of prematurity which relates to the degree of underdevelopment of the retinal blood vessels (Glass, 2002). The presence of retinopathy of prematurity in very low birth weight infants (1.500g - 2.500g) doubles or triples the risk of developing VI (New York State Department of Health, 2007). Retinopathy of prematurity is one of the leading avoidable causes of VI (Mohammadzadeh *et al.,* 2009).

Cortical VI is due to cortical damage, which can occur perinatally, and is the most common cause of bilateral VI in Western countries (Good, Jan, Burden, Skoczenski, & Candy, 2001). Cortical VI is more prevalent in developed countries because further advances in improving mortality rates of children with complex medical problems have been made. As progress in neonatal care is made, the incidence of cortical VI may continue to increase, including in developing countries. Therefore, cortical VI may become globally the most common cause of VI in children (Carden & Good, 2006).

Cortical VI is frequently associated with other neurological impairments including cerebral palsy and epilepsy and, thus, children with cortical VI usually present with multiple disabilities (Good *et al.,* 2001). Cortical VI occurs most often as a result of hypoxic-ischemic injury. Cortical VI develops in approximately 60% of infants with neonatal hypoxic-ischemic encephalopathy. The condition does not only occur perinatally but may also develop due to head injury, central nervous system infections, shunt failure, prenatal drug use, and genetic malformations (Good *et al.,* 2001). Cortical VI affects visual acuity because visual pathway to the macula is damaged. Delayed visual field development may present in preterm children who have perinatal hypoxia-ischemia. Difficulties in contrast sensitivity and ocular motility and the presence of strabismus and nystagmus may also occur (Good *et al.,* 2001).

Postnatal and childhood causes of VI

VI can occur postnatally and in childhood from various infectious diseases, such as HIV/AIDS, and due to deficiencies such as vitamin A deficiency (Cunningham & Margolis, 1998; Holte *et al.,* 2006a; Kello & Gilbert, 2003; Kestelyn & Cunningham, 2001).

HIV/AIDS-associated eye disorders affect 70-80 % individuals at some point during the illness (Kestelyn & Cunningham, 2001). Cytomegalovirus retinitis is the most frequent cause of visual loss in HIV/AIDS sufferers (Kestelyn & Cunningham, 2001) and ocular syphilis is the most common intraocular bacterial infection (Cunningham & Margolis, 1998). Difficulties that may develop include dry eyes, corneal infection, decreased visual acuity, visual field errors, pain, irritation and light sensitivity (Cunningham & Margolis, 1998).

HIV/AIDS related visual disturbances may emerge between the first and third year of life (Belman, 2008) coinciding with the age group seen by early interventionists. Children infected with HIV/AIDS are at an increased risk for neurodevelopmental delay, which includes neuro-opthalamic and communication disorders (Cunningham & Margolis, 1998; McNeilly, 2005, Swanepoel & Louw, 2010).

Understanding the impact of HIV/AIDS on the visual system and communication development is pertinent because South Africa has the highest rate of HIV/AIDS in the world (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2010). Globally the epidemic has shown a significant decline in incidence but not yet in South Africa (UNAIDS, 2010). Due to early medical treatment children infected with HIV/AIDS now have increased life expectancies (UNAIDS, 2010). Therefore, speech-language therapists, especially in the public sector, should expect to treat increasing numbers of children presenting with HIV/AIDS related conditions.

In developed countries cytomegalovirus retinitis affects 30-40% of people with HIV/AIDS. The implications of cytomegalovirus retinitis include loss of visual field, floaters, inflammation, retinal whitening, intraretinal haemorrhaging and optic nerve impairment. A limited number of studies have examined the effects HIV/AIDS can have on ocular functioning in developing countries. These studies suggest that cytomegalovirus retinitis occurs less frequently in developing countries than in developed countries. The proposed explanation for this is that people with HIV/AIDS in developing countries are exposed more frequently to infectious agents, such as tuberculosis, herpes zoster and toxoplasmosis, and present with a higher death rate early in the course of the disease (Cunningham & Margolis, 1998). Cytomegalovirus can affect the visual and auditory system within the first four years of life (Belman, 2008). Therefore children infected with cytomegalovirus are at risk for dual sensory loss (Blumsack, 2009) which has far reaching effects on communication development (Blumsack, 2009).

Corneal scarring due to vitamin A deficiency is the most common cause of VI worldwide (WHO, 2011) and is completely preventable with adequate nutrition (WHO, 2011). In South Africa, the Department of Health is responding by developing a multi-faceted program to

address the malnutrition affecting children from ages one to nine years. The symptoms of vitamin A deficiency, related to the visual system may include night blindness due to poor dark adaptation, dry eyes, inflammation of the eye, thickening of the cornea and conjunctivae, and in extreme case permanent retinal damage (Johnson, 2007).

Multiple disability and VI

Speech-language therapists may not often treat children VI because it is a low-incidence population (Holte *et al.,* 2006b), and that the need for communication intervention for children with VI is underrated (James & Stojanovik, 2006). However, the co-occurrence of visual and communication impairment may be more prominent when treating children with multiple disabilities. Conditions that typically result in multiple disabilities in which both visual and communication impairments may include cerebral palsy and CHARGE association (Peltokorpi & Huttunen, 2008; Tedder *et al.,* 1993).

The causes of VI early in life are both diverse and complex and can occur during all the different developmental periods. Additionally, few children present with congenital blindness in the absence of other sensory, motor or cognitive disorders (James & Stojanovik, 2006). Approximately 70% of children with VI present with multiple disabilities (Chen, 2001). Due to the numerous causes of VI, these children often fall into the same population served by ECI. Children with VI and additional impairments require direct language instruction in order to develop language skills (Chen, 2001).

Causes of VI in South Africa

There are 285 million people in the world with VI (WHO 2012), 90% of which reside in developing countries (WHO, 2010). Of the approximate 19 million visually impaired children (birth to 14 years) worldwide (WHO 2012), an estimated 23% that are blind live in sub-Saharan Africa (Kello & Gilbert, 2003). A significant proportion of the VI in children in sub-Saharan Africa may be attributed to HIV/AIDS. The prevalence rate of VI in South Africa is estimated at 0.75% of the population (South African Department of Health, 2002), and is therefore a low incidence disability. However, *The national guideline for the prevention of blindness in South Africa* (South African Department of Health, 2002) states that the occurrence of VI is expected to increase over the coming decades. Efforts, including early

communication intervention, should be directed to meet the needs of this growing population.

Because of malnutrition and limited health care, children in developing countries are more vulnerable to conditions such as measles and vitamin A deficiency (Kello & Gilbert, 2003). South Africa has an increasing number of people presenting with conditions that have the potential to result in VI and communication delay. These include tuberculosis (Bardien *et al.,* 2009), syphilis (Saloojee *et al.*, 2004), gestational diabetes (Dionne, 2009) and rubella (Schoub, Harris, McAnerney & Blumberg, 2009) and FASD, with the highest prevalence in the world (de Beer *et al.,* 2010).

The risk of VI and communication delay are increased in the rural areas where conditions such as vitamin A deficiency, tuberculosis and HIV/AIDS are more prevalent (Houlihan *et al.,* 2010; Nojilana *et al.,* 2007). This may in part explain why, when considering all ages, 80% of South Africa's visually impaired population reside in rural areas (South African Department of Health, 2002). Pregnant women in rural areas often have limited antenatal care which places the child at risk for conditions such as low birth weight, prematurity and mother-to-child transmission of infection, for example congenital rubella and syphilis (Rossetti, 2001; Saloojee *et al.,* 2004; Schmid, 2004; Siza, 2008). These conditions are known to place the young infant at risk of VI, hearing loss and communication disorders (Rossetti, 2001). Based on these numerous conditions, South African children are at risk for both communication difficulties and VI. In order to provide effective early intervention, the question now arises: What is known about the language and communication development of children with VI? As a prologue to the systematic review of recent research into the language and communication characteristics of young children with VI, literature on the communication and general development of children with VI, dating as far back as 1993 was studied.

1.2. Rationale

1.2.1 Characteristics of young children with visual impairment

According to Rossetti (2001), VI is an established risk factor for a communication delay. The impairment of vision itself may also contribute to the development of a communication disorder. A lack of vision places development at risk because children typically develop skills through interacting meaningfully with their environment (Glass, 2002; Owens, 2005). Children with a visual acuity ranging from 20/70 to 20/500 represent moderate to severe VI. With correction they can perform visual dependent tasks, but not as effective as normally-sighted children. In this instance the impact of VI on communication development may be limited. However, children with a visual acuity of less than 20/500, i.e. profound VI to total blindness, have less access to reliable vision. This range of visual acuity may only be sufficient for gross motor activities (New York State Department of Health, 2007). Children with profound VI to total blindness may experience a variety of challenges in developing communicative abilities.

The severity of VI and its measured effects on development also depends on the nature, the cause, and timing of visual loss in the child's development as well as the assessment procedures used, as few assessment tools accommodate for VI (Davidson & Harrison, 1997). Despite the fact that children with VI is a low-incidence population (Holte *et al.,* 2006b), it is also a highly heterogeneous population (Parker *et al.,* 2008) with diverse difficulties and developmental patterns (Brambring, 2007 Chen, 2001; Wakefield, Homewood & Taylor, 2006). Studies have shown that VI of varying degrees affects 5-10% of pre-schoolers which is also the population that is targeted in ECI (Mohammadzadeh *et al.,* 2009). To understand the implications of loss of vision on early development, a broad literature review of the characteristics of children with VI was conducted.

The information summarised in Table 1 and Table 2 was selected from resources relating to children with VI, their development and/or communication characteristics. The information within the two tables was organised to form a chronology of development. Resources included peer-reviewed journal articles, early intervention position statements, conference papers and panel developed documents. The level of evidence of each publication was classified according to ASHA's hierarchy of levels of evidence (ASHA, 2004). It appears

that until 2006 publications exclusively relied on expert opinion or descriptive studies for information. Since 2007 a marked difference could be identified as sophisticated research designs and statistical methods were used, raising the level of evidence of the findings.

General developmental characteristics of young children with VI

Table 1 contains general developmental characteristics of children with VI arranged according to age intervals and developmental domains. Knowledge of the developmental domains that can be affected by VI is essential for an integrated approach to treatment as approximately 70% of children with VI present with multiple disabilities (James & Stojanovik, 2006).

Children with VI are known to have limited exploration of their environment (Chen, 2001) possibly due to an inability to control the environment, physically negotiate the environment and an over-dependence on caregivers (Parker *et al.,* 2008). Children with VI rely on information from those guiding them which can lead to the development of 'learned helplessness' if independence is not encouraged from a young age (Parker et al., 2008). Behaviour and sensory processing difficulties demonstrated by children with VI appear to be due to the lack of appropriate input resulting in self-stimulation such as eye poking (Tedder *et al.,* 1993). Vision plays an important role in development and VI can impact on all domains. These general developmental characteristics can help speech-language therapists understand the behaviour of children with VI and to adapt their interactions during therapy.

In summary, the loss of visual examining, experimenting with, and exploring of objects and the environment creates unique barriers for the infant to develop to a stage where mastered skills can be exhibited and where the child can compete with expert peers during preschool years.

Table 1: General developmental characteristics of children with visual impairment, indicating chronology of development

	1-6 months	7-12 months	12-24 months	3-5 years	School-age years
Behavioural	Circadian (day/night rhythm) disruptions; can lead to sleep disturbances	May lurch away from something interesting to place it in the best visual field	Often not attracted to the environment and will not explore unless prompted and led	Frequently present with autistic-like behaviour, including poor social skills, due to diminished environmental experiences	Children with peripheral blindness present with stereotyped behaviours
Cognitive	Depend on second-hand information for things that are far away, larger than the child, or dangerous	Systematic learning in all developmental domains does not occur spontaneously Reduced variety of experiences Delayed perceptual skills due to limited movement and play experience	Can be passive in their environments; increased risk for "learned helplessness" Reduced control of the environment and of self in relation to the environment Reduced ability to negotiate/explore the environment	Reliance on auditory, not visual cues, to identify large distal shapes, to develop spatial concept formation and object permanence	Normal abilities in abstract reasoning when based on auditory and tactile concepts, but lag in concepts that depend on a visual context Easily distracted, have short attention spans and/or memory problems as they must rely on auditory and tactile memories
Motor	Delay in motor development is an early indicator of vision impairment From three months of age, visual impairment begins to affect motor development in terms of head control The visual system calibrates the vestibular and proprioceptive systems	Development of righting reactions, rotation and postural tone will be delayed if an infant with severe vision impairment is not provided with vestibular, proprioceptive, and tactile stimulation Have the same potential as sighted infants to learn movement	Explore only parts of objects, and generally experience delays in development of their fine motor and object manipulation skills Auditory-motor integration takes longer without visual cues Possible delay in the development of protective reactions	Often lack hand strength	

Visual	Do not seem to respond to parent's face or follow movements of objects or people Often bring objects closer to their eyes Gaze at lights	Slow, inefficient, and highly variable visual performance	Peripheral vision is often utilised to search for objects. Therefore, children may turn their head before reaching for an object (referred to as retinal reach) with the head turned away from the side of vision loss	See better in familiar surroundings and when relaxed and well rested	Echolocation can be stimulated and encouraged from birth, however, formal training usually commences from approximately 5 years of age
Sensory Processing	May dislike certain textures or temperatures; a reluctance to touch anything placed in the hands, and/or gravitational insecurity	Sensory systems may be either hypersensitive or underdeveloped Patterns of sensory processing difficulties may be established in the absence of early intervention	Sensory deprivation and possible social isolation can lead to self-stimulatory behaviours including eye pressing, light gazing and flicking fingers in front of lights, and motor stereotypes (e.g. rocking, spinning, tapping and twirling)	Stereotypes can delay increased functional use of vision and can interfere with learning new skills	
Adapted from: Carvill, 2001; Dale & Salt, 2007; Davidson & Harrison, 1997; Division on visual impairment, 2003; Erickson *et al.,* 2007; Fazzi *et al.,* 2005; Fazzi *et al.,* 2011; Fazzi *et al.,* 2012; Goldware & Silver, 1998; Good *et al.,* 2001; Hallemans *et al.,* 2011; Holte *et al.,* 2006b; James & Stojanovik, 2006; Molloy & Rowe, 2011; New York State Department of Health, 2007; Owens, 2005; Parker *et al.,* 2008; Peltokorpi & Huttunen, 2008; Prechtl *et al.,* 2001; Ramenghi *et al.,* 2010; Romanczyk *et al.,* 2005; Tadic *et al.,* 2010; Tedder *et al.,* 1993.					

Communication developmental characteristics of young children with VI

Children with VI are predominantly affected in the areas of expressive language skills, pragmatics, and parent-child interaction, whereas speech sound production and articulation may be least affected (Table 2). Difficulties may arise as communication is so dependent on visual input during the foundation period of birth to three years of age (Chen, 1999).

As can be seen in Table 2, specific language skills that children with VI typically struggle with include pronouns, the types of verbs and nouns used, categorisation skills and prepositions (Brambring, 2007; Chen, 2001; Erickson, Hatton, Roy, Fox & Renne, 2007; Goldware & Silver, 1998; House & Davidson, 2000; James & Stojanovik, 2006; New York State Department of Health, 2007; Vervloed, den Hartog, Jespers, & de Wals, 2005; Wakefield *et al.,* 2006). Brambring (2007) found the expressive language abilities of children with VI at the age of 30 months to be 6.4 month delayed when compared to sighted children's skills.

Children with VI display pragmatic difficulties (James & Stojanovik, 2006) possibly because pragmatic skills are predominantly visually based (Dale & Salt, 2008). Visually based social-communication skills include facial expression, joint attention, referential gaze and eye contact. Social interaction is essential to early intervention as it develops communication, behaviour skills, cognition, independence and play skills (Roe, 2008).

Parent-child interaction is impacted as parents of children with VI may struggle to develop synchronicity with their children. Caregivers modulate their own behaviour according to the needs of the child and when the child's needs are met, parental confidence and ability to accurately read their child increases (Rossetti, 2001). Infants and parents who demonstrate poor synchronicity increase the potential for disordered communication development (Rossetti, 2001). Poor interaction patterns by young children with VI, such as quietening when the parent speaks, become learned behaviours that are then reinforced by caregivers (Rossetti, 2001). As already indicated, with knowledge of communication characteristics, professionals are able to identify ways to support the interaction between the child and family (Roe, 2008).

Table 2: Communication characteristics of children with visual impairment, indicating a chronology of development

	1-6 months	7-12 months	12-24 months	3-5 years	School-age years
Speech	The developmental sequence of speech sounds may be different to that of sighted children, but blind children develop fully intelligible speech within the same time frame as sighted children	Delays appeared to be due to the lack of visual information	Children with visual impairment show delays in sounds that are visibly articulated		
Receptive Language		May require more time and repetition of activities before responding	Difficulty transitioning between activities, especially if child does not understand instructions		Difficulty recognising objects belonging to the same semantic category (e.g. T-shirt, pants, shoes and hat are all clothing)
Pragmatics	Poor joint attention and eye contact Limited repertoire of facial expressions (e.g. first smiles emerge later, are less frequent and are more in response to tactile stimulation)	Respond in unexpected or misunderstood ways (e.g., quieting when interested in an activity) Intentional communication is not a prominent communication act; Most prevalent intentional communication is protesting Increased need for parent to encourage independent play and self-help activities	Use physical contact at the most basic level of communication for a number of other purposes: to seek reassurance, establish a position in space, gain attention, or indicate turn taking Reduced ability to imitate peers play in group activities	Breakdowns in social communication: initiating, responding, turn taking and maintaining contacts Congenitally blind children show features that resemble Pragmatic Language Impairment. This behaviour may occur because children miss visually-based social cues that dictate appropriate social interactions	Make comments that appear unrelated to topics; this behaviour has been shown to serve useful functions such as obtaining attention, initiating and responding in conversations and requesting clarification

Child-caregiver interaction	May not recognise the parent's voice until touched or handled Poor parent-child interaction Child's facial grimaces may be incorrectly interpreted as rejection of parent Caregivers of infants with visual impairment often miss or ignore the vocalisations and body movements of their children	Infant may quieten when parent speaks. Parents are discouraged to communicate and may become passive and quiet themselves May require touch cues to sustain interactions Delayed stranger anxiety because infants take longer to bond to caregiver	Concept development and language are limited, not by children's own inability or disinclination to explore the environment, but by parents not adding language to children's actions Exhibit avoidance reactions to strangers only when the stranger touches or tries to pick up the child, not in response to a stranger's voice	Child's visual status appears not only to affect maternal touch but also has an influence on child's own use of touch: overall increased use of active touch during shared focus interactions	
Expressive language	In the absence of other delays, children are likely to develop expressive language skills at the same rate as sighted children Delayed syllable production	Limited babbling Acquire language in qualitatively different ways Non-purposeful sound utterances	Use more specific nouns to represent concrete objects compared to sighted children May not easily attach verbal labels to tactual and auditory experiences e.g. may reach out for a tactile game such as tickling to continue, but not name the game Generally no differences when 10 or 50-word vocabularies are compared to sighted children Prolonged echolalia Increased use of words learned verbatim	Pronoun confusion Overuse of questions Infrequent use of sighted terms (e.g. see or look) Difficulty acquiring spatial-related language e.g. prepositions Delayed acquisition of personal and possessive pronouns Do not typically have difficulties acquiring language structure Learn to name objects spontaneously and give their own names and addresses, at an earlier age than sighted children	Improved phonemic fluency: advantage in identifying mispronounced words in a story Once symbolic language has been acquired, progress in lexical development increases
Adapted from: Alon *et al*., 2010; Brambring, 2007; Chen, 1999; Dale & Salt, 2007; Dale & Salt, 2008; Davidson & Harrison, 1997; Division on visual impairment, 2003; Erickson *et al*., 2007; Goldware & Silver, 1998; House & Davidson, 2000a; Hughes *et al*., 1999; James & Stojanovik, 2006; New York State Department of Health, 2007; Owens, 2005; Parker *et al*., 2008; Peltokorpi & Huttunen, 2008; Rattray & Zeedyk, 2005; Recchia, 1997; Tadic *et al*., 2010; Tedder *et al*., 1993; Trief, 2007; Vervloed *et al*., 2005.					

According to Table 2 there is a discrepancy between the dependency children with VI have on caregivers for communication development and the identified difficulty caregivers have developing a bond with children with VI. Caregivers should be given knowledge about their children's subtle attempts to communicate and that these signs do not demonstrate lack of interest but should rather be stimulated and developed (Erickson *et al*., 2007; Peltokorpi & Huttunen, 2008).

Mothers of children with VI tend to name objects around their children more frequently and ask a greater number of questions, showing increased levels of control and directiveness when compared to mothers of sighted children (House & Davidson, 2000; Vervloed *et al*., 2005). This behaviour results in fewer opportunities to follow the child's lead or for turn-taking interactions (Hughes, Dote-Kwan & Dolendo, 1999). This directive approach may hamper communication development (Rattray & Zeedyk, 2005) as children with VI often demonstrate an overuse of questions (Vervloed *et al.,* 2005). Early intervention focused on parent-child interaction will help develop communication domains that are at risk in children with VI, such as expressive language and pragmatics (Chen, 2001; Rossetti, 2001).

In some children, VI may not result in developmental delay, but rather divergent development as they learn to compensate for their disability (Brambring, 2007; Wakefield *et al.,* 2006). Young children who show delays in the acquisition of language may eventually overcome the delay (Brambring, 2007). However, divergent development can affect the child's progress later as qualitative differences remain (James & Stojanovik, 2006). Children with VI may demonstrate differences in communication skills, specifically with regard to vocabulary labels that are developed through tactile, auditory or visual experiences or concepts that are concrete or abstract (Brambring, 2007). Objects too large for tactile investigation such as animals, may pose difficulties. Divergent development can affect the child's progress later and impacts on school readiness as qualitative differences remain (James & Stojanovik, 2006).

It is evident that unique, but subtle language and communication difficulties may exist in young children with VI. The literature review provided a broad understanding of the existing information over several years. There is a need to systematically review recent research to examine the strength of the evidence and to describe language and communication developmental characteristics in young children with VI. The language and communication developmental characteristics revealed in this systematic review may assist speech-language therapists to build a knowledge base on early intervention for young children with VI and their families

1.3. Research question

The research questions posed in this systematic review were twofold: What is the strength of recent research evidence regarding early language and communication development skills of children with VI and what are the children's characteristics in these developmental areas?

CHAPTER 2: METHODOLOGY

Chapter Aim: The aim of the chapter is to describe the aspects of the methodology that were not discussed in method of the journal article (Chapter 3). The methodological aspects of the systematic review are discussed largely within the journal article but this methodology chapter further adds to those descriptions.

2.1. Research aims

The research methodology describes the process of critically appraising recent peer reviewed literature relating to communication and language development in children with VI.

Main aim

The main aim of this study was to systematically review the recent research evidence regarding early language and communication development skills of children with VI.

Sub-aims

The following sub-aims were formulated in order to achieve the main aim:

- Sub-aim 1: to determine the characteristics of the articles selected through the review process with regard to title, authors, year of publication, country where study was conducted, participant age range and number, method, level of evidence and visual status of participants
- Sub-aim 2: to determine the developmental communication characteristics of participants detailed in the articles; including communication, language and speech development.

2.2. Research design

A systematic review was conducted to answer the research questions posed. A systematic review also allowed for the identification of possible gaps in current research regarding language and communication development in young children with VI in order to suggest future research. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Statement (Moher, Liberati, Tetzlaff & Altman, 2009) was used to structure the systematic review. Systematic reviews are essential tools for collating evidence

accurately and reliably. They are important because they help clinicians keep up-to-date with new evidence and provide a starting point for clinical practice guideline developers. However, if key information is poorly reported then the potential usefulness of the review is diminished. The PRISMA checklist helps ensure the transparent and complete reporting of systematic reviews (Moher *et al*., 2009). Approximately 170 health science journals endorse the PRISMA Statement for the reporting of systematic reviews (PRISMA Statement, n.d.).

2.3. Data collection procedures

The MEDLINE, Scopus, PsycINFO and PubMed Based were used as electronic databases due to their relevance to the subject field. No limit was placed on the form of VI or type of study selected. Since the concepts communication, language and speech are used interchangeably in databases, these three concepts were coupled with development or characteristics in separate searches in each database. The main search phrases were 'communication development' and 'communication characteristics e.g. 'Communication development in children with VI' and 'Communication characteristics in children with VI'. These phrases were used in two respective searches in each of the four databases. For the related search phrases 'language' and 'speech' replaced 'communication' as the main phrases. A total of 24 searches were conducted. This electronic search strategy, limited to 2003 to 2013, resulted in the retrieval of a total of 1661 articles from the initial search. An age limitation of birth to five years was then applied. The last search was run in November 2013.

Once all the English language article titles were identified and duplicate articles were removed 162 articles remained. The abstracts of the selected articles were then reviewed. The remaining nine articles meeting the inclusion criteria were selected (Figure 2). The full articles were reviewed to identify the communication, speech and/or language development or characteristics of preschool children with VI. To avoid bias, consensus was reached between the three authors regarding the final inclusion of articles.

Data extraction took place by studying each article to form summaries of the articles. In terms of data items; information was collected from each article on: (1) characteristics such as title, authors, year of publication, country where study was conducted, participant age range and number, method, level of evidence and visual status of participants; (2) the developmental

communication characteristics of participants detailed in the articles; including communication, language and speech development.

2.4. Ethical considerations

This research project obtained ethical clearance for the study from the Faculty of Humanities (Appendix A). The original proposal included participants but the study was changed due to difficulties in finding a sufficient number of participants who complied with the inclusion criteria of the intended study.

The systematic review appraised published journal articles and no subjects were identified to participate in the study. Therefore, the ethical principles regarding human research subjects were not applicable to this study. The following ethical aspects were considered:

2.4.1. Plagiarism

Plagiarism refers using the work or ideas of others without fully recognising their contribution (Struwig & Stead, 2001). In order to avoid plagiarism all the sources contributing to this study were cited and included in the reference list.

2.4.2. Publication bias

Systematic reviews aim to incorporate evidence from all relevant studies. The absence of information from some studies, which is publication bias, may pose a serious threat to the validity of a review. Data may be incomplete because some studies were not published, or due to incomplete or inadequate reporting within a published article (Moher *et al*., 2009). Multiple databases were searched using more than one primary and secondary search phrase in order to access a large amount of relevant studies. Furthermore the risk of bias within the selected studies was evaluated.

2.4.3. Reliability and validity of research

Validity refers to the degree to which the research is scientifically based and appropriately conducted (Struwig & Stead, 2001). Reliability refers to for striving accuracy, consistency and stability when conducting all research procedures (Struwig & Stead, 2001).

The integrity of the data collected was ensured by:

- Following the PRISMA Statement Checklist (Moher *et al*., 2009) which outlines all the steps that should be included in a systematic review.
- Searching multiple databases using more than one primary and secondary search phrase.
- Selecting and reviewing recently published peer-reviewed articles from journals according to the inclusion criteria and based on consensus between the authors.

CHAPTER 3: LANGUAGE AND COMMUNICATION DEVELOPMENT IN PRESCHOOL CHILDREN WITH VISUAL IMPAIRMENT: A SYSTEMATIC REVIEW

Authors: Renata Mosca, Alta Kritzinger, Jeannie van der Linde

The article has been accepted for publication by the South Africa Journal of Communication Disorders.

Note: This manuscript was edited in accordance with editorial specifications of the journal and may differ from the editorial style used elsewhere in the dissertation.

3.1. Abstract

Background: Language and communication difficulties of young children with visual impairment (VI) are ascribed to intellectual disability, multiple disabilities and autism spectrum disorder (ASD) rather than their sensory impairment. Consequently the communication difficulties of children with VI may have been underestimated and undertreated.

Objectives: This report aims to critically appraise recent peer reviewed literature relating to communication and language development in children with VI.

Method: A systematic search of the literature (2003-2013) was completed using the PRISMA guidelines and primary and secondary search phrases. Nine publications were reviewed in terms of the strength of recent evidence. Thematic analysis was used to describe the early language and communication characteristics of children with VI.

Results: All the selected articles (n=9) were from developed countries and participants from seven of the studies had congenital VI. Five of the studies received an evidence level rating of III while four articles were rated as IIb. Two main themes emerged from the studies, 1) early intervention and 2) multiple disabilities and ASD. Language and communication development is affected by VI especially in the early stages of development. Speech-language therapists should therefore be included in early intervention for children with VI.

Conclusion: Recent evidence on the early language and communication difficulties of children with VI exists, but children in developing countries with acquired VI appear to not be investigated. The identified language and communication developmental characteristics revealed in this systematic review may assist speech-language therapists to build a knowledge base on early intervention for young children with VI and their families.

3.2. Introduction

The impact of visual impairment (VI) on the communication development in young children has been underestimated and undertreated (House & Davidson, 2000; James & Stojanovik, 2006). Underestimation and undertreatment may be because communication difficulties in children with VI are ascribed to intellectual disability and Autism Spectrum Disorder (ASD) (House & Davidson, 2000), or multiple disabilities (Chen, 2001) rather than VI. Another reason may be that speech-language therapists are not trained to treat this population as their main focus of training, with regards to sensory impairment, is on communication delay associated with hearing impairment (James & Stojanovik, 2006).

Early research on children with VI focused more on general development (Carvil, 2001; Davidson & Harrison, 2000; Good, Jan, Burden, Skoczenski & Candy, 2001; Prechtl, Cioni, Einspieler, Bos & Ferrari, 2001) than on communication difficulties. Communication-related studies were predominantly descriptive and mostly relied on expert opinion (Chen, 1999; Goldware & Silver, 1998; Tedder, Warden & Sikka, 1993), whereas the current trend in research is towards a high level of evidence. There is a need to review recent research to examine the strength of the evidence and to describe language and communication development in young children with VI.

Since the visual system is complex and the causes and effects of VI are numerous and intricate (Holte *et al*., 2006a), children with VI form part of a heterogeneous population. Approximately 70% of children with VI present with multiple disabilities (Chen, 2001) and there are more than 80 known genetic and chromosomal syndromes that may result in deafblindness (Holte *et al*., 2006a). The Joint Commission on Infant Hearing therefore endorses the ophthalmological assessment of all infants with confirmed hearing loss (Blumsack, 2009). Multiple disabilities affect clinical decision making during assessment and diagnosis as the characteristics of disorders may mask or mimic each other (House & Davidson, 2000). For example, the social communication difficulties of children with VI may be mislabelled as autistic tendencies (House & Davidson, 2000). Information is needed to help identify and improve the understanding of language and communication characteristics in young children with isolated VI and those with VI as part of multiple disabilities.

VI may affect the play, motor, cognitive, social and communication skills of young children (Chen, 2001) as typical development occurs through unrestricted interaction with the environment (Glass, 2002; Owens, 2005). Despite complexity and diversity within the population, children with VI are unified by a significant absence of visual experiences which shape development. Developmental difficulties of young children with VI and the nature of the development of the visual system suggest the need for intervention within the first 12 months of life (Davidson & Harrison, 2000). Increased information about language and communication development in young children with VI may improve early identification of communication difficulties, assist in goal setting and draw attention to the need for early communication intervention for this population.

Children with VI, and especially those with additional impairments, may require direct language instruction in order to develop language skills (Chen, 2001), highlighting the need to include speech-language therapists in the early intervention team for children with VI. Early intervention, as an evidence-based strategy (ASHA, 2008; SASLHA, 2011), is known to augment young children's development and promotes better long-term functional outcomes for both the child and the family (Fazzi *et al*., 2005). There is a need to review recent research to examine the strength of the evidence and to describe language and communication developmental characteristics in young children with VI.

The research questions posed in this systematic review were twofold: What is the strength of recent research evidence regarding early language and communication development skills of children with VI and what are the children's characteristics in these developmental areas?

3.3. Method

3.3.1. Study design

A systematic review was conducted to answer the research questions posed. The PRISMA Statement (Moher, Liberati, Tetzlaff & Altman, 2009) was used to structure the systematic review. The PRISMA checklist helps ensure the transparent and complete reporting of systematic reviews (Moher *et al*., 2009). This research project received ethical clearance from the Research Committee of the Department of Speech-Language Pathology and

Audiology and the Research Ethics Committee of the Faculty of Humanities of the University of Pretoria.

3.3.2. Study inclusion criteria

The inclusion criteria comprised of articles pertaining to communication, language and speech development and characteristics thereof in young children (birth to five years) with any form of VI. VI is defined as the loss of any aspect of vision that diminishes the ability to see. The International Classification of Diseases -10 (Update and Revision 2006) identifies the following ranges of vision; normal (equal to or better than 20/70), moderate (20/70-20/200) and severe VI (20/200-20/400). Moderate and severe VI are grouped as low vision. Blindness is categorised over three ranges, blind (20/200-20/1200), blind with light perception and blind with no light perception (WHO, 2012).

No limit was placed on the type of study selected. Based on relevance to the subject field, the following electronic databases were searched: MEDLINE, Scopus, PsycINFO and PubMed. Since the concepts communication, language and speech are used interchangeably in databases, these three concepts were coupled with development or characteristics in separate searches of each database. The main search phrases were ‘communication development’ and ‘communication characteristics e.g. ‘Communication development in children with VI’ and ‘Communication characteristics in children with VI’. These phrases were used in two respective searches in each of the four databases. For the related search phrases ‘language’ and ‘speech’ replaced ‘communication’ as the main phrases. A total of 24 searches were conducted across four databases. This electronic search strategy, limited to 2003 to 2013, resulted in the retrieval of a total of 1661 articles from the initial search. An age limitation of birth to five years was then applied. The last search was run in November 2013.

3.3.3. Study selection

All the English language article titles were reviewed and duplicate articles were removed (162 articles remained). The abstracts of the selected articles were then reviewed. The remaining nine articles meeting the inclusion criteria and discussing communication development and/or characteristics thereof, were selected (Figure 2). The full articles were reviewed to identify the communication, speech and/or language development or characteristics of children (birth to

five years) with VI. To avoid bias, consensus was reached between the three authors regarding the final inclusion of articles.

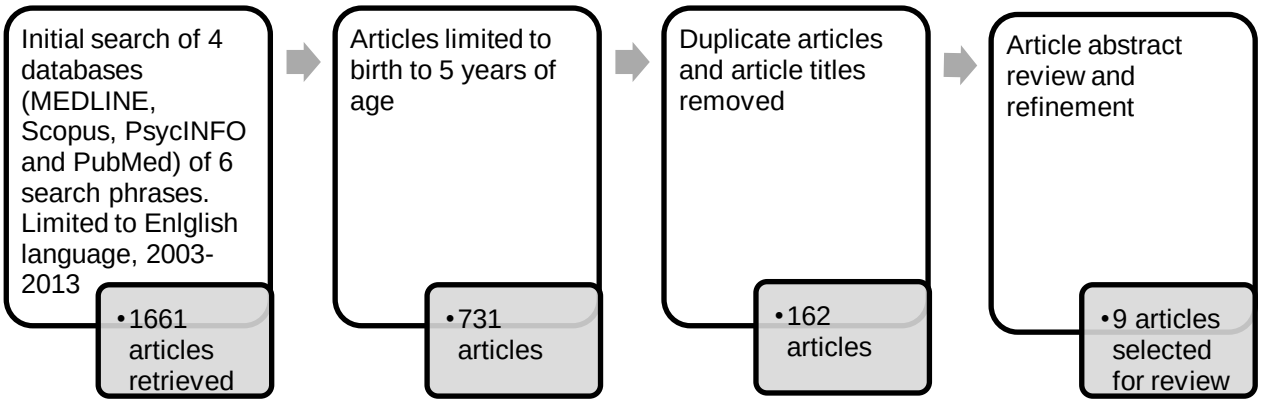


Figure 2. Review phases used to identify articles for inclusion

3.3.4. Data collection process and data items

Data collection took place by studying each article and extracting information to form summaries of the articles, displayed as mind maps. In terms of data items; information was collected from each article on: (1) characteristics such as title, authors, year of publication, country where study was conducted, participant age range and number, method, level of evidence and visual status of participants; (2) the developmental communication characteristics of participants detailed in the article; including communication, language and speech development.

As it is widely accepted in the field of speech-language therapy, the ASHA level of evidence rating scale (ASHA, 2004) was used to categorise the articles in the final selection according to the level of evidence. These ratings are discussed within the results section of this article.

3.3.5. Risk of bias in selected studies

The criteria for the assessment of risk of bias were modified from the Cochrane Collaboration's tool for assessing risk of bias (Higgins, Altman & Sterne, 2011). The following criteria were included: steps taken to avoid selection bias, blinding of participants, personnel or outcome assessors (when information about the study that might lead to bias in the results is concealed), the presence of control groups or tools, the involvement of more than one

clinician in evaluations, interrater agreement and the use of validity, internal item consistency and/or reliability testing. None of the selected articles specifically described an assessment of risk of bias other than providing statements pertaining to possible bias. Decisions on the risk of bias were made by consensus between the authors.

3.3.6. Data Analysis

Thematic analysis (De Vos, Strydom, Fouché & Delport, 2005) was used to organise the information extracted from the selected studies and to synthesise results. Main themes were identified within the data and sub-themes were assigned from the study outcomes.

3.4. Results and discussion

3.4.1. Study characteristics

The characteristics of the nine selected articles are presented in Table 3. The articles ranged from 2005 to 2012 and were all conducted in developed countries. However, it is estimated that there are 285 million people in the world with VI (WHO, 2014), 90% of which reside in developing countries (WHO, 2010). Seven of the nine articles described participants with congenital VI. Of the remaining two studies, one investigated VI acquired at eight weeks old and the other study did not provide the aetiology of VI in the mother-child dyads. The prominence of congenital VI in the study sample may be characteristic of current research in developed countries. Conversely, Gilbert and Foster (2001) state that VI in developing countries is usually acquired.

The cumulative participant age range for all nine articles was birth to 28 years. Participants older than five years were included in the studies, as mental disability resulted in functioning below a developmental level of five years of age.

The number of participants varied widely across each selected study, from one to 83 individuals. Five of the selected articles were longitudinal studies (Funnell & Wilding, 2011; Ashkenazy, Cohen, Ophir-Cohen & Tirosh, 2005; Parr, Dale, Shaffer & Salt, 2010; Peltzer-Karpf, 2012; Rattray & Zeedyk, 2005) of which three utilised the most participants of the nine studies. It is remarkable that such large samples could be recruited as VI is a low incidence disability and participant attrition is a disadvantage of longitudinal research. In the study with

the greatest number of participants (n=83) (Parr *et al*., 2010) this was achieved through a retrospective review of case-notes collected over 32 years. In the study by Peltzer-Karpf (2012), a meta-analysis from four studies was conducted. Participants in the study by Ashkenazy *et al*. (2005) were recruited from a specialised unit for children with VI in a large child development centre.

The strength of recent research evidence of the early language and communication skills of children with VI shows that five of the articles (Ashkenazy *et al*., 2005; Dammeyer, 2012; Funnell & Wilding, 2011; Parr *et al*., 2010; Peltokorpi & Huttunen, 2008) achieved a Level III rating. These studies were either comparative investigations, retrospective and prospective case studies or survey designs. The remaining four articles received a higher rating of IIb as they were identified as well-designed quasi-experimental studies. Two studies (Absoud, Parr, Salt & Dale, 2011; Hoevenaars-van den Boom, Antonissen, Knoors & Vervloed, 2009) developed assessment tools. Peltzer-Karpf (2012) made use of neuroimaging to compare study group results and Rattray and Zeedyk (2005) conducted a longitudinal study with a static four-group comparative design.

Table 3: Summary of articles selected for review

Title	Study: Authors, year and country	Participant age range	Number of participants including controls	Research method	Level of evidence (ASHA, 2004)	Visual characteristics of participants
Development and characteristics of children with Usher syndrome and CHARGE syndrome	Dammeyer, 2012, Denmark	Usher syndrome: 3-17 years CHARGE syndrome: 0-15 years	Usher syndrome: 26 CHARGE syndrome: 19	Survey using medical case records and deafblind consultants	III	Congenital and progressive deafblindness
The dynamic landscape of exceptional language development	Peltzer-Karpf, 2012, Austria	Four studies: 6-10 years, 5-11 years, 18 months-8 years Main case: 18 months-3 years	72	Longitudinal study over 18 months with control groups	IIb	Congenital VI
Development of a vocabulary of object shapes in a child with a very-early-acquired visual agnosia: A unique case	Funnell & Wilding, 2011, England	Study conducted between 2-14 years	1	Longitudinal design over 8 years, single case study with retrospective data included	III	Acquired visual agnosia
Developing a schedule to identify social communication difficulties & autism spectrum disorder in young children with visual impairment	Absoud et al., 2011, England	1 year 9 months-6 years 11 months	23	Comparative design for observational tool development	IIb	Congenital VI
Social communication difficulties and autism spectrum disorder in young children with optic nerve hypoplasia and/or septo-optic dysplasia	Parr et al., 2010, England	10 months-6 years 10 months	83	Longitudinal study over 32 years, retrospective case-notes review with between subject comparison	III	Congenital VI
Differentiating characteristics of deafblindness and autism in people with congenital deafblindness and profound intellectual disability	Hoevenaars-van den Boom et al., 2009, The Netherlands	7-28 years, developmental age of less than 24 months	10	Comparative design for observational tool development	IIb	Congenital deafblindness
Communication in the early stage of language development in children with CHARGE syndrome	Peltokorpi & Huttunen, 2008, Finland	Three participants: 1.4, 3.9 and 8.4 years	3	Descriptive multiple single case study design with survey elements	III	Congenital deafblindness
Early communication in dyads with visual impairment	Rattray & Zeedyk, 2005, England	6-18 months	5 dyads (n10)	Longitudinal, comparative design over 1 year with static four-group design	IIb	Mother or child or both had VI
Emotional status and development in children who are visually impaired	Ashkenazy et al., 2005, Israel	0-5 years	74	Longitudinal, comparative design over 18 years	III	Congenital VI

None of the articles achieved a level of evidence of IIa and above. It appears that controlled studies with randomisation may advance research in this field. By using randomisation, with a representative sample, comparisons could be made between participants with various conditions presenting with VI or between age matched peers without VI (De Vos *et al*., 2005). This would assist in singling out the impact of VI on language and communication development. However, as children with VI are a diverse population, randomisation is a challenging task. There are many possible contributing factors, besides VI, that can influence developmental functioning. Identified factors include multiple disabilities, extended hospitalisation and therefore environmental deprivation, age of identification, economic status, caregiver behaviour, intellectual ability and behavioural difficulties. Although most of the study designs and methods still represent the lowest level of evidence, the difficulty of conducting research on children with VI should be considered. There appears to be a move to more sophisticated designs and objective methods such as the neuroimaging used by Peltzer-Karpf (2012) which may provide a new avenue in research. In summary, the validity of recent research on the language and communication characteristics of children with VI appears to be increasing in level of evidence.

Four (n=9) of the studies (Absoud *et al*., 2011; Dammeyer, 2012, Parr *et al*., 2010; Hoevenaars-van *et al*., 2009) highlighted the lack of assessment tools and Peltokorpi and Huttunen (2008) required the modification of two tools to exclude visually loaded items. This can result in subjective, informal evaluations and/or multidisciplinary consensus diagnoses (Davidson & Harrison, 2000). The lack of appropriate communication- and language-related assessment tools for children with VI further limits the level of evidence that studies can achieve.

3.4.2. Risk of bias within and across studies

The PRISMA statement (Moher *et al*., 2009) regards the assessment of risk of bias as one of the key characteristics of a systematic review as biases pose a threat to the validity of a review. The selected articles were assessed according to the identified criteria (Table 4). It was not always possible to identify if the criteria for the assessment of risk of bias were met as explicit statements were not found in the articles. The conditions that could not be reliably labelled as absent or present were therefore recorded as ‘unclear’ instead.

Table 4: Six criteria for risk of bias within and across studies

	Steps taken to avoid selection bias	**Blinding of participants (1), personnel (2) or outcome assessors (3)**	**Control groups or tools (*)**	**More than one clinician involved in evaluations**	**Interrater agreement achieved**	**Validity (a), internal item consistency (b) and/or reliability testing (c)**	**Possible bias identified in the selected study**
Dammeyer, 2012	✓	Unclear	Unclear	✓	Unclear	Unclear	Small sample size. Comparisons made between the difficulties common between the syndromes.
Peltzer-Karpf, 2012	Unclear	Unclear	✓	Unclear	Unclear	Unclear	Unclear
Funnell & Wilding, 2011	Single case study	Unclear	✓	✓	Unclear	Unclear	Unclear
Absoud et al., 2011	✓	✓ (3)	✓ (*)	✓	X consensus rating used	✓ (a) ✓ (b) ✓ (c)	Referral pattern used. Small sample size. Variation in participant group size.
Parr et al., 2010	✓	✓ (3)	✓	✓	Unclear	Unclear	Retrospective nature of the study as the true rate of ASD in the sample may be higher because ASD knowledge has developed since 1977. The impact of individual differences in environmental experience and input was not assessed.
Hoevenaars-van den Boom et al., 2009	✓	✓ (3)	✓	✓	✓	✓ (b)	Difficulty diagnosing ASD. Small sample size. Diverse aetiologies of VI in participants. Adjustment for behaviour was limited due to the standardisation of the assessment. Psychometric properties of the assessment procedures required further testing
Peltokorpi & Huttunen, 2008	Unclear	✓ (3)	✓ (*)	✓	✓	Unclear	Modifications were required for both analysis methods due to the participants' VI. Short duration of the sample of behaviour for each child may only reveal some features of communication. Testing with multiple partners in different environments is required.
Rattray & Zeedyk, 2005	✓	✓ (3)	✓	✓	Unclear	✓ (c)	Unclear
Ashkenazy et al., 2005	✓	Unclear	✓	✓	Unclear	Unclear	Small sample size. Some children in the control group may have developed difficulties later, after the upper age limit of the study.

According to Table 4, Hoevenaars-van den Boom *et al*. (2009) was the most unbiased study and met all the selected criteria for assessment of bias (Higgins *et al*., 2011). Peltzer-Karpf (2012) met the least measures of bias as 'control groups' was the only criterion identified in the article. In Dammeyer (2012) only two of the six criteria were identified. Assessment criteria for bias not met does not necessarily imply bias, but rather that the description and rationale of methodological procedures were unclear. All but one article, Dammeyer (2012), clearly stated the use of some form of control and all the studies, except Peltzer-Karpf (2012), mentioned the involvement of more than one clinician during the evaluations. Most of the selected studies, except Funnell and Wilding (2011), Peltzer-Karpf (2012) and Rattray & Zeedyk (2005), provided statements on possible biases in their studies. Seven of the selected articles (n=9) met at least three out of six criteria which indicates that risk of bias is being considered in recent research.

3.4.3. Language and communication characteristics of young children with VI

The language and communication characteristics of children with VI were identified from recent research by means of a thematic analysis (Appendix B). The studies by Parr *et al*. (2010) and Peltokorpi and Huttunen (2008) were allocated to both main themes as they discuss early intervention, ASD and multiple disabilities. The first main theme identified in analyses of the nine studies was early intervention (Appendix B). The early developmental difficulties described in the studies highlighted a need to support caregivers and children with VI during early stages of language and communication development.

The study by Dammeyer (2012) identified possible early predictors for language delays in children with VI. Delayed walking was associated with cognitive and language delays in participants with CHARGE syndrome. The study also found that difficulties in vision, hearing and motor skills have a compounding effect on language, cognitive and social development in participants with Usher and CHARGE syndromes (Dammeyer, 2012). It appears that the more severe the multidisabilities, the greater impact on the participants' development.

By means of longitudinal neuroimaging studies Peltzer-Karpf (2012) identified that language acquisition follows the same pattern for participants with VI as for sighted controls but that the progression is slower. With age and maturity the initial gap between the participant with VI and the participant with normal vision diminished. The author found that language delays were more prominent in the early stages of development. Multifaceted training programs focused on developmental progression instead of age-matched abilities were recommended from an early age to help overcome this initial delay sooner and to optimise neuroplasticity (Peltzer-Karpf, 2012).

Funnell and Wilding (2011) showed that phonology and articulation development were not impacted by the VI but receptive and expressive language delays were evident from the age of two years when preschool assessments commenced. Peltokorpi and Huttunen (2008) found that language and communication were impacted from the preverbal stages in children with CHARGE syndrome. This delay resulted in limited intentional communication with a greater dependency on gestures and protesting. The researchers recommended that early intervention be based on parent-child interaction. Parents that are competent and adaptive communication partners help to support communication development (Funnell & Wilding, 2011). Parr *et al*. (2010) found that basic form vision in children with optic nerve hypoplasia (ONH) and septo-optic dysplasia (SOD) is insufficient to support the development of early social and communication skills.

Rattray and Zeedyk (2005) identified three non-visual, alternative communication means to maintain the quality of communication interactions between mothers and their young children with VI. Touch, vocalisations and facial orientation are recommended to help mothers fulfil their important role in language acquisition in children with VI. All the mothers in the study instinctively used active touch and increased vocalisations as modes of communication. Children with VI used active touch during shared attention as a tactile form of communication. Although still a means of communication, the rate of vocalisation was affected by the presence of VI in the mother or child. All the mothers and children made use of facial orientation during shared attention but to a lesser degree than touch and vocalisations, indicating that facial orientation is not as important as an alternative communication means (Rattray & Zeedyk, 2005).

Lastly, Ashkenazy *et al*. (2005) found that the emotional and behavioural status of children with VI impacts on their receptive and expressive language abilities. Early identification and treatment of emotional and behavioural problems in children with VI is therefore important, as delayed language development may be ameliorated.

Recent research therefore suggests that children with congenital VI show the greatest delays in the early stages of development when language and communication acquisition are more dependent on visual input. The greater the degree of VI the more likely children with VI are to present with early social and communication difficulties (Parr *et al*., 2010). It could be that during the early years when children are dependent on caregivers for language development, parents may not be aware of how to adapt their interactions to stimulate development through alternative, non-visual means. It is clear that speech-language therapists need to play a greater role in early intervention for children with VI.

The second main theme identified (Appendix B) was ASD and multiple disabilities. Absoud *et al*. (2011) ascribed the high rate of children with VI that present with social communication difficulties and ASD to multiple factors including visual status, age, gender and psychological and neurological functioning. By developing an observation instrument for early accurate identification of social communication difficulties and ASD in preschool children with VI, early intervention strategies can be implemented (Absoud *et al*., 2011). Parr *et al*. (2010) found that children with VI due to ONH and SOD, especially in the presence of significant cognitive impairment and/or profound VI, are also at risk of ASD. There was, however, no evidence that additional neuro-anatomical abnormalities, other than those associated with ONH and SOD, further increased the risk of ASD. According to Parr *et al*. (2010) the co-occurrence of VI and ASD in a child significantly affects receptive and expressive language abilities. The authors offer an explanation that ASD may result as secondary condition to VI due to sensory deprivation, hormonal influences or genetic factors but these mechanisms require further investigation (Parr *et al*., 2010).

Peltokorpi and Huttunen (2008) state that children with CHARGE syndrome frequently demonstrate ASD traits. Contributing factors to this behaviour may be reduced parent-child interaction due to long periods of hospitalisation and poor health, first smiles emerge later in

children with CHARGE syndrome which, with possible facial paralysis, can affect non-verbal communication, and the children display more stereotyped behaviour than other children with deafblindness (Peltokorpi & Huttunen, 2008). However, children with CHARGE syndrome demonstrated better language and communication abilities than children with ASD (Peltokorpi & Huttunen, 2008).

According to Hoevenaars-van den Boom *et al*. (2009), ASD can be over-diagnosed and mistreated in children with deafblindness due to similarities in behaviour, especially when intellectual disability co-occurs. Despite the tendency of over-diagnosis, there appears to be a high prevalence of ASD in children with deafblindness. Communication and language are the main areas affected by congenital deafblindness and children often remain at a preverbal stage (Hoevenaars-van den Boom *et al*., 2009). The co-occurrence of VI, intellectual disability and ASD has a compounding effect on development. Children with ASD, deafblindness and intellectual disability show greater difficulty with communication functions, pragmatic skills, transitioning, problem solving, play and stereotyped behaviour than in the absence of ASD (Hoevenaars-van den Boom *et al*., 2009). Therefore social interaction and communication skills should guide the diagnosis of ASD in children with deafblindness. ASD symptoms may present in children with deafblindness due to extreme isolation from people and the environment. The inclusion of pragmatic skills across multiple studies may be because the early development of these abilities depends heavily on vision (Dale & Salt, 2008).

The results of the systematic review confirm the observation by Chen (2001) that a characteristic of children with VI is that there are almost always associated conditions which complicates diagnosis and management. According to House and Davidson (2000) speech-language therapists may manage children with VI in the same way as they would treat children with hearing loss, as it is the sensory difficulty that they are most familiar with. However, the presence of multiple disabilities, such as deafblindness, has an accumulated effect on language and communication development as both visual and hearing input are limited. These complex difficulties require the use of different approaches and techniques to stimulate language and communication abilities.

The participants with VI in the studies by Funnell and Wilding (2011), Hoevenaars-van den Boom *et al*. (2009), Peltokorpi and Huttunen (2008), and Peltzer-Karpf (2012) all presented with language and communication difficulties. In the study by Parr *et al*. (2010) 58% of the participants presented with at least one social, communication and/or restrictive or repetitive behaviour. The studies by Absoud *et al*. (2011), Ashkenazy *et al*. (2005) and Rattray & Zeedyk (2005) described language and communication characteristics but did not state how many of the participants demonstrated difficulties. In the study by Dammeyer (2012) 15 of the 26 participants with Usher syndrome and three of the 17 participants with CHARGE syndrome presented with little or no language delay or intellectual disability. This may be because of the relationship between intellectual ability and language competence (Dammeyer, 2012). In summary, language and communication difficulties were common in the participants of the study selection.

An identified study limitation of the systematic review may be inclusion of participants that were older than five years. During the database searches filters were set for the age range of birth to five years old, as identified by the inclusion criteria. However, participants that were older were included in the selected studies due to intellectual disabilities.

3.5. Conclusion

The finding that no studies were identified from developing countries, points to a great research need. Of the approximate 19 million children with VI (birth to 14 years) worldwide (WHO 2014), an estimated 23% are blind live in the developing region of sub-Saharan Africa (Kello & Gilbert, 2003). South African speech-language therapists can expect to encounter children with VI more often than therapists in developed countries. The children's profile of VI and associated disorders and delays may also be different from those living in developed countries. The aetiology of the VI in developing countries is mostly acquired due to a lack of resources and stressful environments (Gilbert & Foster, 2001), while participants in seven of the nine selected studies presented with congenital VI. It appears that recent research is not yet investigating the communication and language development of children in developing countries with acquired VI.

The lack of appropriate assessment tools for children with VI may also limit research on the developmental characteristics of this population. The trend in research should be towards developing appropriate assessment tools, such as the studies by Absoud *et al*. (2011) and Hoevenaars-van den Boom *et al*. (2009). Following on improved assessment measures, effective language and communication stimulation techniques should be developed for caregivers of children with VI to use during the difficult early stages of development.

Investigating the language and communication difficulties of young children with VI is challenging. The visual system is the most complex sensory system but the least mature at birth (Glass, 2002). Thus, the causes and effects of VI are numerous and intricate (Holte *et al*., 2006a). Conducting research with this diverse population is complicated, especially with the common co-occurrence of other conditions.

Based on this systematic review there is recent evidence on the early language and communication difficulties of children with VI. However, language and communication difficulties are not identified or prioritized in children with VI due to the co-occurrence of multiple difficulties such as intellectual disability, ASD and multiple disabilities. Six of the nine articles (Absoud *et al*., 2011; Dammeyer, 2012; Hoevenaars-van den Boom *et al*., 2009; Funnell & Wilding, 2011; Parr *et al*., 2010; Peltokorpi & Huttunen, 2008) attempt to address this problem. The impact of VI itself on communication remains unclear because the effect of VI on language and communication development cannot yet be separated from the primary conditions.

Language and communication development in children with VI is not a large or popular research field in speech-language therapy. Therefore, the carry-over of research into clinical practise may be limited resulting in undertreatment and underestimation of the language and communication difficulties in young children with VI. The language and communication developmental characteristics revealed in this systematic review may assist speech-language therapists to build a knowledge base on early intervention for young children with VI and their families. To add to this knowledge base future research needs to focus on describing the language and communication developmental characteristics of children with acquired VI in developing countries, especially within Sub-Saharan Africa.

CHAPTER 4: DISCUSSION AND CONCLUSION

Chapter aim: The aim of the chapter is to discuss how the analysis of recent research through systematic review may contribute to speech-language therapists' involvement in early intervention for young children with VI.

4.1. The value of the systematic review

The systematic review provided a more in-depth, recent and evidence-based description of the language and communication developmental characteristics of children with VI than the broad collection of information shown in the literature review (Table 1 & Table 2). The PRISMA checklist (Moher *et al*., 2009) allowed for greater accuracy and reliability in the reporting of the identified developmental characteristics.

The developmental characteristics discussed in the literature review (Table 1 & Table 2) were, to a large extent, based on expert opinion whereas the current, more recent research shows a trend towards higher levels of evidence. The new direction in recent literature demonstrates a move towards more objective measures through a greater use of technology such as in the study by Peltzer-Karpf (2012).

The thematic analysis within the systematic review highlighted the gaps and challenges in recent research more explicitly than in the broad literature review (Table 1 & Table 2). The main gaps were the dearth of information on the language and communication development of preschool children with acquired VI in developing countries and the lack of appropriate communication assessment tools for children with VI. The greatest challenge that may confront current research is to distinguish between the impact of VI on language and communication development and the impact of VI on development of common co-occurring conditions, including multiple disabilities, ASD and intellectual disabilities. Consequently, the impact of VI itself on communication remains unclear because the effect of VI on language and communication development cannot yet be separated from the primary conditions. However, the language and communication developmental characteristics

revealed in this systematic review may assist speech-language therapists to build a knowledge base on early intervention for young children with VI and their families.

4.2. Clinical implications

To enable the transfer of language and communication developmental characteristics of young children with VI from research to clinical practice, the guiding principles in early intervention should be taken into consideration. The American Speech and Hearing Association details four elements that are key in providing early and effective communication intervention, namely services that are family-centred and culturally responsive; developmentally supportive and promote children's participation in their natural environments; comprehensive, coordinated, and team-based; and based on the highest quality evidence that is available (ASHA, 2008).

The four guiding principles are applicable to all contexts, including those that are culturally diverse and have limited resources, as is experienced in many developing countries such as South Africa and other Sub-Saharan African countries. Children in developing countries, especially those with impairments or multiple disabilities, are at risk for neglect and often live in insecure environments (Kello & Gilbert, 2003). By encouraging family participation and empowerment, parents of young children may provide appropriate and constant stimulation in natural environments.

However, the challenge now is for speech-language therapists to use the collated evidence-based information to advocate for their role on existing intervention teams that are already providing services to young children with VI. The communication difficulties experienced by children with VI are not prioritised or well-known to other disciplines. Speech-language therapists need to make other professionals, teachers, parents and the public aware of the need for early communication intervention for children with VI.

An additional clinical implication involves the composition of the early intervention team for young children with VI and their families. Audiologists are the professionals that speech-language therapists traditionally collaborate within the treatment of children with hearing loss. For children with VI occupational therapists may be the allied team members that

speech-language therapists should collaborate with, mostly due to the common goal of achieving optimal functionality in the presence of probable multiple disabilities.

4.3. Future research needs

The lack of appropriate communication assessment tools for children with VI limits the level of evidence into developmental characteristics. The trend in research should be towards developing appropriate assessment tools, which was achieved in the studies by Absoud *et al*. (2011) and Hoevenaars-van den Boom *et al*. (2009). Alternatively, efforts should be made to validate the modifications made to existing tools. Improved assessment measures should be used to evaluate the language and communication characteristics of young children with acquired VI in developing countries. The characteristics of children with VI in developing and developed countries should be contrasted to highlight similarities and differences. Following the improvement of assessment protocols, effective language and communication stimulation techniques should be developed for caregivers of children with VI to use during the early stages of development.

Well-coordinated and evidence based early intervention strategies are crucial to help children with VI and their families utilise existing abilities and to develop new skills in order to achieve their full potential (Parker *et al.,* 2008). Children from low income countries are more likely to be negatively affected by early biological and psychosocial factors (Gilbert & Foster, 2001). Early intervention benefits families in developing countries that often lack resources, such as South Africa, because the accumulation of risk factors can be prevented, and established developmental risks are addressed from an early age (Samuels *et al*., 2012). Further research on the benefits of early intervention for young children with VI and their families is required, particularly studies conducted in developing countries.

Early intervention employs an asset-based approach which focuses on identifying resilience that can help to minimise the effect of risk factors (ASHA, 2008). When considering that children with VI explore their environments less than sighted children (Chen, 2001) and that language is stimulated by interacting with the environment (Owens, 2005), the need for speech-language therapists to work in a transdisciplinary team is evident. A transdisciplinary approach is well suited to South Africa because of the improved use of

professionals, reduced financial costs and better time management which assists in the sustainability of services. The benefits of transdisciplinary early intervention for young children with VI should be evaluated in future research.

4.4. Critical evaluation

A limitation of the systematic review may be inclusion of participants that were older than five years. During the database searches filters were set for the age range of birth to five years old, as identified by the inclusion criteria. However, participants that were older were included in the selected studies due to intellectual disabilities which resulted in a low level of functioning.

4.5 Conclusion

Children with VI are a hidden population for speech-language therapists. This systematic review motivated the need for speech-language therapists to become involved in early intervention for children with VI from the perspective of prevention of further delay, intervention for existing delays and advocating for the awareness of the possible communication problems. Children with VI, specifically those in developing countries with acquired VI, require increased attention, not only within research but in clinical practice too. The identified language and communication developmental characteristics and early intervention guidelines by ASHA (2008) provide the framework for improved service provision by speech-language therapists to young children with VI.

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6. APPENDICES

Appendix A

Ethical clearance form

Note: The original topic changed and the researchers chose to conduct a systematic review. Since the change did not involve human participants anymore, and the study leaders approved the new topic, an amendment to the ethical permission was not necessary.

Our Ref: Ms P Woest / 25071999
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UNIVERSITEIT VAN PRETORIA
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Faculty of Humanities

13 July 2011

Miss R Mosca
PO Box 39283
MORELETA PARK
0044

Dear Miss Mosca

TITLE REGISTRATION: FIELD OF STUDY – MCOMMUNICATION PATHOLOGY

I have pleasure in informing you that the following has been approved:

TITLE: **An early communication assessment protocal for children with visual impairment**

SUPERVISOR: **Prof A Kritzinger**

CO-SUPERVISOR: **Ms J van der Linde**

I would like to draw your attention to the following:

1. **ENROLMENT PERIOD**
   (a) You must be enrolled as a student for at least one academic year before submission of your dissertation/essay.
   (b) Your enrolment as a student must be renewed annually before 31 March, until you have complied with all the requirements for the degree. You will only be able to have supervision if you provide a proof of registration to your supervisor.

2. **APPROVAL FOR SUBMISSION**
   On completion of your dissertation/essay enough copies for each examiner as well as the prescribed examination enrolment form which includes a statement by your director of studies that he/she approves of the submission of your dissertation/essay, as well as a statement, signed by you in the presence of a Commissioner of Oaths, must be submitted to Student Administration.

3. **NOTIFICATION BEFORE SUBMISSION**
   You are required to notify me at least three months in advance of your intention to submit your dissertation/essay.

4. **INSTRUCTIONS REGARDING THE PREPARATION OF THE DISSERTATION/ESSAY AND THE SUMMARY APPEAR ON THE REVERSE SIDE OF THIS LETTER.**

Yours sincerely

for **DEAN: FACULTY OF HUMANITIES**

GW-505E

Appendix B

Summary of main themes, sub-themes and study outcomes relating to communication and language characteristics of young children with VI

Main themes	Article	Sub-themes	Study outcomes
Early intervention	Dammeyer, 2012	Language abilities Congenital VI Lack of assessment tool Cognitive impairment Multiple disabilities	No formal test for the language evaluation of children with deafblindness. Language delay was estimated using informal procedures and a rating scale 15 (n26) children with Usher presented with little or no language delay 3 (n17) children with CHARGE presented with little or no language delay Late age of walking may be an early predictor for: - cognitive and language delays in CHARGE syndrome - cognitive delay in Usher syndrome The combination of VI, hearing loss and delayed motor skills provided additional barriers for language, cognitive and social development There was a correlation between the degree of deafblindness and the language delay in Usher There was a correlation between degree of intellectual disability and language delay in Usher and CHARGE
	Peltzer-Karpf, 2012	Language abilities Pragmatic skills Congenital VI Neuroimaging	In children with congenital VI the visual areas of the brain are used for nonvisual tasks such as auditory language processing Language acquisition in children with sensory impairment follows the same overall pattern to sighted or hearing children in terms of macro structural changes but various subsystems, within vison, hearing, language and attention, are selectively affected Therefore there are time lags that are most evident in the early stages of development Development of neural systems for syntax takes longer than systems for semantics Due to the absence of lip reading there is extended sound sorting and delays in phonological learning Congenital VI results in the lack of referential gaze which causes slower concept formation. This affects morphological and syntactic development Initially the single word stage is delayed but this is followed by intense lexical acceleration rate Language delay decreases with age and maturity, resulting in developmental profiles process-oriented and not age-matched Interdisciplinary, process-oriented research helps to apply multifaceted training programs as early and efficiently as possible to optimise children's development
	Funnell & Wilding, 2011	Language abilities Speech production	Language delay identified from the age of two years Progressive receptive and expressive language delay over the years Phonology and articulation were normal as the systems are not dependent on vision Severely impaired visual object naming contrasted with normal understanding of the spoken names of objects
	Parr *et al*., 2010	Pragmatic skills Language abilities Congenital VI Lack of assessment tool ASD	Standard measures of social communication development and ASD are not available for young children with VI There was at least one SCRR difficulty in 48 (n83) of the participants 37% of the sample had difficulties in all three domains Children with one or more SCRR and ASD have a developmental quotient within the learning difficulty range when compared to norms of children with VI Basic form vision is not sufficient to support early social and communication development in

		Multiple disabilities	children with ONH and SOD
	Peltokorpi & Huttunen, 2008	Communication abilities Language abilities Pragmatic skills Congenital VI Stereotyped behaviour Multiple disabilities Parent-child interaction Tool modification required	Communication was impacted from the preverbal stage due to deafblindness, hospitalisation and facial paralysis Children with CHARGE demonstrate more stereotypical behaviour than other children with deafblindness All the children (n3): - used mainly gestures - made initiations slightly under half of the total number of communication expressions, indicating active involvement - used eye contact but limited even though sight was used to explore toys - showed limited requesting - protesting was the most common communication function Intentional communicative acts were present in all three participants but the frequency was low compared to total number of communicative acts Children with multiple disabilities demonstrate only some intentional communication in early stages of language development Careful examinations of the communicative behaviour between a child and parent can serve as a basis for early intervention Atypical features of visual behaviour make interpreting communication challenging Audiological management is important for the development of communication and language in children with CHARGE
	Rattray & Zeedyk, 2005	Communication abilities Communication means Pragmatic skills Parent-child interaction	All mothers used active touch as a mode for communication, but mothers of children with VI used increased active touch before gradually decreasing it All mothers and infants showed more active and passive touch during shared attention, indicating that touch is a communication means Active touch is prominent in children with VI as a tactile form of communication due to the lack of visual communication during shared attention All mothers and children used increased vocalisations during joint attention as a means of communication VI, of mother or child, may affect the overall rate of vocalisation but is still used as a means of communication All mothers and children used facial orientation during shared attention but less than touch and vocalisations, indicating that facial orientation is not as important as a communication means VI itself does not automatically decrease the quality of communication interactions between mothers and infants but does necessitates the reliance on alternative, non-visual communication means The VI status of the mother and/or child impacts the communication interaction Mothers have an important role in children's communication acquisition

	Ashkenazy *et al*., 2005	Language abilities Emotional status Parent-child interaction Congenital VI	Receptive language attainments were significantly affected by the child's emotional and behavioural status The interaction between the child's age and the mother's level of education impacts on receptive language: older children of mothers with less education show compromised receptive language abilities Expressive language attainments were associated with the child's emotional and behavioural status and not significantly with the mother's level of education There was a strong association between development and a child with VI's emotional and behavioural status Early identification and treatment of emotional and behavioural problems lead to better emotional status and thus improved development
ASD and multiple disabilities	Absoud *et al*., 2011	Pragmatic skills Congenital VI Lack of assessment tool Early intervention	There is a lack of ASD and early social communication assessments tools for children with VI A high rate of children with VIs present with social communication difficulties and ASD, but there is no test to confirm this The development of the VI and Social Communication Schedule (VISS) can assist in early ASD diagnosis for children with VI and subsequent appropriate early intervention
	Parr *et al*., 2010	Language abilities Pragmatic skills Congenital VI Stereotyped behaviour	31% of the sample received an ASD diagnosis Significant cognitive impairment in children with ONH and SOD show a greater risk for ASD Slightly more children with SOD where diagnosed with ASD than children with ONH Children with PVI were more likely to present with at least one SCRR difficulty and to show all three SCRR difficulties than children with SVI but were only slightly more likely to receive an ASD diagnosis VI with ASD resulted in significantly lower verbal comprehension and expressive language structure ASD was typically diagnosed in children with ONH or SOD usually between 2.4-4.6 years No evidence that additional neuro-anatomical abnormalities, other than those associated with ONH and SOD, further increased the risk of ASD

	Hoevenaars -van den Boom *et al*., 2009	Language abilities Pragmatics skills Congenital VI Stereotyped behaviour Lack of assessment tool Cognitive impairment Differential diagnosis	It is difficult to distinguish ASD from deafblindness behaviours especially in the presence of intellectual disability and this can lead to over-diagnosis and incorrect intervention The presence of congenital deafblindness showed an increased risk ASD Communication and language development were primarily affected by congenital deafblindness although other developmental areas were likely to be impacted People with deafblindness often remain at a pre-lingual communication level and may never reach a symbolic communication level, especially in the presence of intellectual disability Children with deafblindness demonstrated shared attention but learning and using nonverbal behaviour was compromised by VI Children with deafblindness missed auditory and visual communicative signals, unlike in ASD where signals were not understood The existing standardised tests, questionnaires and developmental scales for ASD are not reliable or valid for people with deafblindness because the accumulated effect of multiple disabilities is not considered Children with congenital deafblindness had similar characteristics to the ASD triad of impairment Children with ASD, intellectual disability and deafblindness had significantly more difficulty than children with intellectual disabilities and deafblindness but no ASD in terms of: - openness for contact - joint attention - communication functions Children with ASD, intellectual disabilities and deafblindness had almost statistically significantly more difficulty than children with intellectual disabilities and deafblindness but no ASD in terms of: - coping with changes - problem solving strategies Children with ASD, intellectual disabilities and deafblindness did not have significantly more difficulty than children with intellectual disabilities and deafblindness but no ASD in terms of: - stereotyped behaviour - exploration and play The stereotyped behaviours demonstrated by children with deafblindness decreased with increased: - age - interaction initiation and maintenance - opportunity to communicate Both children with ASD, intellectual disabilities and deafblindness and children with intellectual disabilities and deafblindness but no ASD demonstrate: - limited functional play as this may have been linked to intellectual disabilities - increased object manipulation Children with ASD, intellectual disabilities and deafblindness had more ASD specific behaviours than children with intellectual disabilities and deafblindness but no ASD The results can assist with differentiation during diagnosis
	Peltokorpi & Huttunen, 2008	Language abilities Communication abilities	Children with CHARGE demonstrated ASD like traits but their language and communication was better than children with ASD Limited eye contact may be due to VI or ASD-like behaviour

		Pragmatic skills Congenital VI	
ASD: Autism Spectrum Disorder, VI: visual impairment, OHN: optic nerve hypoplasia, SOD: septo-optic dysplasia, SCRR: social, communication and/or restrictive or repetitive behaviour, PVI: profound visual impairment, SVI: severe visual impairment			