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Developing a Self-Report Tool to Measure Functional Limitation in Children Aged 7-12 Years with Physical Dysfunction

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ABSTRACT

Objective: To develop a self-report questionnaire to measure functional limitation in children aged 7-12 years with physical dysfunction.
Study design: Methodological research design
Method: The study was conducted in phases: drafting of the questionnaire, content validation, pilot testing, revision of the questionnaire, field testing and test-retest reliability. A total of 66 items were generated through a review of the literature and interviews of twenty five children, their parents and health-care professionals. Qualitative and quantitative content validation through expert review and item reduction resulted in a 59-item questionnaire which was pilot tested on a sample of 10 children with physical dysfunction. With further inputs the questionnaire was revised. Thus, the final questionnaire with 60 items in two versions (a child and a caregiver's version) in both Hindi and English was developed.
Results: Qualitative review and Content validity was established for the Children's Functional Limitation Scale. The questionnaire demonstrated high internal consistency (Cronbach's alpha=0.91), moderate agreement between parents and children (weighted kappa= 0.718) and good test-retest reliability (weighted kappa=0.88).
Conclusion: "Children's Functional Limitation Scale" is a valid and reliable tool for documenting difficulties perceived by children with physical dysfunction. Also, the study demonstrates ability of children to reliably report their limitations.

Keywords: Functional limitation, Activities of Daily living, Self-Report, Questionnaire, Children with physical dysfunctions

INTRODUCTION

There are 27 million people with special needs (approximately 2.2% of the population of India).[1] About 4.6 million are in the age group of 10-19 years. The picture for 0-6 years is also of concern, with about 2 million in the age group having special needs.[2] With such a magnitude disability be it temporary or permanent has significant implications on a child.

Occupational therapy practitioners with their unique ability to assess disability and functional limitation from various perspectives within the context of the client's performance of daily life tasks need to develop and use functional assessments that consider the volitional character of their clients.[3]

While performance measures may be intuitively appealing on several grounds, recent studies do not support the notions that they are more acceptable to patients, clinically feasible, reproducible or sensitive to change or psychometrically "superior" to questionnaire measures.[4] Self-report questionnaire on the other hand is the least expensive method of getting data where

observation is not possible besides taking into account the patient's perspective for goal setting. The only drawback is it may not reflect the patient's performance accurately.[5]Using performance measures to the exclusion of self-report obscures vital personal information such as perception of pain and reasons for the difficulty. Hence neither should be used as a single tool.[6]

Among the functional assessment measures developed for children very few like ASK (Activities Scale for Kids) includes the child's perspective.[7]

This has generated growing consciousness among occupational therapists about the need to listen and to respect children's understanding of themselves as they aim to provide specialised therapy with successful outcomes.[8] Even the United Nations Convention on Rights of the Child has given the right to express their view.

Client-centered approach for clinical use with children has been recently reported. [3,8,9] Harter and Pike (1984) being originators of this concept.[8] In a review of existing self-report assessment tools used with young children Strugess and Rodger et al [8] have stated some compelling arguments for its use with children in some circumstances and quoted extensive evidence supporting effective ways to design self-report tools too. Martin et al 1999[8] have used self-report assessment as early as 3 yrs 5 months.

Several studies have shown that selection of age appropriate word/phrases make it possible to design tools that are not beyond the cognitive abilities of most of the children. Even it is possible to train seriating skills in young 3 yrs old.[9,10,11]

Self-reports may not be sufficient as diagnostic tool but can provide interesting and important descriptive information. It can be effectively used for young children if it assesses the actual focus of therapy.[8,9,10]

Thus the study aims to prove the competency of the children to report their disability reliably and in the process help develop a self-report based functional assessment measure specifically for children.

METHODS

Subjects

Inclusion criteria:

Children with a physical disability (7-12 yrs) with some degree of limitation in activities.

Since a self-report questionnaire was being included in the study, a reading ability of atleast 3rd grade was mandatory.

Exclusion criteria:

Subjects with cognitive, speech, hearing impairment were excluded.

Instrument used: a self-devised questionnaire (both in English and Hindi) constructed for the study with 60 items rated on an ordinal scale with instruction page and practice question.

Procedure:

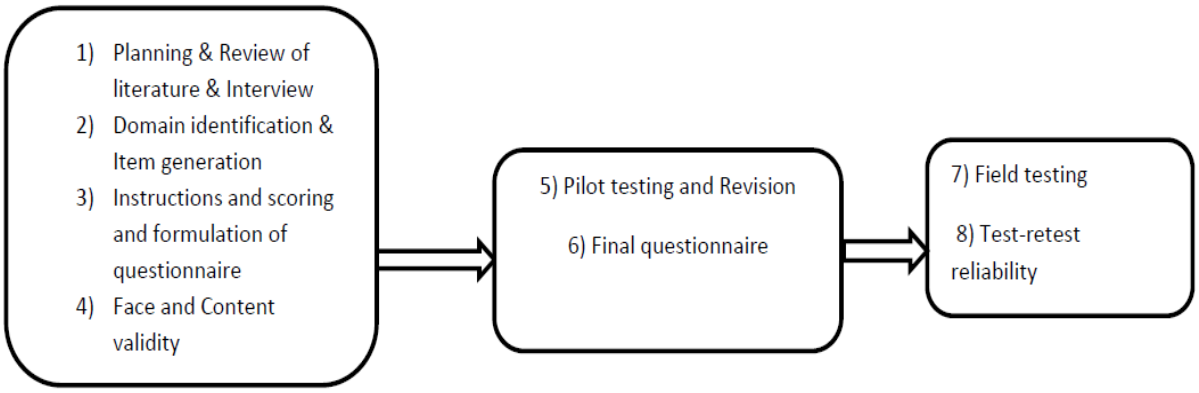

Figure 1: Steps in development of the scale

Item generation and selection

Sixty six items related to physical function were generated for 10 identified domains using a checklist (from input from experts and review of literature) and interviewing parents and their children (25 pairs). Items represented performance in functional areas in which the child faced difficulty. Few items reported corresponded to psychosocial function hence it was developed as optional additional questionnaire.

Formulation and item reduction

Items were phrased in children's language (with inputs from a speech and language pathologist and clinical psychologist). Likert scale was used with 2 scoring patterns (one based on importance to be used for item reduction and the other based on assistance to be used for final field testing) for the Final questionnaire. Due to poor agreement value for almost all of the items of psychosocial function optional questionnaire, it was completely excluded from study at this phase.

The questionnaire was prepared in two versions (child and caregiver version) in both Hindi and English (back translation method was used by a blind translator).

Face validity and content validity was established by 5 senior Occupational Therapist using ICF classification and uniform terminology of AOTA, 3r^{d} edition.

Item reduction and inter-rater reliability – Items were reduced using kappa statistics. Items having weak agreement were eliminated.

Pilot testing- It was done on a random sample of the target population (around 10 children). Inputs were taken to modify the questionnaire for final testing.

Field testing- Thirty pairs were randomly selected for final phase. The children were explained the instructions carefully. The parent/caregiver version of the questionnaire with separate instruction page was sent to them to be filled at home. Written informed consent was obtained from the children's parents involved in the various phases of the study. The children's verbal assent was also obtained, and their right to withdraw from the study at any time was emphasised. The study was approved by the Institutional research committee.

Test-retest reliability- Thirty children were asked to rescore on the questionnaire after two weeks and the data collected was analysed.

RESULTS AND DATA ANALYSIS

Results were analysed using STATA 8.0 software in given steps.

Sample characteristics

Table 1: Demographics of the study group

	Item generation	**Pilot testing**	**Field testing**
Number(N)	25 pairs (25 children + 25 parent)	10 children	30 pairs (30 children + 30 parent)
Age range	7-12 years (mean = 10.4±0.06 yrs)	7-12 years (mean = 10.6±0.42 yrs)	7-12 years (mean = 10.7±0.96 yrs)
Diagnosis	PPRP ,DMD ,SPINA BIFIDA, CONGENITAL ANOMALY,RICKETS AND OTHERS	PPRP	PPRP ,DMD ,SPINA BIFIDA, CONGENITAL ANOMALY, RICKETS AND OTHERS
Sex	MALE (14) FEMALE (11)	MALE (5) FEMALE (5)	MALE (21) FEMALE (9)

**PPRP- POST POLIO RESIDUAL PARALYSIS, DMD-DUCHENNE'S MUSCULAR DYSTROPHY*

Kappa for multiple rater was used for inter-rater agreement for 64 items (2 discarded based on frequency from 66 items generated initially) of the preliminary questionnaire, values for which varied from .4009 to 1. Further five items showing k=<.60 was eliminated.[12] As poor agreement between parents and children was noted for maximum items of psychosocial function optional questionnaire the whole questionnaire was excluded from further study.

Table 2: Kappa table for multiple raters for item reduction

items	kappa	items	kappa	items	kappa	Items	Kappa
1	1	17	1	33	1	49	1
2	0.95	18	1	34	1	50	1
3	1	19	1	35	0.90	51	0.59
4	0.75	20	0.95	36	0.78	52	1
5	0.90	21	1	37	0.52	53	1
6	0.95	22	1	38	0.66	54	0.90
7	1	23	1	39	1	55	0.71
8	1	24	0.95	40	1	56	0.86
9	0.86	25	1	41	1	57	0.80
10	1	26	1	42	0.90	58	0.95
11	1	27	0.93	43	0.80	59	0.48
12	0.40	28	0.86	44	1	60	0.42
13	0.84	29	1	45	0.83	61	0.76
14	0.95	30	1	46	1	62	0.95
15	0.87	31	1	47	0.95	63	1
16	1	32	0.85	48	0.71	64	0.90

Pilot testing- Item "can you unbutton and button?" was split to 2 questions for ease of understanding as it was confusing for some of the children due to two opposite actions being clubbed together. Also pictorial depiction for the scoring on Likert scale was removed as it was distracting to many children particularly younger ones.

Field testing

Table 3: Weighted kappa for level of agreement of parent and child for different domains (final questionnaire)

Domains	No of items	Kappa range for items	Kappa (average)
I EATING AND DRINKING	6	.4706-.8454	.6530
II PERSONAL CARE/ HYGIENE/GROOMING	7	.7512-.5175	.7512
III UNDRESSING AND DRESSING	15	.7957-.6591	.7957
IV TOILETING	3	.5745-.6949	.6597
V BATHING	4	.5810-.6853	.6878
VI CARRYING	2	.6244-.7462	.6853
VII MOBILITY/TRANSFER/TRANSPORTATION	5	.6677-.7872	.7407
VIII ACADEMIC	6	.2174-.6552	.5288
IX GROSS MOTOR	8	.5925-.7964	.7101
X ENVIRONMENTAL	4	.7242-.9233	.8274

Weighted kappa for level of agreement between parents and their children was calculated. The value of kappa for items ranged from 0.217 to 0.9233. No of items having kappa value less than 0.4=1; 0.4-0.6 =9, 0.6-0.8=37; >0.8=13. Mean Kappa values ranged from 0.5288-0.8274 for the domains. Academic domain showed moderate agreement (0.53) while Environmental hardware showed near perfect agreement of 0.83. Overall agreement between parent and their children for the complete questionnaire was 0.718.

Test and retest reliability

Table 4: Weighted kappa for test –retest reliability.

Domains	No of items	Kappa range for items	Kappa (Average)
I EATING AND DRINKING	6	.7877-1	.9642
II PERSONAL CARE/ HYGIENE/GROOMING	7	.7391-1	.8859
III UNDRESSING AND DRESSING	15	.6403-1	.8954
IV TOILETING	3	.8435-1	.9308
V BATHING	4	.8864-1	.9354
VI CARRYING	2	.9501-1	.9750
VII MOBILITY/TRANSFER/TRANSPORTATION	5	.7170-1	.9049
VIII ACADEMIC	6	.4737-.8077	.6791
IX GROSS MOTOR	8	.8315-1	.9199
X ENVIRONMENTAL HARDWARE & WORKING	4	.8454-1	.9400

Values for items following test retest after 2 weeks ranged from 0.47 to 1. No of items having values within 0.4 to 0.6 =2, 0.6 to 0.8 =8, > 0.80=50. For domains values ranged from 0.6791 (academics) to 0.9750 (carrying). Other domains had value > 0.80

i.e almost perfect agreement. Overall agreement for the scale on retest was 0.88.

Also, the questionnaire had high internal consistency (Cronbach's alpha=0.91)

DISCUSSION

The result indicated that the scale is a reliable and valid tool and also established the use of self-report for children of age group 7-12yrs.

In the item generation stage children reported 12 items more than their parents supporting the fact that children can report facts validly as also reported by many authors in their study. [13.14,15,16] Items selected corresponded to performance / functional areas mastered by the age of 6 yrs by a child and in which the child was facing difficulty.

Few items reported corresponded to psychosocial issues. Since poor agreement between parents and children was noted during interview for psychosocial function hence it was developed as optional additional questionnaire.

Face validity and content validity was established and the items got reduced from 66 to 59 based on inter-rater agreement. Inter-rater agreement for psychosocial function domain additional questionnaire was poor for maximum items, hence excluded from further study. A possible reason for such as stated by Sallis can be attributed to limited knowledge of the adults regarding child's behaviour, response bias, social desirability and the time spent by the parent with the child.[8] Several studies have reported similar results [16,17,18,19,20,21]. When a parent answers questions on behalf of the child, the parent is expressing his or her perception, which may be biased by the parent's view of the experience.[22] Context based understanding of a child's behaviour is necessary to show good agreement.

Discrepancies between informants do not necessarily imply "right" and "wrong" but are probably an inescapable consequence of different point of view. Parent and child are likely to differ in their awareness of, sensitivity to and tolerance for different child problems.

The result of the study is in accordance with the findings reported in the literature. Good agreement was noted between parents and children (k=.718) for complete questionnaire and the domains showed moderate to near perfect agreement. Doherty and colleagues[23] compared pain and disability scores on a modified version of children's health assessment questionnaire and had found high concordance (ICC=0.86) between children and parents.

Duffy[21] found a mean agreement of 0.60 weighted kappa across 140 items; gross motor 0.51, fine motor 0.64, psychosocial 0.56 and general symptoms 0.64. They concluded both parent and child to be reliable informants.

Lovell and Howe et al[24] in the development of JAFAR (questionnaire to assess physical function in children with JRA) demonstrated good reliability for both parent and child versions.

Young et al 1995[13] reported good concordance between parent and child (ICC=0.96) over the summary scores on physical function on non-specific population of children with physical disability. In a similar study Mclimont et al, 2010[16] reported overall excellent level of agreement (kappa=0.75) between parents and their children

The overall value of retest for the questionnaire was 0.88 which is strong agreement showing that the questionnaire had good test retest reliability as supported by Young et al, 1995[13] on the children's self-report (aged 5-15yrs) on level of assistance of different activities. They showed excellent test retest (ICC=0.97) similar to this study.

Agreement was found on each item rather than on summary scores as reliability of functional measures over summary score had been questioned by some authors .[25,26] .

Hence the results support the view that both children and parents are reliable reporters of physical disability.

Limitations

1. Small sample size with very few children of 7-8yrs (due to random sampling).hence results not to be extrapolated to this age group.
2. Contamination of view
3. Education
4. Generalizability of population

Future recommendations

1. Age wise difference in agreement between parents and child.
2. A short form of the questionnaire can be devised.
3. Questionnaire's ability to differentiate between different levels of disability.

CONCLUSIONS

The study proves that

1. Children with physical disability 7-12 years can reliably report their disability.
2. There is good agreement between children and parents though differences of perspectives do occur. Thus parents are reliable surrogates when child is unavailable for testing.
3. The "Children's Functional Limitation Scale" hence developed for the study is a reliable and valid tool.

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Conflict of Interest: None

Source of Funding: None

Ethical Approval: Approved

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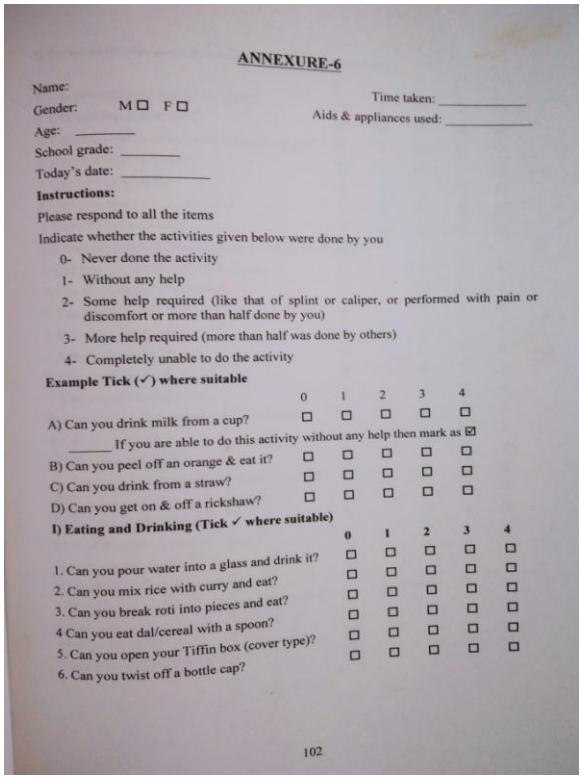
APPENDIX
(CFL Scale in English & Hindi)



ANNEXURE-6

Name:
Gender: M☐ F☐ Time taken: _____
Age: _____ Aids & appliances used: _____
School grade: _____
Today's date: _____

Instructions:

Please respond to all the items

Indicate whether the activities given below were done by you

0- Never done the activity
1- Without any help
2- Some help required (like that of splint or caliper, or performed with pain or discomfort or more than half done by you)
3- More help required (more than half was done by others)
4- Completely unable to do the activity

Example Tick (✓) where suitable

	0	1	2	3	4
A) Can you drink milk from a cup?	☐	☐	☐	☐	☐
_____ If you are able to do this activity without any help then mark as ☑					
B) Can you peel off an orange & eat it?	☐	☐	☐	☐	☐
C) Can you drink from a straw?	☐	☐	☐	☐	☐
D) Can you get on & off a rickshaw?	☐	☐	☐	☐	☐

I) Eating and Drinking (Tick ✓ where suitable)

	0	1	2	3	4
1. Can you pour water into a glass and drink it?	☐	☐	☐	☐	☐
2. Can you mix rice with curry and eat?	☐	☐	☐	☐	☐
3. Can you break roti into pieces and eat?	☐	☐	☐	☐	☐
4 Can you eat dal/cereal with a spoon?	☐	☐	☐	☐	☐
5. Can you open your Tiffin box (cover type)?	☐	☐	☐	☐	☐
6. Can you twist off a bottle cap?	☐	☐	☐	☐	☐

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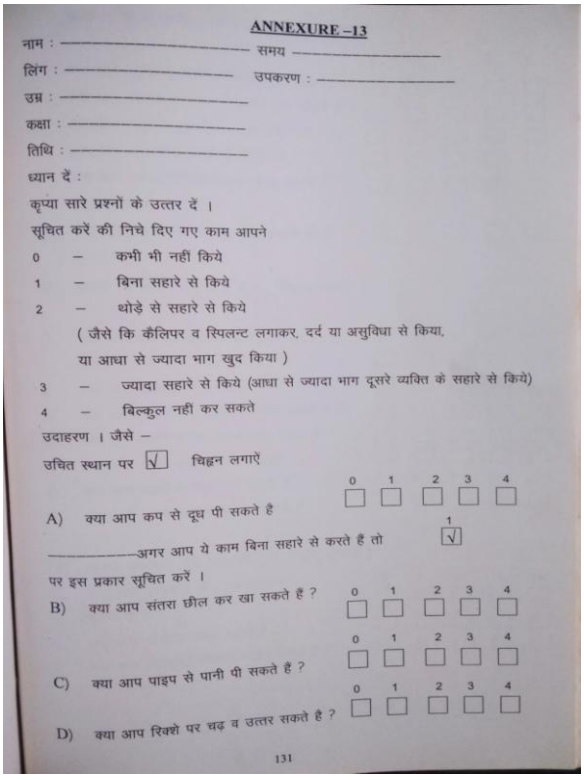

ANNEXURE –13

नाम : _____ समय _____
लिंग : _____ उपकरण : _____
उम्र : _____
कक्षा : _____
तिथि : _____

ध्यान दें :

कृप्या सारे प्रश्नों के उत्तर दें ।

सूचित करें की निचे दिए गए काम आपने

0 – कभी भी नहीं किये
1 – बिना सहारे से किये
2 – थोड़े से सहारे से किये
(जैसे कि कैलिपर व रिपलन्ट लगाकर, दर्द या असुविधा से किया, या आधा से ज्यादा भाग खुद किया)
3 – ज्यादा सहारे से किये (आधा से ज्यादा भाग दूसरे व्यक्ति के सहारे से किये)
4 – बिल्कुल नहीं कर सकते

उदाहरण । जैसे –

उचित स्थान पर ☑ चिह्न लगाएँ

	0	1	2	3	4
A) क्या आप कप से दूध पी सकते है	☐	☐	☐	☐	☐
_____अगर आप ये काम बिना सहारे से करते हैं तो		1 ☑			
पर इस प्रकार सूचित करें ।					
B) क्या आप संतरा छील कर खा सकते हैं ?	☐	☐	☐	☐	☐
C) क्या आप पाइप से पानी पी सकते हैं ?	☐	☐	☐	☐	☐
D) क्या आप रिक्शे पर चढ़ व उत्तर सकते है ?	☐	☐	☐	☐	☐

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