

Content validity and usefulness of Picture My Participation for measuring participation in children with and without intellectual disability in South Africa and Sweden

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Abstract

Background: Participation comprises attendance and involvement in everyday situations.

Picture My Participation (PmP) is an instrument intended to measure participation in children with disabilities, particularly in low and middle income countries.

Aim: To investigate content validity and usefulness of PmP for measuring participation in children with intellectual disability (ID) in South Africa and Sweden.

Methods: A picture supported interview with 149 children, 6-18 years, with and without ID. Twenty everyday activities were provided. The three most important activities were selected by the child. Attendance was rated on all activities. Involvement was rated on the most important.

Results: All activities were selected as important by at least one child with ID in both countries. There were similarities in perceived importance between the children with and without ID from South Africa. The children from South Africa with ID were the only subgroup that used all scale points for rating attendance and involvement.

Conclusion: The 20 selected activities of PmP were especially relevant for children with ID in South Africa. The usefulness of the scales was higher for the children with ID in both countries. PmP is promising for assessing participation across different settings but psychometrical properties and clinical utility need further exploration.

Keywords: Low and Middle Income Countries, Everyday Functioning, Picture supported Interview, Cognitive Support, Self-ratings

Introduction

The Convention on the Rights of the Child [1] and the Convention on the Rights of Persons with Disabilities [2] state that children with disabilities have the same right as typically developing children to function fully in all life situations. According to the integrative approach towards disability provided by the International Classification of Functioning, Disability and Health (ICF), participation has been identified as an essential reflector of functioning, disability and health in an everyday context [3,4]. In the ICF, participation is defined as “involvement in a life situation” [3,4]. Participation is therefore considered the ultimate everyday outcome of interventions and services for children with disabilities, and thus it is an important outcome for health and education.

Measuring participation in everyday life requires assessment instruments that determine performance in culturally relevant everyday activities. Probably activities partly vary with culture [5]. The content validity of assessment instruments includes aspects of relevance (the items of the measure are meaningful and important for the specific population and context of use) and comprehensiveness (key aspects of the construct are covered). Content validity can be defined as the degree to which the content of an instrument adequately reflects the construct assumed to be measured [6,7]. Ratings of participation that uses instruments developed in high-income settings may not be as relevant and useful in surveying the participation experiences in everyday activities of children with intellectual disability (ID) in a low and middle income country (LMIC) context. Children with disabilities are at risk of lower participation and increasing health problems, and for children with cognitive and intellectual impairments, this risk is even higher [8-10]. Children with ID in Western countries, compared to those without disabilities, participate less frequently in recreational, active-physical and skill-based activities such as organised sporting activities with friends or

others [11]. This pattern is also found in LMIC countries [12]. Instead, children with ID participate more frequently in activities at home. This may be due to their poorer physical, cognitive and social skills, but can also be explained by a lack of supportive context [8,9,11].

For example, a systematic review by Shields, King, Corbett and Imms [13] shows that children with ID participated in fewer community-based social activities and in fewer formal (probably adult-led) activities. A less supportive context may decrease the number of formal organised opportunities of being involved in situations where the demands for functioning require social skills such as cognitively loaded reasoning [14]. This implies that an instrument that is intended to assess participation and participation restrictions in children with ID may need to focus on participation in more informal types of activities than an instrument in a context with high societal resources [12,14,15]. It is likely that children in lower resource settings participate more frequently in activities related to taking care of home and family, and they participate less in formal activities outside the home.

Systematic reviews of instruments intended to measure participation in children and adolescents with a disability showed that none of these instruments were originally developed or culturally validated in the everyday contexts of low-and-middle-income countries (LMIC) [15,16]. For example, only two of the 21 measures evaluated by Rainey et al. [16] were developed in LMIC countries (China and Taiwan) and both focused on participation in a clinical setting (hospital and physical therapy) – not in everyday contexts. Rainey et al. [16] also argue that there is a shortage of good quality information regarding the psychometric properties of all 21 instruments. Besides this shortage of suitable instruments, the ICF does not provide a straightforward methodology for the operationalisation or measurement of participation. The ICF suggests that the qualifier ‘performance’ (describing what a person

does in their actual environment) can be used to assess participation, whereas it does not mention the involvement aspect explicitly [17]. Studies aiming to assess participation have operationalised participation in different ways [16,18]. Imms et al. [5] suggest that participation comprises two essential aspects: first, the actual *attendance* of an activity in an everyday setting and second, the aspect of perceived *involvement* while attending the activity. Using this definition of participation, Adair et al. [19], tried in a systematic review, to identify participation measures and then mapped those that have been used in at least two empirical studies to the definition. A total of 51 measures attempting to measure participation were identified; of these, 21 assessed frequencies of participation and 10 assessed involvement. The other measures assessed factors relating to participation, of which the most common one was ‘activity competence’, which is ability of the child to do the activity correctly. In addition, very few measures contained children’s self-ratings and most measures were validated for use with children with cerebral palsy or autism, rather than children with ID. The result again confirms a lack of participation instruments based on self-ratings and validated for use with children with ID [19].

The attendance aspect of participation can be measured as the frequency of attending a certain activity/situation, while the involvement aspect can be measured as the level of perceived involvement/engagement when actually attending the activity [5]. Attendance is considered as a prerequisite for involvement (to be involved requires one to be present in the situation to some degree). Theoretically, the two aspects of participation are related to intrinsic factors such as individual skills and preferences, as well as to contextual and environmental factors [5].

Due to possible difficulties with regard to abstract thinking, a measurement of participation for children with ID has to be adapted – both in terms of the level of abstraction and the scale used for rating [20]. For example, a three- or four-point Likert scale is easier for an individual with ID to understand than a visual analogic scale of 0-100 [20]. To decrease the level of abstraction of the different activities used for questioning about attendance and involvement, one option is to choose activities that the individual has had experience of attending and/or perceives as important to participate in [21]. For individuals with moderate and severe ID, as well as for younger children with mild ID, their understanding of questions asked can be supported and promoted when pictures and/or other adaptations are used to facilitate communication [22].

Children in low-resourced contexts may not have had the same language experiences and opportunities for literacy as their counterparts who live in better resourced contexts. This lack of experience may hinder sufficient understanding of different activity items in instruments that are used to assess participation. Thus, the different activities provided in an instrument that aims to assess the participation (operationalised as both attendance and involvement) of children with ID in LMIC have to appear as meaningful and adequate for the target group.

Picture My Participation is an instrument that intends to measure participation – operationalised as both attendance (i.e. frequency of attendance) and involvement (i.e. level of involvement) in everyday contexts – for children with disabilities, especially in LMIC settings. It contains 20 items related to home, social and community activities (see Table 2) and is administered as a picture supported interview with children with disabilities. The items were selected by reviewing existing participation measures developed in high resource settings such as Children’s Assessment of Participation and Enjoyment [31], Participation and

Environment Measure-Children and Youth [32] and the Paediatric Activity Card Sort [33]. In addition, items were matched to the Convention on the Rights of Children (CRC) [1] and articles of the Conventions of the Rights of Persons with Disabilities (CRPD) [2]. The selected items were furthermore reviewed in relation to resource-poor environments to identify areas not covered in measures developed in high-income settings. Finally, items were selected to represent the activity/participation chapters of the ICF-CY [4] ensuring that the activities selected (and/or the examples of the activity types selected) included those that could be considered important and relevant in LMIC settings, as well as representative of the activity/participation chapters of the ICF-CY [4]. The child's own rating attempts are supported by using graphic symbols to represent the activities and the responses. The main intent of the structured interview is to have a guided conversation with the children involved to elicit their responses about their frequency of attendance and degree of involvement in everyday settings.

The overall aim of this study was to investigate aspects of content validity by exploring the relevance and meaningfulness of the 20 selected items of the Picture My Participation instrument. The study investigated content validity in terms of rank order correlations and the use of all scale points of the participation instrument in children with ID in general, and in LMIC in particular. By comparing a LMIC setting (South Africa) and a high-income country (HIC) (Sweden), it was possible to investigate if the content of the items was setting/country specific or not. The first specific aim was to explore relevance of the items by determining the extent to which the 20 items were chosen as important (i.e. to attend them and to be involved in them) by four subgroups of children (children with ID in South Africa; typically developing children in South Africa; children with ID Sweden; and typically developing children in Sweden). The second specific aim was to compare the frequencies of the chosen

item across the four subgroups of children. A third aim was to investigate the usefulness of the scales used for measuring attendance and involvement in the participants with ID.

The research questions were:

To what extent do the four subgroups of participants (children with ID in South Africa; typically developing children in South Africa; children with ID in Sweden; and typically developing children in Sweden) choose the 20 items of the Picture My Participation instrument as important to attend and to be involved in?

What are the differences and similarities, in terms of rank order correlations, among the four subgroups regarding frequencies of the items chosen as most important?

To what extent are all the scale points used for rating attendance (four-point Likert Scale) and involvement (three-point Likert Scale) by the children with ID in South Africa and Sweden?

Materials and Methods

Design

Content validation studies commonly use methods such as cognitive interviewing to ask participants directly about the relevance of content. In this study, the relevance and usefulness were assumed to be reflected by the extent to which the participants chose the items as important to attend and to be involved in, and the extent to which they used each point of the measurement scales to answer the questions in the Picture My Participation.

Ethics

Approval for the study was obtained from the Ethics Committee Boards in each country, as well as the relevant local Departments of Education and school principals. In Sweden approval was obtained from the Regional Research Ethics Committee at the Universities and

relevant authorities. In both countries, the relevant local Department of Education, School principal provided permission for the study. Informed consent was obtained from every child's primary caregiver, and assent was also sought from each participating child in both countries.

Setting

Data were collected in South Africa and in Sweden: in South Africa in a large city of approximately 200 000 inhabitants, and in Sweden in two middle-sized cities in different parts of the country with approximately 100 000 inhabitants each.

Participants

The purpose of the sampling strategy was to ensure variation in the samples in terms of age, gender, country/context and level of disability. Besides targeting samples from two different countries, we also sought children with either an ID or typically developing children in both countries. Four subgroups were recruited: (i) children with ID in South Africa (n=99); (ii) typically developing children in South Africa (n=37); (iii) children with ID Sweden (n=20); (iv) typically developing children in Sweden (n=17). Children with ID were eligible for inclusion if they attended a special school for children with ID or were diagnosed with mild or moderate ID. Children with either ID or typically developing children needed to meet the following criteria to be included: (i) aged between 7 and 17 years; (ii) able to speak and understand English (in South Africa) or Swedish (in Sweden); (iii) assented to participate in the study. In both Sweden and South Africa, the children with ID had been diagnosis according to the guidelines of Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [23] including significant limitations both in intellectual functioning and adaptive functioning.

Variables and Measurements

All the data were collected by clinical researchers or specially trained postgraduate students with knowledge about the target group and the Picture My Participation. Data relating to participant characteristics, including date of birth, gender and level of perceived disability, was collected using a parent-report survey.

Picture My Participation

Picture My Participation is designed for children and youth aged 5-21 years and measures participation in 20 home and community activities (see Table 2). It is administered with a child as a picture supported interview supported by pictures for each item and for each scale. It consists of four sections:

- 1) Frequency of attendance for each item, rated on a four-point Likert scale (Never; Seldom; Sometimes; Always).
- 2) Selection of the three activities that the child perceived most important to participate in
- 3) Perceived involvement in these three activities, rated on a three-point Likert scale (Not involved; Somewhat; Very). In this section, the children were also asked if there was any other activity, besides the provided 20, that they would select as important.
- 4) Evaluation of perceived barriers to and facilitators of participation in relation to the activities that were most important to the children.

The instrument took 10-20 minutes for the child to complete. For the purposes of this study, only data from sections 1-3 was used. The fourth section was administered but was not the focus of this study.

The Picture My Participation instrument, including the manual, was developed in English. It was translated into Swedish using Brislings method [24]. The translation was completed by two translators competent in both English and Swedish. Translator 1 translated from English to Swedish. Thereafter, Translator 2 back translated into to English [24]. Discrepancies in the translations were discussed between the two translators until consensus was reached or a third translator was consulted. Further linguistic and cultural equivalence was addressed by piloting the translated version with typically developing children (n=7).

Ten Questions Screen

The Ten Questions Screen is a screening tool that assesses the level and nature of the child's disabilities, e.g. cognitive, motor and seizure disabilities [25]. It includes 10 closed (yes/no) questions about whether the child has a problem or not; zero points indicate no problem at all in relation to disability and ten points indicates problems in all areas. The Ten Questions Screen was completed by the primary caregiver to describe the different target groups in terms of their level of disability.

Data collection

Picture My Participation was completed by using graphic symbols from the aided symbol set of Picture Communication Symbols (PCS™) [26], which are available as part of the Boardmaker™ software program by Mayer-Johnson, LLC [27]. PCS™ symbols were used during the child assent procedure and as part of the Picture My Participation instrument. A specific picture supported interview approach, namely the Talking Mats™ was used [28]. The Talking Mats™ framework is a strategy to facilitate conversations with persons with disabilities, as well as an instrument for facilitating communication with for instance children with ID. The strategy involves placing a mat (a piece of carpet measuring 49x34.5 cm) in

front of the child. For the ratings of attendance, one mat was divided into four equal columns using masking tape. The upper part contained the visual scale that represented the four-point Likert scale items depicted with pictures of baskets of apples: “Never” (showing basket filled with no apples), “Seldom” (showing basket filled with two apples), “Sometimes,” (showing basket filled with five apples) and “Always,” (showing basket filled with apples). In the lower part of the mat, the child participants could place their PCS™ symbols regarding the different activities to indicate their responses. Separate mats were arranged to facilitate the conversation with the child for each of the four sections of Picture My Participation. Three trial items were created to facilitate their understanding of Section 1 of Picture My Participation which ensured that the children understood the instructions. The children were asked (in respect to the attendance construct), “How often do you participate in daily routine activities” while being shown the PCS™ symbol of the specific activity. The child had to place the PCS™ symbol on the mat in the column to indicate the item that they felt most represented their frequency of participation. The researcher recorded the response in a separate score sheet and then moved on to the next question until all 20 items were completed. Non-contingent feedback such as “Good job” and “You doing well” were provided during the interview. Data were collected in the same way for in all four subgroups. A total of nine interviewers were involved in the study. In Sweden and South Africa, four and five researchers respectively conducted the interviews. All had extensive experience working with children with intellectual disabilities and they were all trained in interviewing children with disabilities using the Picture My Participation. The same protocol for training was used in both countries and included an interview schedule, a training video and role playing.

Data analysis

For the data analysis, the Likert scales were prepared with values in the following way: The four-point Likert scale for attendance (1= Never; 2= Seldom; 3= Sometimes; 4= Always). The three-point Likert scale for involvement (1= Not; 2= Somewhat; 3= Very).

The relevance and meaningfulness of the 20 items of Picture My Participation were assessed in two ways. First, by determining how often (frequency counts) each of the 20 items of the Picture My Participation instrument was chosen as most important to attend and to be involved in. Due to the rather small sample for the subgroups with typically developing children, items were considered relevant if they were selected by any child from each subgroup of participants. We considered Picture My Participation as more relevant for children with ID in a LMIC, therefore, each item was expected to be selected as important by a higher proportion of children with ID from South Africa in comparison to typically developing children from South Africa, and in comparison to both groups of children from Sweden.

Second, relevance was considered by assessing the relationships between the four different subgroups of participants (children with ID in South Africa; typically developing children in South Africa; children with ID in Sweden; typically developing children in Sweden), as well as between all children from South Africa and all children from Sweden, regarding the items chosen as most important. The relationships were calculated by using Spearman Rank Order Correlations. For each of the four subgroups, the rank order of the 20 items was based on frequencies of the items being rated as one of the three most important to participate in. As we considered the 20 items to be more relevant for a LMIC (South Africa), the relationship between rank orders for the children from South Africa was expected to be stronger than for

the children from Sweden. As we considered the 20 items to be more relevant for children with ID, the relationship between rank orders should be stronger for the children with ID than for typically developing children.

The usefulness of the scales used for rating attendance and involvement were analysed, item by item, by calculating frequencies of ratings for each point of the four-point Likert scale (Never; Seldom; Sometimes; Always) for attendance and for each point of the three-point Likert scale (Not involved; Somewhat; Very) for involvement. For the scale to be considered useful, all the points on the scale should be used by at least some participants.

Results

Participants and Descriptive Data

Descriptive data for the four subgroups, as well as the total for all participants together, is presented in Table 1. All the participants (n=149) were invited to complete all the sections of Picture My Participation, but for five of the children with ID from South Africa there was missing descriptive data (of age and gender), as is displayed in the tables of results. Overall, there were equal numbers of girls (n=73) and boys (n=71), who were aged between 6 and 18 (mean = 11.9 years, SD 2.2). The level of disability as rated by the parents using the Ten Questions Screen, showed similar patterns for the children with ID in both countries, a mean score of 1.9 (SD 2.1) problems of ten possible problems for the South African children and 1.4 (SD 1.4) problems of ten possible problems for the Swedish children), as well as for typically developing children; a mean score of 0.0 for the South African children and 0.1 for the Swedish children (indicating no problems related to disability for the typically developing children). The general level of disability was rated higher for the children with ID. None of

Table 1. Descriptive data regarding gender, age and results of Ten Questions Screen for the four samples and for all participants together

		Children from South Africa		Children from Sweden		All participants (n=149)
		With ID (n=79)	With typical dev. (n=33)	With ID (n=20)	With typical dev. (n=17)	
Gender: n (%)	Girls	36 (46%)	22 (67%)	6 (30%)	9 (53%)	73 (49%)
	Boys	38 (48%)	11(33%)	14 (70%)	8 (47%)	71 (48%)
	Missing	5 (6%)	0	0	0	5 (3%)
Age (years)	Min – Max	9 – 16	9 – 14	7 – 18	6 – 15	6 – 18
	Mean (Sd)	12,7 (1,7)	11,2 (1,6)	11,7 (3,1)	10,4 (2,8)	11,9 (2,2)
	Median	13	10	12,5	10	12
	Missing	5	0	0	0	5
Ten Questions Screen (ratings of problems of ten possible problems)	Min – Max	1 to 6	0	0 to 5	0 to 1	0 to 6
	Mean (Sd)	1,9 (2,1)	0 (0)	1,4 (1,4)	0,1 (0,2)	1,2 (1,8)
	Median	2	0	1	0	0
	Missing	0	0	0	0	0

the children reported additional activities (besides the provided 20 in Picture My Participation) as important.

The Relevance and Meaningfulness of the 20 Items of Picture My Participation

Frequencies of how often the 20 items of the Picture My Participation instrument were chosen as most important to attend and to be involved in

Table 2 presents the frequencies, item by item, of how often the 20 activity items of Picture My Participation were chosen as important to attend and to be involved in. Data are presented for each of the four subgroups, total by country, total by ID, total by typically developing children, as well as for boys and girls. Table 2 shows that all 20 items were selected as important by children with ID, both from South Africa and from Sweden. For the Swedish children with ID, 20% missing ratings were reported, which is considered rather high. The missing ratings were mainly because the children didn't come up with any more activities they found important to participate in. For the typically developing children in South Africa, four items were not selected as important by any child, while for the children with typical development in Sweden, five items were not selected as important by any child.

The relationship between the four subgroups of participants regarding frequencies of the items chosen as most important

The analyses from the Spearman Rank Order Correlations show that there was a small or no relationship between the rank orders of the most important activities for children from Sweden with ID and both groups of children from South Africa ($r = -0.14$ for children with ID and $r = -0.18$ for typically developing children). In terms of Rank Order Correlations, there was also a small or no relationship between the two groups of children from Sweden ($r = 0.18$). The relationship between the two groups of children from South Africa was $r = 0.60$.

Table 2. Proportion of children who chose each activity item as one of the three most important activities. Note: The results are presented as follows: the four subsamples separately (with intellectual disability (ID) in South Africa (SA) and in Sweden (SWE); with typical development (TD) in SA and in SWE); total numbers with ID or TD in each country; total numbers per gender (Boys, Girls); total for all participants together (All).

Activity item in PmP	SA		All SA	SWE		All SWE	All ID	All TD	Girls	Boys	All
	ID (n=79) (%)	TD (n=33) (%)	(n=112) (%)	ID (n=20) (%)	TD (n=17) (%)	(n=37) (%)	(n=99) (%)	(n=50) (%)	(n=73) (%)	(n=71) (%)	n=149 (%)
Personal care	8,9	19,2	11,9	3,3	0	1,7	7,7	9,6	10,0	8,9	7,8
Family mealtime	4,6	8,1	5,7	1,7	3,9	2,8	4,0	6,0	5,5	4,2	4,6
My own health	1,7	4,0	2,4	1,7	3,9	2,8	1,7	4,0	3,7	1,4	2,8
Gathering supplies	2,5	0	1,8	3,3	2,0	2,6	2,7	1,0	1,8	2,3	2,0
Meal preparation	3,0	2,0	2,7	8,3	0	4,2	4,0	1,0	2,7	3,3	3,3
Cleaning at home	1,7	2,0	1,8	1,7	5,9	3,8	1,7	4,0	2,7	1,9	2,8
Caring for family	5,9	7,1	6,3	1,7	3,9	2,8	5,0	5,5	5,5	5,6	4,6
Caring for animals/pets	4,6	12,1	6,8	6,7	5,9	6,3	5,1	9,0	8,2	5,6	7,3
Family time	9,7	14,1	11,0	5,0	9,8	7,4	8,8	12,0	11,4	8,0	9,7
Celebrations	5,9	1,0	4,5	3,3	2,0	2,6	5,4	1,5	3,7	4,7	3,1
Playing with others	1,7	0	1,2	8,3	5,9	7,1	3,0	2,9	2,7	2,8	4,0
Organised leisure	11,0	2,0	8,3	1,7	17,6	9,7	9,1	9,8	6,4	9,9	8,1
Quiet leisure	7,6	6,1	7,1	5,0	5,9	5,4	7,1	6,0	7,3	6,1	6,1
Spiritual activities	7,2	7,1	7,1	1,7	0	0,8	6,0	3,5	5,0	6,6	4,0
Shopping	1,3	0	0,9	5,0	3,9	4,5	2,0	2,0	1,8	1,9	2,5
Social activities	1,3	3,0	1,8	3,3	2,0	2,6	1,7	2,5	2,3	1,4	2,4
Health centre	1,3	2,0	1,5	6,7	0	3,3	2,3	1,0	2,3	1,9	2,5
School	8,4	7,1	8,0	3,3	17,6	10,5	7,4	12,4	5,5	10,3	9,1
Overnights visits and trips	3,0	2,0	2,7	6,7	3,9	5,3	3,7	3,0	2,3	4,7	3,9
Paid/unpaid employment	1,3	1,0	1,2	1,7	0	0,8	1,3	0,5	0,9	1,4	1,0
Missing ratings	7,6	0	5,4	20,0	5,9	12,9	10,1	2,9	8,2	6,6	8,4
Total	100	100	100	100	100,0	100,0	100	100,0	100	100	100,0

There was a moderate relationship between the children from South Africa with ID and the typically developing children from Sweden ($r = 0.39$).

There was a strong correlation between the rank orders of ratings from boys and girls ($r = 0.78$), which suggests that the children in the study selected similar activities as important, regardless of their gender.

The extent to which the Children with ID in South Africa and Sweden used all the Scales for rating Attendance and Involvement

Frequencies of ratings for each point of the Likert scale (Always; Sometimes; Seldom; Never) that measured attendance per item are presented in Table 3. Within the group of the children with ID from South Africa ($n=79$), all four points of the scale were used for all of the 20 activity items. For South African typically developing children ($n=33$), all points on the scale were used for 12 of the items. For three of the items only two scale points were used and for the remaining five three scale points were used.

For the Swedish children with ID ($n=20$), all four points on the scale were used for 17 of the activity items and for one of the remaining items only two points on the scale points were used. For typically developing Swedish children ($n=17$), all scale points were used for 14 activity items. For the remaining six items, only two scale points were used for three of items.

Frequencies of ratings for each point of the Likert scale (Very involved; Somewhat involved; Not or minimally involved) that measures involvement per item are presented in Table 4. Each point of the scale was used for at least one of the three most important activity items

Table 3. Proportion of ratings, item by item, allocated to each grade of the attendance scale for the four subgroups

Activity item in PmP	Children from South Africa (n=112)										Children from Sweden (n=37)									
	With ID (n=79)					With typical development (n=33)					With ID (n=20)					With typical development (n=17)				
	Never (%)	Seldom (%)	Sometimes (%)	Always (%)	Missing (%)	Never (%)	Seldom (%)	Sometimes (%)	Always (%)	Missing (%)	Never (%)	Seldom (%)	Sometimes (%)	Always (%)	Missing (%)	Never (%)	Seldom (%)	Sometimes (%)	Always (%)	Missing (%)
Personal care	2,5	3,8	24,1	62	7,6	0	0	15,2	84,8	0	0	5,0	10,0	85,0	0	5,9	5,9	5,9	82,4	0
Family mealtime	7,6	8,9	29,1	46,8	7,6	0	0	18,2	81,8	0	5,0	5,0	45	45	0	0	0	17,6	82,4	0
My own health	29,1	24,1	17,7	21,5	7,6	12,1	6,1	36,4	45,5	0	15,0	35,0	15,0	35,0	0	23,5	17,6	23,5	17,6	17,6
Gathering supplies	32,9	7,6	22,8	29,1	7,6	27,3	18,2	45,5	9,1	0	15,0	25,0	35,0	20,0	5,0	64,7	17,6	17,6	0	0
Meal preparation	40,5	13,9	22,8	13,9	8,9	9,1	9,1	45,5	33,3	3,0	30,0	35,0	15,0	20,0	0	17,6	47,1	35,3	0	0
Cleaning at home	13,9	20,3	35,4	22,8	7,6	3,0	6,1	69,7	21,2	0	35,0	15,0	20,0	25,0	5,0	11,8	23,5	52,9	11,8	0
Caring for family	13,9	12,7	30,4	35,4	7,6	6,1	18,2	33,3	42,4	0	25,0	10,0	20,0	35,0	10,0	11,8	0	58,8	29,4	0
Caring for animals	32,9	17,7	16,5	25,3	7,6	39,4	9,1	12,1	39,4	0	35,0	20,0	15,0	30,0	0	29,4	11,8	35,3	17,6	5,9
Family time	5,1	8,9	41,8	36,7	7,6	0	9,1	3,0	87,9	0	10,0	20,0	10,0	60,0	0	0	5,9	41,2	52,9	0
Celebrations	11,4	15,2	32,9	32,9	7,6	0	9,1	48,5	42,4	0	0	10,0	15,0	75,0	0	0	0	23,5	76,5	0
Playing with others	16,5	12,7	31,6	31,6	7,6	3,0	15,2	45,5	36,4	0	20,0	10,0	45,0	25,0	0	0	5,9	52,9	41,2	0
Organised leisure	16,5	16,5	30,4	29,1	7,6	12,1	21,2	24,2	42,4	0	35,0	15,0	10,0	40,0	0	5,9	11,8	29,4	52,9	0
Quiet leisure	13,9	16,5	25,3	36,7	7,6	0	6,1	30,3	63,6	0	25,0	40,0	5,0	30,0	0	0	17,6	41,2	41,2	0
Spiritual activities	11,4	20,3	26,6	34,2	7,6	0	6,1	18,2	75,8	0	35,0	40,0	15,0	10,0	0	41,2	5,9	41,2	5,9	5,9
Shopping	15,2	19,0	29,1	29,1	7,6	0	12,1	63,6	24,2	0	25,0	30,0	25,0	15,0	5,0	17,6	41,2	23,5	17,6	0
Social activities	49,4	16,5	15,2	10,1	8,9	24,2	18,2	48,5	9,1	0	35,0	15,0	30,0	10,0	10,0	29,4	41,2	17,6	5,9	5,9
Health centre	15,2	17,7	36,7	22,8	7,6	6,1	24,2	57,6	12,1	0	15,0	30,0	40,0	15,0	0	23,5	47,1	23,5	5,9	0
School	7,6	3,8	29,1	51,9	7,6	0	0	3,0	97,0	0	0	0	20,0	80,0	0	0	0	11,8	88,2	0
Overnight visits	16,5	19,0	34,2	22,8	7,6	3,0	12,1	60,6	24,2	0	10,0	30,0	25,0	35,0	0	11,8	5,9	52,9	29,4	0
Employment	51,9	11,4	15,2	12,7	8,9	66,7	24,2	6,1	3,0	0	25,0	25,0	35,0	15,0	0	35,3	17,6	17,6	23,5	5,9
Total	20,2	14,3	27,3	30,4	7,8	10,6	11,2	34,3	43,8	0,2	19,8	20,8	22,5	35,3	1,8	16,5	16,2	31,2	34,1	2,1

Table 4. Proportion of ratings allocated to each grade of the involvement scale for children with intellectual disability in South Africa and in Sweden

Activities chosen as most important	Children with intellectual disability							
	From South Africa (n=79)				From Sweden (n=20)			
	Not or minimally involved (%)	Somewhat involved (%)	Very involved (%)	Missing (%)	Not or minimally involved (%)	Somewhat involved (%)	Very involved (%)	Missing (%)
Activity 1	1,7	15,0	78,3	5,0	0	35	55	10
Activity 2	6,7	31,7	56,7	5,0	0	30,0	45,0	25,0
Activity 3	8,3	36,7	50,0	5,0	5,0	25	40	30,0
All three (Average)	5,6	27,8	61,7	5,0	1,7	30,0	46,7	21,7

selected by every child for all the subsamples. However, for the Swedish sample, 21.7% of the data were missing.

Discussion

The main findings from this study indicate that the 20 selected activity items of the Picture My Participation instrument are especially relevant and meaningful for children with ID in South Africa, which in this study is representative of a LMIC, as indicated by selection of items and use of scales. None of the children reported additional activities (besides the provided 20 in Picture My Participation) as important. For typically developing children, the relevance of content seemed to be somewhat lower, especially for children from Sweden. However, the findings indicate that the selected activity items may also be relevant for children with ID in Sweden. In both countries, relevance as indicated by the use of all scale points seems to be higher for children with ID than for typically developing children.

The relevance of the 20 selected activity items was analysed by calculating the frequency with which members from all four subgroups selected the 20 activity items of Picture My Participation as important to attend and to be involved in. The fact that all items were selected as important by at least one of the children with ID (n=99), but not by all typically developing children (n=50), indicates that the items may be more relevant and meaningful for the children with ID. The smaller group size for the typically developing children (n=50) might of course be an explanation to why not as many activity items were chosen as important. This smaller group size was motivated by the tendency in earlier research that children with typical development have less variation (in terms of lower standard deviation) in responses when self-rating participation than children with ID, thus a smaller sample is sufficient [29]. Fifty participants is still a relatively high number and was considered sufficient to support the

indication. The content of the 20 activity items selected for Picture My Participation seems to cover essential aspects of everyday activities for the intended target group, and this indicates content validity [7].

This extent of missing data (20%) (i.e. missing observations) may indicate problems regarding the relevance and meaningfulness of the 20 items for the Swedish children with ID [7]. One possible explanation could be that there might be other activities that the Swedish children (i.e. in a high-income setting) with ID consider as more important than the 20 activities included in the Picture My Participation. This argument is supported by the fact that overall, more of the 20 items were selected as important by South African children compared to Swedish children. In addition, South African children used more scale points when they rated the importance of attendance.

When the children selected the activities they perceived as most important to participate in, they were also asked to report if there was any other activity besides the provided 20 that they consider important. They did not report another activity as important, which might indicate that the selected items represented the most relevant activities. However, this result may also have arisen from the methodology that was used to ask for other important activities, because children with ID often have difficulty answering open-ended questions [20]. It is a limitation of this study that other possible important activities were not explored in a manner that fits the target group. One possible way to explore this could be to systematically ask the primary caregiver about other activities that are considered as important for their child.

In this study, all items were explored regarding possible aspects of participation. Some items, e.g. the 'personal care', could be considered as non-complex routines. Even for children with

ID, the expectation is that this activity should be performed often and that it also could be redundant to ask for the importance of e.g. 'personal care'. However, when exploring participation in context it could be better to not make a priori assumptions about the perceived complexity or importance of an activity [30]. Embedded in a context, i.e. being a crucial part of a more complex activity, even the performance of a basic activity such as 'personal care' may be experienced as complex and as more or less important [30]. For all activities that are performed often there is always a risk that the question about importance can be perceived as difficult and/or redundant. Depending on how the children perceive the item, it can also be questioned whether it is the same item or not that is rated. For example 'personal care' may contain activities like going to the bathroom, showering, brushing teeth or doing make up. When exploring the psychometrical aspects of validation, this can of course be considered as a limitation of this study but also as a strength in terms of the usefulness to detect possible participation restrictions [17,30].

The fact that primarily low to moderate rank order correlations between the important items selected by each subgroup of participants supports the notion that the different subgroups might have had different standards or preferences when selecting important activity items. However, the relatively strong relationship between the most important items selected by the two groups of children from South Africa, combined with the low relationship between selected activities for the two groups of children from Sweden (0.18) indicates that country (i.e. coming from a LMIC) is of greater relevance than having an ID (or not) in relation to the level of importance of activities [12,14]. This result provides support for the use of the Picture My Participation instrument in a low income setting. It may also indicate that it is important to further investigate the extent to which participation instruments developed in a high-income setting can be used in LMIC.

In the current study, the selection of activity items as the most important to participate in (i.e. to attend and to be involved in), did however, show greater similarities between the groups of children with ID in the two countries than between the groups of typically developing children in the two countries. This may indicate that the impact of having an ID affects children's participation pattern to such an extent that the relative impact of being in a high- or low-income setting is moderated. In other words, the effect of living in a HIC or LMIC will be less pronounced if the child has an ID.

The study shows that the children with ID from South Africa (n=79) used all four points on the scale when rating attendance for each of the 20 activity items. This implies that all levels of the scale were relevant for this subgroup, and that the participants were able to use the response alternatives in a nuanced manner when they were interviewed with support in the form of graphic symbols. The Swedish children with ID (n=20), however, did not use all the scale points to rate three activities: none of this subgroup selected 'never' or 'seldom' for attending school, celebrations and personal care. This finding could be interpreted as possible indicator of difficulties in using the scales. Alternately, it could indicate that children with ID in Sweden, a high income country, have overall a more assured attendance at these activities. It is also possible that the small sample resulted in a lack of variation in outcome. The fact that the typically developing children in South Africa and in Sweden (to an even larger extent) did not use all the points on the scale, provides some evidence of the potential gap in participation opportunity, as expressed through this measure of 'attendance', between the two subgroups (children with ID and typically developing children) in both countries. At least it shows that most of the 20 items included in Picture My Participation are attended by typically developing children aged 5-17 also in a high income setting (Sweden).

The sample of children with ID in South Africa also used all three levels of the involvement scale when rating each of the three most important activities suggesting the levels were useful in this target subgroup. Although not all levels of the scale were used by children in the other three subgroups for each of the three important activities, each level was used within at least one of the selected activities, supporting the usefulness of the scale. That few children in the other three subgroups used the ‘not involved’ rating might reflect the variation in interpreting why an activity was selected as being important. The instructions are as follows:

Of all of the activities that we have talked about, what are the three activities that are the most important to you? They might be important because you have to do them really often, they might be important because you really love to do them, they might be important because you really want to be able to do them – there are lots of reasons why an activity might be important to you.

The intent of this section of Picture My Participation in practice is to assist in establishing priorities for therapy or education for those with disability. In this study we did not collect ‘involvement’ data for every item which might have provided evidence about the distribution of ratings across the scale for each activity.

Another important finding from this section was the amount and distribution of missing data. There were missing data for 5% of the subgroup of children with ID in South Africa, suggesting the concept may be more difficult to understand for some children. There were no missing data in the subgroup of South African typically developing children, suggesting they had no difficulty in understanding the concept or how to use the scale. However, there were

high levels of missing data in the subgroup of Swedish children with ID (21.7%). This could indicate that a high proportion were not able to understand the concept or had difficulty in using the scale. However, both the Swedish samples had marginally lower levels of disability than the South African sample with ID as measured using the Ten Questions Screen. Another potential explanation might relate to their compliance in data collection. Perhaps this subgroup (those with ID in Sweden) did not find this section of the instrument (selecting three important activities) relevant to them. This might need further exploration. Overall, the findings confirm that the content of the 20 activity items is valid for rating participation, operationalised as attendance and involvement, for children with ID, and especially for children with ID in a LMIC.

The four subgroups of participants differed both in terms of number of participants and in terms of their descriptive characteristics (Table 1). The samples were purposively selected, and the largest sample represented children with ID in South Africa (considered a LMIC). The Swedish children were selected in order to generate knowledge about the instrument, Picture My Participation. In particular, we wished to explore the extent of meaningfulness and usefulness of the 20 activity items and the rating scales and whether the procedures were perceived in the same way as children with ID in LMIC (as in South Africa). The two groups of children from South Africa were selected to obtain knowledge about similarities and differences regarding the meaningfulness and usability of the Picture My Participation for children with and without ID from a similar context. These strategic differences between the samples may be considered both as a strength and a limitation of this study. Larger sample sizes would have been an advantage. Based on the numbers of participants, we did have sufficient data to compare rank order of the South African groups, and to describe how the scales were used in two quite different settings (one LMIC and one HIC). The number of

participants to compare the two Swedish groups is low. Therefore the comparison between children with ID and typical development in Sweden has to be interpreted with caution. In all, we have enough data to provide preliminary evidence of the content validity of the instrument and its relevance to the type of LMIC setting for which it was designed [29].

If Picture My Participation is to be used to compare participation outcomes across settings, between groups (e.g. those with different types of impairments) or as an outcome measure, further research is required to establish internal consistency and structural validity and establish test-retest reliability.

In this study, attendance and involvement are explored separately and not as a combined measure of participation, as suggested by for example Arvidsson et al. [30]. For screening purposes, it may be sufficient to explore the attendance aspect as a prerequisite for being involved [5; 17]. In a public health or a children's rights context, high frequency of attendance may be a preferred outcome of intervention at group level [5,18,30]. However, when applied to individuals in a practical setting, attendance in combination with involvement (i.e. both aspects of participation) may be more relevant to explore [5,30]. In a clinical or individual treatment setting, a combination of attendance and involvement in activities that are perceived as challenging for the individual (that represents a participation restriction), may be the most essential aspect of functioning about which further knowledge should be obtained [30].

Therefore, further studies are required to increase the body of knowledge about the potential of Picture My Participation as a useful clinical instrument for assessing participation by children with disabilities in LMIC. Furthermore, the potential to use of the Picture My Participation for children with various disabilities including children with Cerebral Palsy,

children with Autism Spectrum Disorder and those with long terms health conditions could be investigated.

Limitations

The design of the current study did not make provision for gaining certainty about other key aspects of participation that may not have been covered by the instrument. To overcome this limitation, future research should pose systematic questioning of the participants to identify missing key aspects. The different group sizes are also considered as a limitation of this study since in a larger group the probability for all items to be chosen as important is higher.

Declaration of interest

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