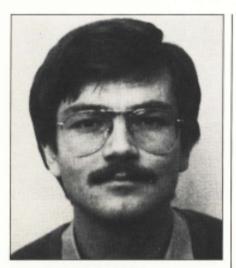
Results and Methodological Problems of a Community Survey of Developmental Delays in Rural African Children Under 37 Months of Age – H Cornielje



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Curriculum vitae

Huib Cornielje qualified as a physiotherapist in the Netherlands. After qualifying in 1982, he worked for 2 years in private practice. From 1984 to 1990 he worked in the Gelukspan Health Ward as head of the rehabilitation department. Since 1990 he has been working as co-ordinator of rehabilitation services at the Alexandra Health Centre. His main interest and expertise is in the field of Community Based Rehabilitation. Currently his function is that of PHC training manager and as such he is involved in the development of courses for PHC workers.

Summary

We report on the methodology and the results of a community survey looking for neuro-developmental delays in 618 randomly selected children under 37 months. The study was done in a rural area of South Africa, and had two phases. Phase 1 was an interview study; phase 2 was a follow-up of persons identified in phase 1 as being disabled. Of the 618 children 45 (73 per 1 000 population under 37 months and 7 per thousand total population) were reported as having a neuro-developmental delay in one or more of the following areas of investigation: gross-motor, feeding, speech, behaviour. During the second phase 7 children were confirmed with neuro-developmental delays. The crude prevalence rate of confirmed developmental delays was 11 per 1 000 population under 37 months (1 per 1 000 total population).

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KEYWORDS:

Child Development Disorders; Research; Physiotherapy; Patient Outcome Assessment; Methods; Rural Population.

Introduction

The Gelukspan Health Ward (GHW), is part of a rural district in Bophuthatswana with a population of about 90 000 people.

Before 1978 the services were mainly curative. Since then a Primary Health Care (PHC) approach emphasized an expansion of peripheral and mobile clinics and, in some cases (mental care) home based care. The emphasis shifted from curative to preventive and promotive care, including maternal and child care, family planning, nutrition, immunization, mental health, dental health, health education and rehabilitation.¹

Until 1984 rehabilitation services for disabled people were almost nonexistent. A more comprehensive rehabilitation service started to evolve.

To assist with the planning of these services in 1984/1985 a house-tohouse survey was done in one of the traditional villages.2 Although a large data set was gathered and used to set up and develop a Community Based Rehabilitation (CBR) programme in that specific village, this study had certain limitations and the results could not be generalized to the whole GHW. As a result a more generalizable survey was planned.84 As part of this survey children younger than 37 months of age were screened for neuro-developmental delays.

Population and Methods

The study had two phases. Phase 1 was an interview study. Phase 2 was a follow-up of persons identified in phase 1 as being disabled.

... Developmental delays

Phase 1: The Sampling

The measurement tool for the first phase of the study was an interview schedule to detect reported neurodevelopmental delays in children younger than 37 months of age. The interviews were conducted in Setswana by two female physiotherapy assistants, after appropriate training. The respondent was the wife of the household head or, if not available, another senior female household member.

The age criteria for screening for neuro-developmental delays are shown in Table I. The maximum age at which development in a certain area was considered to be normal was used as the borderline, ie exceeding the age for that specific activity meant a developmental delay. The questions were developed on the basis of experiences in neuro-developmental screening at the Parent Guidance Centre at the Gelukspan Hospital.

Phase 2

The study population was children reported in the first phase as having a neuro-developmental delay.

Children younger than 37 months identified during the phase 1 as having a developmental delay, were tested by means of a neurodevelopmental assessment. The measurement tool was a Denver Developmental Test⁵ and a history assessment as described by Illingworth.67 The neurodevelopmental assessment began with a repetition of the basic screening questions from phase one; if no abnormalities were reported, no further investigations were done. If abnormalities were reported the Denver Developmental Test was

Smiling	6	weeks
Rolling	5	months
Sitting	8	months
Crawling	10	months
Standing	12	months
Walking	18	months

Tabel 1A. Suggested more Flexible Ages for Developmental Screening			
Smiling	6	weeks	
Rolling	7	months	
Sitting	9	months	
Crawling	10	months	
Standing	14	months	
Walking	22	months	

applied and a history was taken. Although the test is supposed to be assessed on the basis of a fail-pass categorization we allowed ourselves some latitude on the basis of experience in the Parent Guidance Centre of the Gelukspan Hospital.

The neuro-developmental assessment was piloted on five known children with a developmental defect.

Field work

For both phases the study population was surveyed at home. Phase 1 took place from June to September 1988 and phase 2 from April to June 1989.

Results

Characteristics of the Study Group

During phase one 961 of the 1 020 households were studied (a response rate of 87%). The total study population was 8 581 with 6 551 (76%) residents included in the study. Sixteen percent were younger than 5 years of age. The < 15 population accounted for 48%.

The number of children younger than 37 months was 618 (9%). The ratio of males to females was 50,4: 49,6.

... Developmental delays

Table II. Neuro-developmental delays: results for the first phase screening. n = 618

Function		Number Delayed	Percentage	
feeding		21	3,5	
speech		10	1,6	
behaviour		1	0,2	
- walking		19	3,1	
gross motor	standing	19	3,1	
	crawling	9	1,5	
	sitting	9	1,5	
	_ rolling	12 .	2,0	
overall		45	7,3	

Reported Neurodevelopmental Delays

Of the 618 children 45 (73 per 1 000 population under 37 months and 7 per thousand total population) were reported as having a neurodevelopmental delay in one or more of the following areas of investigation: gross-motor, feeding, speech, behaviour (Table II).

Confirmed Neuro-Developmental Delays

The response to the screening questions used in the second phase of the study is indicated in Table III. Besides the 6 children confirmed during the second phase of the study as having a developmental problem, 2 other children who were reported to have a serious problem could not be screened because they had moved and another child died. Another child was detected by the researcher as having a very serious developmental problem. This child was recorded as a member of a household during the first phase but no report was given on her developmental status and handicap. The above 7 children had their neuro-developmental delays confirmed when their developmental status was further assessed with the adapted Denver Developmental Test. The developmental assessment comprised of tests in four different areas:

- fine motor activities
- gross motor activities
- personal/social development
- communication/speech

All 7 children were reported to have had delays, varying in severity, in reaching milestones (Table IV). In fine-motor development, 4 showed a delay of more than seven months, while the other 3 had a delay of less than seven months. Gross motor activities were delayed in 4, of whom 2 had a delay of more than seven months.

Personal and social development was delayed in 3 children.

Table III. Neuro-developmental delays: results second phase screening. n = 45

	No	%
No problem at all	25	56%
Still having a problem	6	13%
Were ill during first stage, now fine	5	11%
Moved to other area/couldn't be traced	3	7%
Walking late, but now no problems	3	7%
Died, was definitive cerebral palsy	1	2%
Moved, according to relatives: Hemiplegia	1	2 %
Moved, according to relatives: Blind/CP	1	2%
Total	45	100%

Devel	lopmental	delays
		ere any o

Table IV. Milestones of the 7 children reported with neurodevelopmental delays during phase 2

Case No	Smiling	Rolling	Sitting	Crawling	Standing	Walking
1	16/52	5/12	5/12	2	10/12	-
2	21/52	6/12	8/12	11/12	16/12	18/12
3	16/52	?	?	?	?	15/12
4	26/52	7/12	8/12	14/12	22/12	24/12
5	18/52	4/12	6/12	10/12	17/12	-
6	8/12	3/12	4/12	5/12	14/12	24/12
7	16/52	?	9/12	?	?	17/12

Communication and speech development was delayed in 4 children: all of whom had a delay of more than seven months (Table V).

Asked whether the mother/caretaker considered the development of their child to be slow, normal or fast, only 13 (2%) responded "slow". The youngest child reported to have a delay in development was only 2 months of age, and the oldest child was 28 months.

The muscle tone of all 7 was tested and 3 had an abnormal muscle tone (Table VI). The pathological muscle tone was validated by testing the tendon reflexes.

Factors Associated with Neurodevelopmental Delays

Of the 7 children with neurodevelopmental delays, only 2 were reported with a low birth weight Table VI). Three mothers said that similar problems existed in other family members. Five children showed an abnomal presentation at birth. Other problems at birth are reflected in table VI. Neuro-developmental delays at this early age are due essentially to birth related problems

Multiple Disabilities

Three children were reported to have other abnormalities:

- one child with impaired speech.
- one child with impaired vision, hearing, intellect and burns.
- one child with impaired vision and hearing (Table VI).

Discussion

The minimum crude prevalence rate of neuro-developmental problems in children younger than 37 months of age is 10 per 1 000 of the population younger than three years. We are not aware of any other community surveys (in South Africa) of neuro-developmental delays in young children. It is therefore not possible to compare our data with that of other regions. Still the survey raised important methodological issues and provided data with implications for service development. We will address both.

Table V. Results of Developmental assessment using the Denver Developmental scale.

Case No	Fine Motor	Gross Motor	Personal Social	Communication Speech	Age
1	11/12*	11/12*	12-15/12	12/12	15
2	15/12**	24/12	21-24/12	24/12	24
3	24/12**	30/12	30/12	6/12 **	32
4	12/12**	18/12 **	15/12 **	5/12**	25
5	11/12**	11/12 **	15/12 *	10/12 **	19
6	18/12 **	24/12*	21-24/12 *	21/12 **	28
7	18/12 *	12/12	24/12	24/12	24

... Developmental delays

Methodological issues

The relevance of neurodevelopmental screening has been challenged in developed countries.⁷ Although there is acknowledgement of a need for methods of early diagnosis of disabling and handicapping conditions in very young children^{7,8} the existing methodologies lack sensitivity and specificity.

This is compounded by the problem of different rates of development in different cultures. In tropical Africa many observers have noted that African infants appear advanced in their powers of locomotion as compared with European and American infants or African infants in a sophisticated urban environment.⁹

The most vulnerable are those with an abnormal presentation at birth

Despite these observations and recommendations developmental screening is still recommended as an important routine at some stage in child care.^{10,11,12} Aware of these recommendations, and for lack of a better tool, we elected to base our survey of young children on the screening procedures already described. The limitation is that the rates described here are likely to underestimate the true prevalence of disabilities in small children.

The sample included babies younger than 5 months of age. Knowing that even moderate to severe neurodevelopmental problems can usually only be diagnosed at a later stage

Case		CLAR - THE					
No				Specific Harrison			
1	Left Hemiplegia						
2	Normal						
3	Normal						
4	Spastic Diplegia						
5	Normal						
6	Decreased						
7	Normal						
Birth	n weight and du	ration of g	estation in childre	en with			
conf	irmed neuro-de	velopmenta	al delays				
	Age	Sex	Birth Weight	Duration of Gestation			
1	15/12	м	2950 GR	37 Weeks			
2	24/12	M	2 800 GR	40 Weeks			
3	32/12	M	3 000 GR	40 Weeks			
4	19/12	F	3 000 GR	40 Weeks			
5	25/12	F	;	39 Weeks			
6	28/12	M	2 400 GR	40 Weeks			
7	24/12	F	1 450 GR	1			
	dition at birth o tal delays	of 7 children	n with confirmed	neuro-develo			
1	Blue						
2	Blue and in incubat	or for 2 days					
3	Normal						
4	Normal						
5	Malformation right ear, otherwise normal						
6	Yellowish, in Incubator for 3 days (CS)						
7	Blue/Grey						
	wn abnormalitie ne mothers.	es (other th	an motor impairi	nent) reporte			
1	None						
2	None						
3	Impaired Speech						
4	Impaired Vision, H	earing and Intel	lect				
5	Impaired Vision and Hearing						

None

None

6

(sometimes only after 1 year of age)^{6,7} no pretensions were made to develop an appropriate and reliable measurement tool to diagnose problems at that early age. However, during the first phase of the survey, a child of three months of age was reported to have a developmental delay, which was confirmed during the second phase.

During the second phase of the survey all the children with reported developmental delay were traced. The initial idea was to screen and test all these children. Due to time constraints, this was not feasible. It was therefore decided to screen the children again before administering the questionnaire and tests. The questions related to neurodevelopmental delay in general, used in the first phase of this study, were repeated. Only 20% of the children reported to have delayed milestones showed a true delayed development during the second phase. The 80% who were "over-reported" could have been reported by concerned and

Existing screening methods lack sensitivity and specificity

anxious mothers. It could also be that some of the remaining 80% had a slightly delayed development at the time of the first screening, which could well have been conquered at a later stage of the development.

Also, attention should be given to the long interval (7 to 12 months) between the first phase and the second phase of the study, resulting in possible bias. As not all children

... Developmental delays

initially reported to have developmental delays could be tested, underdetection probably occurred, contributing again to our assumption that we are dealing with a minimum prevalence rate for neurodevelopmental delays.

While over-reporting and the relation between the long interval in terms of time and slight developmental delays could contribute to difficulties in the interpretation of the results, an other important area of discussion is the screening tool itself. We chose for a sensitive screening tool (Table I). If we allow some more flexibility in terms of the maximum ages for milestones (Table 1A) fewer "overreporting" would occur and consequently this would reduce the number of referrals. If we had resorted in this study to the maximum ages for milestones as indicated in table 1A, with the exception of smiling as a milestone, based on the combined other milestones we would have detected 6 children with developmental delay.

During testing, all 7 children showed a delay in fine motor development. Because the principal researcher was aware of the limitations of the testing methods it was decided to interpret the test results with much caution. However, five out of the seven children showed a delay in fine motor development of more than seven months, and such a marked delay provided, for us, confirmation of a true delay.

Issues of relevance for service development

It is apparent that neuro-developmental delays and disability at this early age are due essentially to birth related problems. From the histories it is apparent that the most vulnerable group of children are those with an abnormal presentation at birth (5/7). This points to the need to strengthen the maternity centres in the GHW.

To ensure early detection of neurodevelopmental delays it is suggested that high risk neonates should be

A referal and follow-up system needs to be developed for high risk infants in each health district

followed up at important stages of their development and be promptly referred if any abnormalities detected. The lines of referral in a rural area with limited resources and with a high turnover of medical and rehabilitation professionals should probably be conducted via a professional nurse with appropriate training.

We recommend routine screening of all children in the GHW. Although child care in a developing country is not about comprehensiveness but about choices we believe that screening of children for developmental delays can be done in an efficient and effective way.

Primary concerns expressed by parents must be taken seriously. These parents should then be referred for appropriate professional support. It is therefore, appropriate to ask parents routinely if they have concerns about the development of the child followed by routine screening for neuro-developmental delays.

... Developmental delays

If any abnormalities are detected during this screening stage the child should be referred for correct professional investigations and intervention.

In order to allow screening to take place at districts level, all staff involved in the mother-child outreach services need to be trained in developmental screening by a professional. A proper referral and follow-up system needs to be developed as well.

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