Developmental screening in South Africa: comparing the national developmental checklist to a standardized tool

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Abstract:

Background: Worldwide, more than 200 million children in low- and middle-income countries have developmental delays and/or disabilities. In South Africa the only nationally implemented developmental 'screening' tool is integrated as part of 'The Road to Health Booklet (RTHB).

Method: The study employed a comparative cross- sectional within-subject design to evaluate the accuracy of the RTHB developmental checklist against a standardized international tool i.e. the PEDS tools, consisting of the PEDS and PEDS:DM. A total of 201 participants were included through convenience sampling at primary health care facilities in Tshwane, South Africa.

Results: Sensitivity of the RTHB developmental checklist is low, but specificity is high. The RTHB developmental checklist failed to identify more than half the infants at risk of delays or disorders. The nationally implemented developmental checklist is ineffective to identify at-risk infants. It should be adapted and validated or replaced in order to improve identification of at-risk infants.

Key words: developmental screening, early identification, developmental delays or disorders, at-risk infants.

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Introduction

Worldwide, more than 200 million children in low- and middle-income countries have developmental delays and/or disabilities with an increasing prevalence due to medical advances that markedly reduce mortality among children under 5 years of age.[1] The true prevalence and early detection and intervention strategies for this population in low- and middle-income countries, such as South Africa, must still be established.[1] Early identification of developmental delays and disability, as a secondary prevention strategy, is widely acknowledged as the optimal way to minimize adverse consequences and maximize developmental outcomes.[2–4] Apart from benefitting at risk infants, early detection programs as a needs assessment enable government agencies to determine the incidence of delays or disorders towards appropriate planning.

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Early identification strategies are strongly endorsed in many high-income countries such as the USA where policy statements are in place.[1,5,6] However, in South Africa and other low- and middle-income countries, early identification is often not prioritized due to the high burden of life-threatening health related priorities such as HIV/AIDS, infant mortality and tuberculosis.[1] Ironically these same conditions are important causes of secondary developmental delays and disorders in infants and young children.[4,7]

Limited research on improving early detection of infants and young children through developmental surveillance or screening tools and the implementation thereof is currently available for lower to middle income countries like South Africa.[8–10] The only developmental surveillance or screening tool, currently implemented nationally in South Africa, is integrated as part of The Road to Health Booklet/RTHB[9](See Attachment A). The revised booklet was introduced in October 2010 as part of the Department of Health's initiative to improve service delivery to infants and young children. The RTHB is a parent-held record used to monitor and promote early child health, growth, and development[11,12] and is distributed to all newborns at state and private facilities by the Department of Health to be checked periodically at well baby visits.[12,13] The RTHB developmental checklist is, therefore, the only tool available to all health care workers in the public health care context to conduct screening for developmental delays or disorders. However, the accuracy of the booklet's checklist in the identification of developmental disabilities is yet to be established.[4,14] Also, no clear referral strategy has been specified for the screening tool.[14] Consequently few guidelines are provided for the health care worker to aid the decision making process of who should be referred, when they should be referred and to whom they should be referred. To date no evidence on the validation, reliability or accuracy of the RTHB screen is available in published literature. It is, therefore, important to compare the RTHB developmental checklist against a valid, reliable and accurate standardized screening instrument.

Apart from selecting a validated standardized screening instrument against which the RTHB screen can be compared, the tool must also be appropriate for use within the South African primary health care context. For instance, since South Africa's public health care context is generally overburdened[15] and therefore a parent completed screening tool, instead of a clinician administered test, may be easier and more likely to be adopted.

Many development screening tools have been developed and validated internationally.[16] A systematic review on the evidence behind developmental screening instruments rendered the following: The Denver Developmental screening test/DENVER II[17] with 58 research studies, the Ages and Stages

Questionnaire/ASQ[18] with 45 studies, the McCarthy Screening test19 with 40 research studies, and the Parents' Evaluation of Developmental Status/PEDS20 with 20 research studies have the largest body of supporting evidence of screening tools that ranges from birth to kindergarten.[16] Although the DENVER-II has been evaluated in 58 research studies between 1971 and 2010[16], the reported sensitivity and specificity ratings of the PEDS are higher than those of the DENVER-II.[17] Furthermore the PEDS and ASQ are the only parent administered tests, as the DENVER II, and the McCarthy Screening test are both clinician administered tests.

The McCarthy Screening test, developed 36 years ago, lacks current supporting evidence, as the most recent utility study conducted on this test was published 10 years ago (in 2004).[16] The ASQ on the other hand is well supported by current evidence, i.e. 45 studies between 1998 and 2011.[16] Both the PEDS and ASQ have reasonable test characteristics for developmental screening in primary care settings and ultimately the selection of the test should be determined by the population served, the setting and the clinician's preference.[21] Since the ASQ includes an expensive materials kit, whereas the PEDS only has the questionnaires, the PEDS was deemed more appropriate for the current study as financial constraints within the South African primary health care context had to be considered.

The PEDS[22] can also be applied in combination with the Parents' Evaluation of Developmental Status: Developmental Milestones (PEDS: DM) with which parental concerns are identified as well as the presence/absence of domain specific developmental milestones.[22] The PEDS has been validated in 8 studies during 2001 to 2010 with 12 additional utility studies, i.e. the application of the tool on specific populations, has been conducted during the same time period.[16] Across these studies the participants were aged between birth and six years with a total of 7213 children assessed.[16] The PEDS has proven to be a reliable tool that is highly consistent in test-retest reliability (88%) and inter-reliability measures (88%) Furthermore the PEDS test has demonstrated sensitivity of 75% and specificity of 80% for developmental delays in infants from birth to 18 months of age. The PEDS: DM has also demonstrated high sensitivity and specificity scores (respectively 82% and 83%) for infants aged between 0-12 months.

The PEDS tools offers an algorithm of evidence based support for health care personnel in the decision making process.[22] The amount of time that it takes to conduct and score the test is less than 10 minutes.[22] Furthermore a recent study confirmed the accuracy of the PEDS tools in South Africa.[23] Since the standardized

PEDS tools have a large body of evidence confirming the accuracy, validity and reliability of the tool, it was considered a suitable benchmark screening tool against which to compare the RTHB developmental checklist. The current study therefore investigated the screening outcomes on the PEDS tools and the RTHB in a representative South African population of infants.

Method

A comparative cross-sectional within-subject design was employed to evaluate the accuracy of the RTHB developmental checklist against the PEDS tools, consisting of the PEDS and PEDS: DM, in a sample of representative infants in South Africa. Setting Three primary health care clinics (Olievenhoutbosch clinic, Salvokop clinic and Daspoort Poli clinic) in underserved communities of the Tshwane district, Gauteng province of South Africa were utilized for data collection. Olievenhoutbosch is an area of 11.39 km^2, situated in centurion, with a population of 70 863 individuals and 23 777 households.[24] Salvokop and Daspoort form part of the Pretoria sub-district.

The clinic situated in Salvokop serves an area of 4,09 km^2 with a population of 7123 and 1685 households.[24] Similarly Daspoort is an area 2,16km^2 with a population of 6355 and 1582 households.[24] Permission and ethical clearance was obtained prior to data collection from the Tshwane district research committee, Department of Health as well as from the Faculty of Health Sciences and Humanities, University of Pretoria.

Participants

Convenience sampling was used as all parents or caregivers of infants aged 6-12 months, who can speak English or Afrikaans, visiting the PHC clinics, were asked to participate in the research study. Data was collected three times per week over a period of 4 months (May-Sept 2013). A total of 201 participants were included in the research study. Gender was evenly distributed (45% female). Home language distribution was Sepedi (33%), followed by isiZulu (16%), Shona (11%), Ndebele (10%), Xhosa (6%), Southern Sotho (5%), Setswana (5%), Venda (4%), Tsonga (3%), Tsumbuga (2%), Afrikaans (2%), Shangaan (1%), Siswati (1%), Swahili (0,5%) and Sesotho (0,5%). While none of the participants reported English as their home language, all participants were proficient in either Afrikaans or English as an additional language. The majority of the participants resided in the Olievenhoutbosch area (94%), with the remainder from other areas such as Salvokop (2%) and Mamelodi (0.5%). Most participants (98.5%) were Black and the remaining 1.5% was other ethnicities.
Only six infants (out of 201) were born prematurely and also seven infants were from teenage pregnancies. 62% of parents or caregivers left the educational system at Grade 10 or less and 71% reported a household income of less than R3000 (US$300) a month. 32% of the infants have two or more siblings. In general 16.5% of South Africans (20 years or older) are functionally illiterate, 34% completed some secondary levels of education and 29% completed grade 12.[24] Furthermore 45.5% of the South African population is deemed poor and 20% live in extreme poverty.[25]

Material

The RTHB developmental checklist forms part of the Road to Health Booklet (See appendix A). The screen consists of 21 questions in total. The first three questions must be asked to caregivers with every visit, and in addition to these questions there are three questions that must be asked when infants are 14 weeks, six months, nine months, 18 months, 3years and 5-6years of age. The developmental domains include sensory functioning such as sight and hearing, communication and gross motor and fine motor development. However all these developmental domains are not represented at the different age intervals. The tool suggests referral to allied health care professionals if milestones are not met.

The PEDS tools, i.e. the PEDS and PEDS: DM, consists of questions posed to the parent/caregiver. The PEDS identifies parental/caregiver concerns, by means of 10 open-ended questions, regarding the infants' development on the following areas, global/ cognitive, expressive language and articulation, receptive language, fine-motor, gross motor, behavior, social-emotional, self-help skills. Each of these areas is represented irrespective of the child's age. The PEDS has a clear score guide and algorithm for referral.[20] The algorithm consists of five paths, namely Path A – E.

- Path A - When two or more predictive concerns about self-help, social, school, or receptive language skills are present, refer for audiological and speech-language testing. Use professional judgment to decide if referrals are needed for other services such as occupational therapy, social work etc.
- Path B - When one predictive concern is present administer second stage developmental screen, if screen is failed refer for testing in areas of difficulty
- Path C - When non-predictive concerns are present, counsel in areas of difficulty and follow-up in several weeks
- Path D - When parental difficulties communicating due to foreign language barrier are present, use translator in second screen
- Path E - When no concerns are present, elicit concerns at next visit Furthermore in Path B distinction is made between development-related predictive concerns and health related concerns.

The PEDS: DM consists of six questions posed to parents regarding their infants or children's developmental milestones. The six questions differ in each of the age intervals and represent the following developmental domains: fine-motor, receptive language, expressive language, gross motor, self-help and social- emotional.

Procedures and data processing

Data was collected by a qualified speech-language pathologist, registered at the Health Professions Council of South Africa, with 8 years of experience in the assessment of infants and young children. Parental/ caregiver informed consent was required before data collection commenced. The RTHB screen was conducted first as the parents/caregivers are familiar with the screening test. After the RTHB screen, the PEDS tools were conducted on each participant. The PEDS and PEDS: DM questions were asked as an interview to parents or caregivers.
In order to be able to determine sensitivity and specificity the data had to be processed into a pass or fail (see Table 1). The infant failed the RTHB if they had one or more unmet milestone. Since the PEDS algorithm subdivides the infants into five categories (Path A-E) the results were interpreted in two different ways: i.e. Path A and B was considered a fail, whereas Path C, D and E represented a pass.

Alternatively Path A-D was considered a fail and Path E a pass. Two different interpretations of the PEDS was decided on as Path A and B represents the predictive concerns only (a more stringent interpretation), while Path A-D includes all concerns (a more inclusive interpretation). Both these pass/fail classifications was recommended by the author of the test[26].
If an infant had one or more unmet milestone in the PEDS:DM the outcome of the test is a fail.[22] The interpretation of the PEDS tools started with the PEDS, where Path A represented a fail irrespective of the PEDS: DM result, but with Path B-E the PEDS: DM results determined the actual pass or fail (see Table 1).

Table 1: Summary of the pass/fail criteria of the tools

	RTHB	PEDS	PEDS (Path A and B as fail)	PEDS:DM	PEDS tools
Pass	0 unmet milestones	Path E	Path C,D and E	0 unmet milestones	Path B-E if 0 unmet milestones on the PEDS:DM
Fail	≥1 unmet milestone	Path A-D	Path A and B	≥1 unmet milestone	Path A or Path B-E if ≥1 unmet milestone on the PEDS:DM

Results

Outcomes of the PEDS: tools and RTHB developmental checklist (Table 2) indicate that 52% of the sample (104 infants) failed the PEDS tools, 49% (98 infants) failed the PEDS: DM and 47% (94 infants) failed the PEDS. The RTHB developmental checklist failed 17% (35 infants) of the sample, and the PEDS (path A and B) failed 30% (61 infants) of the sample.

Table 2: Pass/Fail distribution of the RTHB developmental checklist, PEDS tools and PEDS

	RTHB developmental checklist	PEDS tools	PEDS:DM	PEDS	PEDS (Path A and B as fail)
Pass	166	97	103	107	140
Fail	35	104	98	94	61
Referral rate	17% (35/201)	52% (104/201)	49% (98/201)	47% (94/201)	30% (61/201)

There were numerous ways to compare the RTHB's outcomes with the gold standard. The RTHB developmental checklist identified 26 of the 104 participants who failed the PEDS tools. The sensitivity of the RTHB developmental checklist was limited, 25%, but the specificity was high, 91% (Table 3). Twenty-six of the 35 infants who failed the RTHB also failed the PEDS tools. Table 3 also reports the RTHB and PEDS comparison with a stricter PEDS fail criterion applied. Sensitivity and specificity of the RTHB developmental checklist in comparison to the PEDS tools was similar to the RTHB developmental checklist and PEDS (Path A and B) comparison. However, the positive predictive value was lower and the negative predictive value higher in the PEDS (Path A and B) comparison than with the PEDS tools.

Table 3: Performance of the RTHB developmental checklist screen

	PEDS tools	PEDS: Path A and B indicating fail
Sensitivity	25% (26/104)	25% (15/61)
Specificity	91% (88/97)	86% (120/140)
Positive predictive value	74% (26/35)	43% (15/35)
Negative predictive value	53% (88/166)	72% (120/166)
Overall hit rate	57% (114/201)	67% (135/201)

Since the RTHB screen appears to evaluate developmental domains inconsistently across ages (see Appendix A) the accuracy of the tool for gross motor, fine motor, receptive language and expressive language was determined. The RTHB developmental checklist identified a total of 1 out of 20 infants who failed the PEDS tools on their gross motor development (Table 4). A lack of test items for gross motor development in each of the age intervals of the RTHB developmental checklist resulted in a missing value of 96 participants. Sensitivity of the RTHB developmental checklist for gross motor development was limited (1%) with perfect (100%) specificity (Table 5). Similar results were evident for fine motor, receptive and expressive language.

Table 4: Developmental domain specific pass/fail distribution of the RTHB developmental checklist and PEDS tools

		Gross motor	Receptive language	Expressive language	Fine motor
Frequency missing*		47% (96/201)	4% (8/201)	0% (0/201)	56% (113/201)
RTHB developmental screen	Pass	104	191	199	83
	Fail	1	2	2	5
	Referral rate	0,9% (1/105)	1% (2/193)	1% (2/201)	6% (5/88)
PEDS tools	Pass	85	174	180	69
	Fail	20	19	21	19
	Referral rate	19% (20/105)	10% (19/193)	10% (21/201)	22% (19/88)

*Due to lack of test items in the RTHB developmental checklist a number of participants had to be excluded in the different developmental domains

Table 5: Developmental domain specific results of the RTHB developmental checklist (using PEDS tools Combined)

	Gross motor	Receptive language	Expressive language	Fine motor
Sensitivity	5% (1/20)	5% (1/20)	5% (1/21)	21% (4/19)
Specificity	100% (85/85)	99% (173/174)	99% (179/180)	99% (68/69)
Positive predictive value	100% (1/1)	50% (1/2)	50% (1/2)	80% (4/5)
Negative predictive value	82% (85/104)	91% (173/191)	90% (179/199)	82% (68/83)

Developmental domains that do not form part of the RTHB developmental checklist include self-help and social-emotional skills. The PEDS tools identified two infants who failed both on their self-help skills and on their social emotional developmental domain, four who failed on their self-help skills, and 11 who failed on their social- emotional developmental domain. All of these infants (17 in total) passed the RTHB developmental checklist. Therefore 8% of participants were not detected by the RTHB developmental checklist due to the absence of self-help skills and social- emotional development screening in this early detection tool.

Appendix A: Road to health booklet developmental checklist

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

Discussion

Prematurity, limited education of parents, poverty and teenage pregnancies have been described, among others, as factors placing infants at risk of developmental delays or disorders.[27] Multiple risk factors increase the likelihood that development will be delayed and high-risk children are 24 times more likely to have IQs below 85 than low-risk children[28] Therefore a higher percentage of failed developmental screenings in the current study was expected. Similar pass/fail distributions as found in the current study were reported in a previous study in which at risk populations were targeted.[29] Since an at-risk population was selected it was expected that the incidence of delays and disorders would be elevated in comparison to a low risk population.

An accurate screening tool should have a high sensitivity (between 70-80%) and high specificity (between 70-80%).[26] Similar to the results where the RTHB screen and the PEDS tools are compared, the accuracy of the RTHB against the PEDS test (Path A and B) is low. Therefore even when a more stringent interpretation of the PEDS was used the accuracy of the RTHB was still poor. Low sensitivity of the RTHB screen is a great concern, as it clearly illustrates the failure of the screen to detect developmental delays in infants, which will result in the majority of infants in need of early intervention services remaining unidentified. Some developmental areas such as social- emotional and self-help skills are not included in the RTHB screen, and the inconsistency of the other developmental domains across the ages is problematic.

Some questions can be raised by the above findings, such as whether it is realistic to compare the RTHB developmental checklist to another broad ranging developmental screening tool. Screening tools, such as the PEDS tools, measure multiple developmental aspects ranging from mild and 'difficult to identify' developmental problems to severe problems such as mental retardation.[30] Consequently such a broad ranging instrument ensures that the strengths and limitations of the RTHB developmental checklist may be established. A limitation in the current study, however, is the limited age range (6-12months of age).

Consequently future research on infants and young children older than a year is recommended. Although the accuracy of the PEDS tools have been confirmed in South Africa,[23] the possibility of a western cultural bias had to be taken into consideration. However, as a previous study has demonstrated that the accuracy of the PEDS tools were similar to previous research conducted in under served communities in America,[29] it can be assumed that cultural differences probably did not influence the outcome of the tools in great extent.

Findings suggest that additional development of the RTHB screen is needed. Test items at each age interval should represent all the developmental domains i.e. receptive language, expressive language, gross motor, fine motor, social-emotional, self-help and global-cognitive skills and the test should be extended to the preschool years. Age intervals should also be used consistently throughout the RTHB,for instance 0-3, 4-6, 7-9 months and so forth. Scoring guidelines and a clear referral framework should also be developed. The tool should then be validated and standardized for the South African context. The fact that these aspects were omitted during the development of the test may explain why the test lacks accuracy in identifying risk of developmental delay. It is recommended that since the accuracy of the RTHB developmental checklist is poor, alternative screening tools should be considered or integrated to ensure a validated screening tool to be used nationally in South Africa. Because this study compared the RTHB to a combination of screens, future research should involve replication of this study using diagnostic developmental tests as benchmark.

Finally, the utilization of an early developmental screening tool provides opportunity for other preventative strategies such parental education[15].

Consequently the implementation of an accurate screening tool in primary health care in South Africa also has educational value for the families, which in turn may support infant development as awareness was created.

Conclusion

The RTHB developmental checklist failed to identify more than half of infants at risk of developmental delays or disorders within the PHC context. The nationally implemented developmental screening tool requires adaption with subsequent validation or replacement by existing tools appropriate for the context to ensure timely identification of at-risk infants towards improved outcomes. In addition developmental screening provides a platform for other preventative strategies such as parental training.

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