Comparing the effect of different living environments on the development of independent living skills in children with visual impairment

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ABSTRACT

Introduction: *The World Health Organisation (WHO) recognised visual impairments in children as deserving priority treatment and intervention. Research indicated that caregivers play an important role in the development of independence in children with visual impairments. This study aimed to compare the independent living skills of children with visual impairments who resided in a school residence designed for children with visual impairments with those who lived at home.*

Methods: *A descriptive study, comprising both quantitative and qualitative data collection methods, was implemented. A convenient sample was used and data collection was by means of the Paediatric Evaluation of Disability Inventory (PEDI) and semi-structured interviews.*

Results: *Results on the PEDI yielded no significant difference on all the measured scales in the living environments between those living at home or in a residence. However, from the qualitative data four themes concerning independent functioning emerged, namely familiarity; adaptations; resources; and personal factors.*

Conclusion: *The importance of the environment for children with visual impairments, especially concerning familiarity (of the layout of the environment and the people within the environment) and making adaptations should be given more attention during the phase of independence development and should be incorporated in informing and training of caregivers.*

Key words: Activities of daily living; Independent living skills; Living environment; Visual impairments

Introduction

Previous studies reported that caregivers of children with visual impairment (including biological parents, grandparents and residential caregivers) play a significant role in the development of independence in children with visual impairments during pre-school years[1,2,3]. It was also found that they usually respond effectively to the amount of support the children need[3]. The physical location of schools that provide for children with special educational needs are often limited and far from the child's home, resulting in many children placed in residential schools[3-5].

Visual impairments are the most prevalent disabilities in South Africa, with 32% of all people with disabilities having visual impairments[6]. The independence of children with visual impairments has also been internationally researched and documented[7-11], but not in South Africa. There were no studies that investigated the independent living skills of children with visual impairments or the influence of different living environments (home or school residences) on their independence.

This led the researcher to question whether or not there is a difference in the independent living skills of children with visual impairments living at home with those living in school residences.

Literature review

The World Health Organisation (WHO) defines visual impairments as a condition where impaired visual function occurs, even after treatment or standard refractive correction. A visual acuity of less than 6/18 is regarded as low vision, while 3/60 or a visual field of less than 10 degrees from the point of fixation indicates blindness[7,12].

Vision is regarded as an important prerequisite for general development and achievement of independence in children[13-15]. The ability to see assists children with cues to summarise situations and the motivation to incidentally learn and acquire independent living skills[16]. There are several classifications for independent living skills. Haley et al.,[17] divided independent living skills into self-care, mobility and social functioning skills. *Self-care skills* are similar to personal hygiene activities[18], which enable children to take care of themselves[1,8]. *Mobility and social functioning* are home, school and play activities that assist children to navigate and interact with the

world[17,19]. *Mobility* is the ability to traverse a living environment[20,21] whilst *social functioning skills* include verbal and non-verbal communication skills[19,22]. Researchers reported that children with visual impairments, who were encouraged by people in their living environment to be independent in their daily living skills, have a better chance of becoming adults capable of integrating into society[8,23,24,25]. It was found that children with visual impairments who are independent in their daily living skills are able to take care of themselves[8,26] while Pilling et al.,[27] attributed residential schools to enhancing independence in self-care and social behaviour in some children with disabilities.

Methods

Aim of the study

The aim of this study was to compare the independent living skills of children with visual impairments who reside in a school residence to those who live at home.

Study design

A mixed methods study that comprised quantitative and qualitative research methods was implemented. In the quantitative phase a standardised measurement instrument, the Paediatric Evaluation of Disability Inventory (PEDI)[17], was used for data collection. The qualitative phase consisted of audio taped semi-structured interviews. Statistical methods and content analysis[28,29] were used to analyse the data.

Methods of data collection

The **PEDI** is a norm-referenced and criteria-referenced behaviour checklist and rating scale[17,30] designed for children with disabilities between the ages six months and seven and a half years. The PEDI can also be used for older children with diverse ranges of impairments who potentially experience functional limitations in performing independent living skills[30,31,32-34]. The PEDI (see Table I) consists of three domains, *self-care*, *mobility* and *social functioning*[17,32], subdivided into scales, termed *functional skills* (FS), *caregiver assistance* (CA) and the *modification scale*[17,30].

The construct, discriminate and concurrent validity of the PEDI were reported to be representative of the PEDI con-

Table I: The PEDI domains and scales

Domain	Scale	Number of Items	Scoring
Self-care	Functional skills (FS)	197	0 = incapability 1 = capability
Mobility	Caregiver assistance (CA)	20	Rating independence from 0–5
Social functioning	Modification	20	Rating from extensive modification to none

tent[17,30,34]. The contents and aims of the PEDI correlate with one another. The PEDI was further rated a reliable instrument to use for research on children with disabilities. The scores are consistent and stable[30,34].

Semi-structured interviews were conducted to obtain qualitative data that could not be collected through the PEDI[17]. Semi-structured interviews were used as these allow for questions to be rephrased for better understanding[35,36].

Participants

A convenient[37] sampling method was chosen for this study. The sampling started off by selecting both schools for children with visual impairments in the Western Cape. During further investigation it was found that there was a high turnover of caregivers at the one school and caregivers were assigned to children on a rotational and ad hoc basis resulting in not knowing the children well enough to complete the PEDI. Therefore only one school was selected. The inclusion and exclusion criteria aided the researcher in the identification of the children.

All the children between five and nine years of age, who fitted the WHO classification of visual impairments, were included in the study. None of the children fitted the exclusion criteria of having additional cognitive, hearing or motor disabilities. Sixteen children adhered to the inclusion criteria - five lived at home and eleven lived in the school residence.

The names of the caregivers were then provided to the researcher by the school principal. The participants (caregivers) thus consisted of five parents of children who lived at home and three caregivers who cared for eleven children in the school residence (see _Table II_). One of the mothers of a child who lived at home declined the invitation to take part in the study and one child in the residence was excluded. This child scored very low on the PEDI and the researcher was informed that the child was admitted recently

to the school; was going through an evaluation process at the time of data collection; and was Xhosa-speaking. These factors could have attributed to the low scores on the PEDI.

Pilot study

A pilot study was carried out with one caregiver of a child in a school residence and one caregiver of a child who lives at home. It became evident during the pilot study that certain items of the PEDI (which were English) had to be replaced by Afrikaans words. Substituting words slowed down the completion of the PEDI, resulting in planning more time allocation for data collection.

Data collection

Caregivers were divided into two groups; those who took care of children who live in a school residence and those who took care of children who live at home. The researcher explained the procedures of data collection to the caregivers, including measurements that would be used, as well as issues around confidentiality and voluntary participation in the study.

The researcher completed the demographic information on the PEDI Score Sheet and recorded the responses given by the caregivers. Raw scores for the domains of the PEDI were converted to scaled scores using tables provided in the manual. Scaled scores were used to determine the functional capabilities of each child as well as the assistance needed to perform daily living skills.

The semi-structured interviews of the care givers followed directly after completion of the PEDI. The questions were based on the literature review and the independence of children with visual impairments. The questions were also linked to the PEDI and enquired about the amout of prior experience of the care giver and the support given to the children while fostering their independence in daily living skills. Although the PEDI was completed for each child individually, the caregivers in the residence answered the questions during the interview in general and not specific to a child. The interviews were audio taped and transcribed by an experienced research scriber as set out in the proposal and approved by the Human Research Ethics Committee.

Table II: Summary of participating caregivers and children

	Caregivers of children in school residence				Caregivers of children living at home			
	Care-giver	Educational level	Experience (years)	n	Care-giver	Educational level	Experience (years)	n
	B1	Grade 10	20	4	H1* Mother employment	Grade 12, full-time	15	1
					H2 Grand-mother	Grade 12	8	1
	B2	Grade 10	6	3	H3 Mother	LSEN teacher, full-time employment	10	
	B3	Primary school teacher	10	3**	H4 Mother	Grade 12, full-time employment	8	1
					H5 *** Mother	N/A		1
Subtotal	**3**			**11**	**5**			**5**
Excluded/Declined	**0**			**1**	**1**			**1**
TOTAL Caregivers/children	**3**			**10**	**4**			**4**

n   Number of children per caregiver
*   Caregiver H1 also had an older child with visual impairment
**   One child excluded after completion of PEDI due to low scores
*** Declined participation

Table III: Summary of results on the PEDI

			Total	Children living in Residence	Children living at Home	Residence vs. home p-value
		n=	14	10	4	
Functional Skills (FS)	**Self-care**	x̄	76.71	79.17	71.18	p=0.31
		SD	12.55	15.78	13.35	
	Mobility	x̄	79.52	80.83	76.55	p=0.67
		SD	15.51	15.78	16.77	
	Social functioning	x̄	67.62	67.21	68.55	p=0.86
		SD	11.69	13.35	9.38	
Caregiver Assistance (CA)	**Self-care**	x̄	79.92	78.79	82.47	p=0.61
		SD	11.48	10.24	15.32	
	Mobility	x̄	80.45	82.63	75.55	p=0.06*
		SD	6.37	4.30	8.17	
	Social functioning	x̄	77.47	75.51	81.9	p=0.28
		SD	9.43	9.31	9.31	

FS = Functional Skills completed by the caregiver for each child independently.
CA = Caregiver assistance as provided by the caregiver for each child independently
x̄ = Average Score on the PEDI
SD = Standard Deviation in group score
* = Tendency, but not significant; significance level set at $p \geq 0.05$

Data analysis

Quantitative data analysis:

A statistician assisted in analysing the scores obtained from the PEDI. The F-test and measures of central tendency, such as means and standard deviations, were used to analyse raw scores of PEDI and to calculate p-values. A 5% significance level ($p < 0.05$) was used as guideline for determining significant differences between the two groups. All these measurements were influenced by the small sample of this study and the magnitude of the measurement scales[38]. The modification scores could not be converted, since the "none" option was chosen in the majority of cases. This did not influence the Score Summary, since the modification frequencies are reported separately.

Qualitative analysis:

Content analysis was used to thematically analyse the transcribed interviews[39]. Each interview was read separately and sentences that were frequently used were marked and allocated a unit of meaning by means of codes. Similar codes were later grouped together. Coded interviews were re-read and categories generated from the coded data. Some of the categories strongly related to the domains of the PEDI. The codes and categories were constructed in a mind map and displayed graphically in columns.

Trustworthiness and addressing bias

Bias was addressed by conducting a pilot study to practice the administering of the PEDI as well as by administering and scoring the PEDI according to the standardised measures[17] provided in the manual. Trustworthiness was ensured by professional conduct and clear explanation of the process. Credibility was attained by using different research methods to confirm the research findings. Transferability was considered by describing the experiences of the group of caregivers used in this study and not extrapolating the results to cover a wider population.

Ethical considerations

Ethical clearance was granted by the Human Research Ethics Committee at the Faculty of Health Science, Stellenbosch University. Permission to conduct the research was also obtained from the Western Cape Department of Education and the Principal of the school. The information regarding the research was explained to the caregivers where after they signed the informed consent forms.

Results

Quantitative results

The findings on the PEDI for *Functional Skills* (FS) and *Caregiver Assistance* (CA) under the domains for self-care, mobility and social functioning are displayed in *Table III*. No significant difference on any of the six scales between the children who reside in a residence at the school and those living at home was found. There was a tendency towards a significant differences observed on the Caregiver Assistance (CA) scale for mobility (p=0.06), showing that children in the school residence needed less assistance in the Caregiver Assistance (CA) scale in the mobility skills domain (x̄ = 82.63, SD 4.30) than the children living at home CA (x̄ = 75.55, SD 8.17).

The average scores for most of the domains were over 70 for both groups, except for Functional Skills (FS) in the social functioning domain, which were the lowest for both groups of children. Children in residence obtained slightly lower mean scores on the Functional Skills (FS) scale than children living at home (FS residence x̄ = 67.2, SD 13.35; home x̄ = 68.55, SD 9.38) and Caregiver Assistance (CA) scales (CA residence x̄ = 75.51, SD 9.31; home x̄= 81.9, SD 9.31).

The modification scales were scored but not analysed because caregivers mostly chose the "none" option, indicating that the children under their care did not frequently use modifications described in the PEDI. However, some modifications and adaptations were reported by the caregivers during the qualitative phase of the research and will be discussed in the next section.

Qualitative findings

Four themes emerged from analysing the transcribed interviews namely *familiarity*, *adaptations*, *resources* and *personal factors*. The themes *familiarity* and *adaptations* were refined into subcategories. Familiarity was subdivided according to the domains of the PEDI, namely mobility, social skills and self-care skills. Adaptations was subdivided into verbal cues; auditory cues; responsibilities, expectations, and encouragement; practising of skills; and adaptations of self-care skills.

Theme 1: Familiarity

Caregivers reported that children needed to be orientated and taught about objects, clothes and the layout of their environment, including the orientation and placement of objects and people in order to gain independence. Caregivers of both groups of children also shared the opinion that children were more independent in mobility in familiar places and in social functioning skills. This is supported by the results obtained from the PEDI (p=0.06).

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Familiarity regarding mobility skills

Independence in mobility skills was influence by how familiar children were with the layout and objects in the environment. [B1: *As hulle hulle omgewing ken, dan sal hulle op hulle eie loop.*]

Familiarity regarding social functioning skills

In contrast to the findings on the PEDI for social functioning skills, caregivers in both groups reported that they perceived the children to be more independent in social functioning skills [H1: *Ek het gesien by ons kerk, jy weet haar Sondagskoolklassie, sy 't maatjies gemaak. Gaan eet, gaan speel saam met hulle. Jy weet, so daar 't sy nie 'n probleem nie*]. The caregivers at home attributed their children's independence in social skills to the opportunity of interaction with other children without disabilities in their neighbourhoods. In some families, socialising was also part of the daily routine.

However, the caregivers in the residence noted that children tend to engage mainly in solitary play. *[H1: Most of them play …uhm… engage in solitary play. They play in a group, but when they play they play parallel play. They're in a group, but everyone's playing their own game]*

Familiarity regarding self-care skills

Caregivers in both groups, particularly caregivers of children living at home, mentioned that children were more dependent in self-care tasks [H2: *Sy kan nie die broeke lekker verstaan wat is agter en wat is voor nie*] to that seen on the PEDI.

Caregivers in both groups further reported that unfamiliarity with the position, shape and direction of food and clothes, as well as children taking extra time to execute tasks, led to dependency in self-care skills. These factors resulted in family members helping children with the tasks or performing the tasks for them. Caregivers of children living at home mentioned that children had limited abilities to cut food, judge the position of their mouths for placing food into the mouth and scooping the last bit of food from the plate. They also experienced problems in teaching children to eat with a knife and fork.

Theme 2: Adaptations

Adaptations are actions taken to alter or change steps of the tasks or the whole task while strategies are considered to be either a method or technique used in the process of adaptation[19]. Caregivers of both groups reported on strategies such as verbal and auditory cues; setting expectations; encouragement; and allowing for practice and extra time to enhance and maintain children's' independence.

Verbal cues

Caregivers in both groups found the use of speech and tone of voice helpful strategies to increase independence in children. Speech was used to explain steps and the processing of tasks. Tones of voice were used to guide children to understand the context of activities and learning skills. [B2: *'n Mens praat 'n blinde in 'n ding in – jou stem is daai blinde se gids, sal ek maar sê. Dit gaan nie alles vir hom doen nie, maar jy gaan hom daarin praat. Hoe moet hy dit doen, wanneer moet hy dit doen, waar moet hy ... uh ... loop links of regs of ... Jy gaan nie aanmekaar vir die kind aan die hand vat en vir hom loop net waar hy moet wees nie*].

Auditory cues

Caregivers of children living in residence used sound such as clapping hands or shaking objects to orientate children and enhance independence. Listening to sounds enabled children to know and estimate direction. Some children reacted better to voices while others preferred sounds. [B3: *So I tap [tapping] with my fingers or clap hands to direct them to where they are ...]*

Responsibilities, expectations and encouragement

Caregivers in both groups mentioned the importance of encouraging and rewarding children as well as putting time aside to work on independent living skills. Partial participation, setting expectations and encouraging children to perform independent living skills enabled independence. [H3: *Uhm, ons moedig hom ook aan, soos met bed opmaak in die kamer; al wend hy net 'n poging aan. Sien hy het probeer, dit hoef nie glad te wees nie.*]

Practicing skills as an adaptation

Caregivers in both groups reported on the importance of the children practicing skills, such as tying shoelaces. Time constraints in the home environment often compel parents to look for other solutions, like buying shoes with Velcro fastenings rather than practising tying shoelaces. [H2: *Ons het nou sommer die laaste tyd vir haar tekkies gekoop met hierdie plakgoedjies*]. However, in the residence, caregivers have set times to practise skills [B1: *So ons het elke dag het ons 'n uur selfstandigheid-opleiding wat ons met hulle moet doen. In die middag rustyd.*]

Adaptation of self-care skills

Various adaptations were employed to enable children to dress, eat and brush teeth independently. Caregivers in both groups taught children about the orientation of clothes or food on plates (by using the layout of a round clock as an example). Caregivers of children in residence reported on teaching children to orientate clothes by shape, size and seams and clothes are labelled by means of pictures for children with low vision or the use of nametags. They also used the hand-over-hand technique to assist children during eating. Another adaptation by caregivers in residence is teaching the children to place the toothpaste directly in their mouths, which aids in estimating an adequate amount of toothpaste.

Theme 3: Resources

Some of the resources identified as helpful included written information, training and interaction with other parents to be important. All the caregivers regarded the school as a good resource and support structure to inform and assist them. [H3: *Toe hy baie klein was en ons net in Worcester gekom het, was sy ... uhm ... drie jaar oud, het ek baie inligtingstukke en boeke by die skool gekry, wat die skool vir ons geleen het om vir ons 'n bietjie meer te lees oor die versorgingstyd en om hom selfstandig en meer onafhanklik te maak.*] The internet was also described as a source for obtaining information about visual impairments by one of the home caregivers.

The close proximity between the residence and school made it easier for the caregivers of the children in the residence to access the support services and training opportunities. They also commented on the positive experience of working in a team with other caregivers, teachers and supportive health professionals.

Caregivers of children living at home found that interaction with other parents gave the opportunity to compare the development of their child to others. They did not report using specific strategies to enable independence and solved problems as they arose. Although some caregivers mentioned that the school provided the necessary support, others suggested that support groups could be helpful when children are admitted to the school.

Theme 4: Personal factors

Caregivers argued that independence in daily living skills was also influenced by personal factors such as age, motivation, self-confidence and the extend of visual impairment [B2: *Die wat mos nou 'n bietjie sig het, is mos nou vinniger*].

Caregivers of children in residence had between 6 to 20 years' experience working with children with visual impairments. This meant that certain adaptations, such as using a hand-over-hand eating techniques could be applied from the beginning, whereas a caregiver at home may still engage in trial and error efforts looking for a solution and often based her training on her experience with an older sibling of the child.

Discussion

The discussion will follow the four themes presented in the results.

Theme 1: Familiarity

The tendency towards better *mobility skills* in children in the school residence could be attributed to the purposely adapted school environment, such as paved pathways and removal of obstacles.

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Caregivers in the school residence also received training in orientation and mobility techniques, while this was not offered on a formal base to caregivers at home.

The reasons for children in the school residence engaging in solitary play could be due to their inability to follow visual cues during interaction or a lack of knowledge with regards to playing cooperative games. Engaging in cooperative games require children to compensate for lack of sight. Sheiman noted that children with visual impairments may have to alter the way cooperative games are played in order to engage[15].

The lower scores on both the Functional Skills and Caregiver Assistance scales for the domain of *social functioning* could be attributed to items such as "the use of gestures". This skill requires the child to copy others, which requires visual ability. Perez-Pereira and Conti-Ramsden[40] found that children with blindness could use gestures such as shaking heads to indicate "no" but that they did not use elaborate gestures during communication.

The results found in the *self-care* domain mirrored that of other researchers who found that the acquisition of self-care skills are based on perceptual skills such as spatial orientation, body concepts, body scheme and visual motor systems[19,24]. Optimal acquisitions of independent eating skills in children with visual impairments also require a set routine and consistency in the environmental layout.

Theme 2: Adaptations

The PEDI was developed with a section for "modifications", but this section was too general and caregivers of children with visual impairments mostly selected the "none" response option. During the interview they identified several modifications (in this article identified as adaptions) that could be regarded as specific to children with visual impairments, such as the use of verbal and auditory cues, setting expectations, allowing for practising skills, allowing extra time and trying to follow the same routines and restrict changes.

Expectations, rules and routines may also differ between the residential and home environment, for example the expectation of making their own bed in the residence, but receiving help from a parent or sibling when at home. Caregivers sometimes tend to help the child with a visual impairment to execute tasks to save time (as mentioned by caregivers of children living at home), which may lead to dependent behaviour or 'learned helplessness' in some children[1,24,41].

Some caregivers mentioned executing tasks for the children or taking children by the hand when walking with them. Although this action, when in a hurry, is a natural response by caregivers, children with visual impairments cannot learn incidentally by relying on their vision to provide them with cues for interpreting situations. Walking at a fast pace may thus result in children having to rely on people to guide them, which impacts on independence. Opportunities must therefore be created in terms of making the necessary adaptations so that learning can occur[41,42].

Theme 3: Resources

The experience of teamwork expressed by the residential caregivers is similar to the findings by Fazzi et al.,[43] who noted that a good relationship between professionals and caregivers helped to foster resilience in caregivers.

Theme 4: Personal factors

Children with visual impairments may have a range of visual abilities which could aid independence. Grey found that the speed of executing tasks increased with a better visual ability in children with visual impairments and decreased the possibility of developmental delays[2]. Caregivers also commented that age influenced independence in daily living skills. Training of caregivers should therefore include normal development to better fit expectations according age-appropriate abilities

The experience of caregivers influenced the ease of enhancing the children's independence, emphasising the importance of training all caregivers in anticipating problems that they may encounter as well as in techniques and solutions that will help them overcome the problems.

Conclusion

Although the PEDI was previously used in a study with children with visual impairments, it was found in this study that the "modification" domain was too general and that the semi-structured interview generated better insight into the adaptations that were regarded as important for a child with a visual impairment. This needs further investigation.

The small numbers of participants could have been a factor in not being able to find differences between the independence of children living at home and those living in a school residence. A study with a bigger sample is therefore recommended.

Future studies should also aim to develop standardised evaluation instruments that address the independence of children with visual impairments. Evaluation instruments should particularly consider issues such as familiarity and different adaptations that are unique to children with visual impairments.

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