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Adaptation and validation of the Child and Family Follow-up Survey (CFFS) tool to measure participation of children with disabilities in Uganda

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ABSTRACT

Definitions and frameworks from high-income countries dominate tools used to measure impairment level, barriers and enablers to participation of children with disabilities in low-income countries. Disability scholars have argued that multiple perspectives and a different discourse are needed to study disability, participation, and inclusion in low-income countries. We examined the use, reliability, and cultural acceptability of the Child and Family Follow-up Survey's (CFFS) Child and Adolescent Scale of Participation CASP, Child and Adolescent Factors Inventory (CAFI), and the Child and Adolescent Scale of Environment (CASE) scales to measure participation of Ugandan children with disabilities and their peers. The tool testing and adaptation was conducted as part of a pilot and feasibility study of the 'Obuntu bulamu' intervention in five private and five public primary schools. Based on disability type, gender, age, and social class, 32 8-14-year-old children with disabilities were enrolled. The translated Luganda CFFS showed excellent internal consistency with CASE, CASP, and CAFI subscales showing good test re-test reliability. Our consistency and reliability results show the three tools are valid and effective to measure environmental issues, childhood social participation, impairment children with disabilities type and severity from a parental perspective in the Ugandan setting. To ensure more in-depth understanding of child participation in the cultural context, we suggest the CFFS scales are used in combination with qualitative child-inclusive methods such as drawings, participatory workshops, and Photo Voice. The study contributes to the existing literature that there need for more Afrocentric interventions and adaptions and development of culturally relevant measurement tools, which build on African cultural values and practices.

KEY TERMS: *Africa, children, disability, inclusion, participation, measurement, Uganda*

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INTRODUCTION

In many Low- and Middle-Income Countries (LMICs), including those in Africa, approximately one in 20 children under the age of 15 live with a moderate or severe disability. The need for culturally appropriate methods to assess children's levels of engagement in various dimensions of their lives is essential to determine which impairment and environmental variables form barriers and enablers to improve participation. This paper discusses the importance of assessing and measuring participation in culturally relevant everyday activities for children with disabilities to advocate for action and plan interventions to improve their lives. While there are existing measures for participation, there are fewer measures that address the overall construct of participation including various dimensions of a child’s life, and there are no feasible and standardized tools for collecting data on disability and participation as an outcome in the general population. The article also emphasizes the need for cultural adaptation of measures to better capture the construct most relevant for specific settings and communities, especially in low-income countries, where instruments developed in high-income countries may not be applicable. The study tests the use of a culturally adapted version of the Child and Family Follow-up Survey (CFFS) to measure participation of children with disabilities and their peers in Wakiso district in Central Uganda.

BACKGROUND

According to the United Nations Convention on the Rights of Persons with Disabilities, disability is a long-term physical, mental, intellectual, or sensory impairment that, in combination with various barriers, may hinder full and effective participation in society on an equal basis with others (United Nations, 2006). Approximately one in 20 children under 15 years of age live with moderate or severe disability and about 90% of these children live in Low- and Middle-Income Countries (LMICs) (United Nations, 2006). Disabled people worldwide have worse health outcomes, lack access to education, have lower economic participation, and are more likely to be poor (Banks, Kuper, & Polack, 2017; Kuper et al., 2014).

Uganda supports and protects adults and children with disabilities with progressive policies. The 2005 "National Policy on Disability" promotes disability equality. The 2006 "Disability Act" (revised in 2020) helped legalize disability inclusion. The Ministry of Education and Sports created a "Special Needs and Inclusive Education Policy" to encourage special needs students to enrol and graduate. The country recently launched a "Child participation strategy" to increase school enrolment and voice for children with disabilities (Emong & Eron, 2016; Ministry of Gender Labour and Social Development, 2017). These national policies support the UN's Sustainable Development Goals (SDGs) of inclusive education and healthcare for all children and promote participation of children with disabilities in all areas of daily life.

Participation and measuring participation of children with disabilities

In Article 23 of the United Nations Convention on the Rights of Child, States Parties recognize that a mentally or physically disabled child should live a full and decent life in conditions that promote dignity, self-reliance, and community participation. Assessing participation in culturally relevant everyday activities requires assessment instruments (United Nations, 1989). Reliable and detailed data on all aspects of disability are needed to advocate and plan interventions for children with disabilities. Disability and participation data collection in the general population in Uganda is not standardized (Nelson, Masulani-Mwale, Richards, Theobald, & Gladstone, 2017) (Garcia-Ptacek, Dahlrup, Edlund, Wijk, & Eriksdotter, 2019). To our knowledge there are no standardized tools to measure participation of children with a disability in the general population (Coenen, Sabariego, & Cieza, 2016; De Bock et al., 2019). Coster and Khetani (Coster & Khetani, 2008) suggest that without clear definitions, different instruments may be developed that identify as participation measures but have very different definitions of these constructs. Some tools measure participation in one area of daily life, others measure disability-specific participation in children. The CFFS, a parent-report measure originally developed to measure the needs and outcomes of children with traumatic and other acquired brain injuries and their families, developed and tested three measures described below. These tools have successfully been adapted and evaluated for use in children with other conditions and disabilities (Bedell, 2011c) (Bedell).

Cultural adaptation of measures of participation

There is limited information on measures to address the overall construct of participation that includes various dimensions of a child’s life. Participation of children with disabilities in low-income countries has been measured by using instruments which have been developed and validated in high-income countries (HIC). Ratings of participation that use instruments developed in high-income settings may not be as relevant and useful in surveying the participation experiences in everyday activities of children with disability in a LMIC context

(Arvidsson et al., 2020; Chilisa, Major, Gaotlhobogwe, & Mokgolodi, 2015). 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 LMIC (Rainey, van Nispen, van der Zee, & van Rens, 2014).

Gaotlhobogwe (Gaotlhobogwe, Major, Koloi-Keaikitse, & Chilisa, 2018) mentions paradigms and theories from the Global North have been imposed on African researchers. African communities have been studied "on," "for," and "about," but rarely "with" or "by". Each community and indigenous group have different values and beliefs and tools need to be adapted and validated to ensure they are culturally appropriate for the population under study. Abessa (2016) stated Africans must create evaluation tools that are culturally relevant and reflect African worldviews (Abessa et al., 2016). For more meaningful and culturally accepted data, Owusu (2013) recommends using African knowledge and research methods (Owusu-Ansah & Mji, 2013). We must adapt or develop new tools to measure participation in African settings to better capture African constructs of participation. The tools from the HIC are a good resource but directly using them for settings like Uganda may not always be applicable, due to classroom and environmental setting, limited skills and human resource in working with children with disabilities, low-income levels etc. (Bannink Mbazzi et al., 2020), and therefore most of the tools require adaptation to fit the setting.

In this study we tested the use, reliability, and internal consistency of a culturally adapted version of the CFFS to measure participation of children with disabilities and their peers in Wakiso district, Central Uganda. The aims were to culturally adapt the CFFS for use in Central Uganda, test its validity and internal consistency, and compare participation of children with disabilities and their peers.

Obuntu bulamu: An African intervention model

Obuntu bulamu is a Luganda term for an accepted and consistent behaviour that signifies a shared set of values, which promote well-being, togetherness and unity (Karlström, 1996; Otiso, 2006). It is part of the Ubuntu philosophy, which has been described as a key component of African disability discourse (Chataika & McKenzie, 2013).

The '*Obuntu bulamu'* study is described elsewhere by Bannink-Mbazzi et al (2020) and explores African concepts of disability and inclusion with an emphasis on belonging and family and community responsibilities. The intervention was developed and tested with children with disabilities, parents, teachers, academics, health and rehabilitation workers and community and district leaders in Uganda (Bannink Mbazzi et al., 2020). The study described in this paper is part of the larger '*Obuntu bulamu'* cross-sectional and intervention study.

The '*Obuntu bulamu'* intervention promotes social responsibility, use of culturally appropriate methods and locally available curricula and materials to achieve change. The overall study hypotheses are that the intervention will result in the following outcomes:

1. Improve inclusion and participation in school, resulting in increased education access, retention and learning outcomes of children with disabilities, classroom and playtime interaction of children with disabilities, their peers and teachers, as well as inclusive teaching methods and attitudes used by teachers.
2. Increase inclusion in the home, resulting in increased participation in daily living activities and home interactions between household members and children with disabilities.
3. Improve inclusion in community activities, leading to improved attitudes of community members towards children with disabilities and increased participation of children with disabilities in community activities.
4. Improve participation of children with disabilities and their families in research, including in data collection, interpretation of findings and dissemination of results.
5. Improve quality of life for children with disabilities.

This study focused on finding a standardized tool and culturally adopting it to measure the first 3 outcomes on participation in the home, school, and community, in addition to qualitative tools utilized in the study.

METHODOLOGY

Study population

The 2017–2019 the '*Obuntu bulamu'* study in Wakiso district in Central Uganda piloted a one-year intervention in 10 primary schools that included training and peer-to-peer support for teachers, parents, and children. The CFFS measured participation of children with disabilities and their peers and assessed the type and severity of impairments and problems with physical, social, and attitudinal environment features before and after the intervention. 32 children with disabilities aged 8-14 from the 10 sampled study schools selected a classmate to participate in the intervention. The reliability and internal consistency of the CFFS were assessed using data on the 32 children with disabilities and their 32 peers enrolled in the study.

Table 1a and 1b describe the children and parents' socio-demographic and impairment characteristics.

Table 1a. Socio-demographic characteristics of children participating in the study (n=64)

Variable	**level**	**Children with disabilities (n=32)**	**Peers (n=32)**
Age-child	Mean SD range	10.5 2.05 08-15	9.34 1.84 07-14
Gender-child	Female Male	18 (51.43%) 14 (48.28%)	17 (48.57 %) 15 (51.72 %)
Class-child	Nursery school P.1 P.2 P.3 P.4 P.5 P.6 Step up class	2 (6.25%) 2 (6.25%) 10 (31.25%) 7 (21.88%) 2 (6.25%) 2 (6.25%) 4 (12.50%) 3 (9.38%)	2 (6.25%) 1 (3.13%) 11 (34.38%) 8 (25.00%) 2 (6.25%) 2 (6.25%) 4 (12.50%) 2 (6.25%)
Disability-child	Autism Spectrum Disorder Down Syndrome Hearing impairment Hydrocephalus Intellectual disability Muscular dystrophy Physical disability Spina bifida Visual impairment	4 (12.50%) 2 (6.25%) 4 (12.50%) 4 (12.50%) 8 (25.00%) 2 (6.25%) 1 (3.13%) 4 (12.50%) 3 (9.38%)	0 0 (20.00%, n=1/5) 0 0 0 (60.00%, n=3/5) 0 (20.00%, n=1/5)
Mode of communication-child	Non-verbal gestures Verbal speech (1-2-word phrases) Verbal speech (full sentence)	3 (11.11%) 7 (25.93%) 17 (62.96%)	12 (8.33%) 1 (8.33%) 10 (83.33%)
Use of assistive devices-child	Walking Crawling Assistive devices	21 (77.78%) 1 (3.70%) 5 (18.52%)	12 (100%) 0 0

Compared to children without impairments, 26 (81.82%) of the children with disabilities used walking as a mode of mobility.

Table 1b. Socio-demographic characteristics of parents who participated in the study (n=64)

Variable	**Level**	**Parents of children with disabilities (n=33)**	**Parents of peers (n=31)**	**Total n (%)**
Gender	Female	31 (93.94%)	26 (83.87%)	57(89.06%)
	Male	2 (6.06%)	5 (16.13%)	7(10.94%)
Age	Under 35	14 (42.42%)	12 (38.71%)	26(40.63%)
	35-50yrs	16 (48.48%)	13 (41.94%)	29(45.31%)
	51yrs and above	3 (9.09%)	6 (19.35%)	9(14.06%)
Marital Status	Married	19 (57.58%)	16 (51.61%)	35(54.69%)
	Separated	10 (30.30%)	7 (22.58%)	17(26.56%)
	Single	1 (3.03%)	5 (16.13%)	6(9.38%)
	Widowed	3 (9.09%)	3 (9.68%)	6(9.38%)
Average net income (monthly)	<50 USD	25 (75.76%)	25 (80.65%)	50(78.13%)

	50 – 100 USD	6 (18.18%)	1 (3.23%)	7(10.94%)
	101 – 150 USD	1 (3.03%)	4 (12.90%)	5(7.81%)
	>150 USD	1 (3.03%)	1 (3.23%)	2 (3.13%)
House ownership	Owned	13 (39.39%)	13 (41.94%)	26(40.63%)
	Relatives	2 (6.06%)	0	2(3.13%)
	Rented	18 (54.55%)	18 (58.06%)	36(56.25%)
Occupation	Homemaker	13 (39.39%)	1 (3.23%)	14 (21.88)
	Self employed	12 (36.36%)	14 (45.16%)	26 (40.63%)
	Unemployed	2 (6.06%)	7 (22.58)	9 (14.06%)
	Formal employment	6 (18.18%)	9 (29.03%)	15 (23.44%)

The average household size for children with disabilities was 5 members, and 6 for peers. Most parents had attained primary education level, with only a few having gone up to university level. The education level was slightly higher for parents of children with disabilities, with 54.6% having completed secondary school compared to 45.5% of peers. 27 parents reported that not all their age-going children attend school, with parents of peers being a larger number at 59.26% compared to parents of children with disabilities at 40.74%.

Adaptations of the CASP, CAFI & CASE tools before testing

CASP, CAFI & CASE are standard tools part of the larger CFFS that individually access different aspects. Bedell (2011c) the primary author of CFFS describes CASP as a tool that measures children and adolescent's extent of participation and restrictions in home, school and community life situations and activities compared to same-age peers as reported by a parent or caregiver. The CASP consists of 20 items divided into 5 subsections and rated on a four-point scale. The 5 subsections are 1) Home Participation (6 items), 2) Community Participation (4 items), 3) School Participation (5 items), and 4) Home and Community Living Activities (5 items). The 20 items are rated on a four-point scale: "(4=*Full participation*)," "3=Somewhat Limited," "2=Very Limited," "1=Unable." A "Not Applicable" response is selected when the item reflects an activity in which the child would not be expected to participate. The CASP also included and open-ended 4 questions that asked about things that interfere and help with children participation, changes made to the children's homes, schools, communities like rearranging furniture and building a ramp. It also asked about the assistive devices or equipment that children use to help them participate. The CAFI consists of a list of 15 potential problems that the child may be experiencing because of his or her diagnosis or condition related to health and cognitive, psychological, physical and sensory functioning. Each item or problem is rated on a 3-point ordinal scale: 1) No problem; 2) Little problem; 3). CASE has 18 items that ask parents/guardians about the impact of problems experienced and is rated on a 3-point scale. Each CASE item or problem is rated on a 3-point ordinal scale: 1) No problem; 2) Little problem; 3) Big problem. There is a "non-applicable" response as well. For example, the items referring to school or work would not be applicable for those not attending school, or a structured program or work setting). Prior to using the tools, all 3 tools were analysed by the research team to check if any of the items needed adaption or replacement at the development phase for use in the *obuntu bulamu* study. Ugandan social scientists translated the tools from English to Luganda, the language most spoken in Central Uganda. An English-Luganda-speaking social scientist at the MRC/UVRI & LSHTM Uganda Research Unit reviewed the preliminary translation and concluded the questionnaire's goal and item intent were clear. An independent social scientist who had not seen the original questionnaire translated it back into English.

The cross-language equivalent was assessed by giving the original English and translated Luganda versions to 10 participants—5 parents and 5 children—who understood both languages. 95% responded similarly. Due to cultural differences and results from piloting, changes in the questionnaire's wording and other elements were made to better suit the Ugandan setting.

For CASP, the following items were replaced, paraphrased or restructured. Item 2, 'social, play or leisure activities with friends at home (can include conversations on the phone or internet) was modified: 'can include conversations on the phone or internet' was removed because most children in Ugandan do not have a phone or access to internet. Item 3 'Family chores, responsibilities and decisions at home *(For younger children* this may be getting things or putting things away when asked or helping with small parts of household chores; *For older children* this may be more involvement in household chores and decisions about family activities and plans)' was simplified to 'Family chores, responsibilities and decisions at home (e.g., involvement in household chores and decisions about plans') as all children have household responsibilities in the Ugandan setting but are not necessarily involved in decision making. Item 6 'Communicating with other children and adults at home was paraphrased to ‘Communicating with others at home’ as households often exist of extended family members who are not necessarily categorized by age but rather by role. Item 7, ‘Social, play, or leisure activities with friends in the neighbourhood and community (e.g., casual games, “hanging out,” going to public places like a movie theatre, park or restaurant)’ was modified to ‘Social, play, or leisure activities with friends in the neighbourhood and community (e.g., casual games, “hanging out,” going to public places like the market, or church)’. Children in our setting would rarely visit a cinema, park or restaurant, yet they do frequently visit markets and churches with peers. The ‘home and community living activities’ section was changed to ‘daily living activities. The last item: 20 was modified from ‘Work activities and responsibilities (e.g., completion of work tasks, punctuality, attendance and getting along with supervisors and co-workers)’ to ‘School activities and responsibilities (e.g., completion of tasks, punctuality, attendance and getting along with teachers)’ to fit the study population which comprises of primary school children. Unlike the CASP, none of the 15 CAFI items and 18 CASE items were modified prior to and after the baseline data collection.

English is Uganda's official language, but few people speak it fluently. After testing the tools, we kept English and Luganda version and offered to use either in the participant's preferred language.

Data collection

Two female research assistants with experience collecting quantitative and qualitative disability data for regional social science research projects collected the data. Data were collected at baseline and endline (one year after intervention).

Data analysis

Descriptive statistics [mean (M), standard deviation (SD), frequency and ranges] of the CASP, CAFI and CASE parent report were used to examine demographics. Computation of CASP, CAFI, and CASE scores by parents of children with disabilities and peers was made (Bedell, 2011a, 2011b).

Internal consistency of the three tools was determined by computing Cronbach’s alpha. Test re-test reliability was tested using Interclass Correlation coefficient. For the CASP, a higher score indicates a better level of functioning, whereas for the CAFI and CASE a lower score indicates a better level of functioning. Pearson correlation was computed to investigate the test-retest reliability of the CFFS, using the total scores of the CASP, CAFI and CASE at both phases. Principal Component Analysis was done using the baseline data to determine the internal structure. Factorability of items was examined by the Bartlett test of sphericity and the Kaiser–Meyer–Olkin measure of sampling adequacy. The number of factors was determined by a screen test and eigenvalues greater than 1. To determine whether there is a statistically significant difference between the means of the children with disabilities and their peers without disabilities, as well as to determine any changes in scores before and after the intervention, a t-test analysis was carried out.

RESULTS

At baseline and endline, the Luganda-adapted CASP and CAFI had good internal consistency of 0.97 and 0.89. Both baseline (0.91) and endline CASE internal consistency was good (0.77). At baseline, daily activities, school, community participation, and home participation all had good reliability. CASE and CASP had excellent test-retest reliability (Interclass correlation coefficient = 0.97 and 0.90, respectively), while CAFI had good reliability (0.87). Only three factors (12.70, 1.91, and 1.29) had eigenvalues greater than one in CASP's principal component analyses, but Kaiser's rule required them to be retained. The three CASP factors—household activities (8%), school: communication (11%), and home: mobility (12%)—accounted for 80% of the variance and had low unexplained variance. The youth report version of the Child and Adolescent Scale of Participation (CASP): assessment of psychometric properties and comparison with parent report by McDougall yielded similar results [37]. Kaiser–Meyer–Olkin measure of adequacy of 0.76 and Bartlett test of sphericity ($p < .001$) for the 20 CASP items. The CAFI showed 4 factor loadings with eigenvalues greater than one (6.24, 1.78, 1.71, and 1.07) that explained 72% of data variations with a Kaiser–Meyer–Olkin measure of.812 and a significant Bartlett test of sphericity ($p < .001$). Kaiser–Meyer–Olkin measure of adequacy 0.731 and Bartlett test of sphericity ($p < .001$) for the 18 CASE questions. 5 factor loadings with eigenvalues over one explained 78% of data variations. CASE items had low unexplained variation, with 42% the largest.

Table 2a: Participation scores of children with disabilities and their peers at baseline and endline

Participation scores	**Item**	**Baseline**			**Endline**		
		Children with disabilities Mean (SD)	**Peers Mean (SD)**	**t-score**	**Children with disabilities Mean (SD)**	**Peers Mean (SD)**	**t-score**
Total		73.45 (16.48)	96.98 (6.81)	-7.38***	76.82 (15.30)	95.91 (7.60)	-6.09***
Home		80.67 (15.69)	97.57 (6.00)	-5.62***	81.44 (14.76)	96.84 (6.55)	-5.18***
	1. Social, play, leisure with family members	3.30 (0.81)	3.94 (0.25)	-4.17***	3.33 (0.82)	3.90 (0.31)	-3.50***
	2. Social, play, leisure with friends	3.27 (0.80)	3.94 (0.25)	-4.41***	3.33 (0.69)	3.90 (0.31)	-4.04 ***
	3. Family chores	2.52 (0.87)	3.71 (0.94)	-6.58***	2.58 (0.71)	3.76 (0.44)	-7.79***
	4. Self-care activities	3.33 (0.96)	3.90 (0.40)	3.07**	3.18 (0.92)	3.86 (0.35)	-3.76***
	5. Moving around	3.64 (0.74)	4.00 (0)	2.73**	3.61 (0.66)	3.97 (0.19)	-2.84**
	6. Communicating with others	3.30 (0.92)	3.94 (0.25)	-3.71***	3.52 (0.67)	3.86 (0.44)	-2.38*
Community		76.70 (18.96)	98.59 (4.76)	-6.24***	77.46 (18.75)	96.98 (7.01)	-5.29***
	7. Social, play, leisure with friends	3.18 (0.85)	3.94 (0.25)	-4.77***	2.97 (0.85)	3.86 (0.35)	-5.28***
	8. Structured events	2.85 (1.03)	3.94 (0.25)	-5.69***	2.85 (0.94)	3.83 (0.38)	-5.24***
	9. Moving around	2.97 (0.92)	4.00 (0)	-6.24***	3.12 (0.93)	3.93 (0.26)	-4.55***
	10. Communicating with others	3.27 (0.94)	3.90 (0.30)	-3.55***	3.45 (0.79)	3.90 (0.41)	-2.70**
School		61.36 (15.17)	78.87 (3.81)	-6.24***	82.73 (14.15)	97.07 (6.62)	-5.00***
	11. Educational activities with other pupils	2.76 (0.97)	3.81 (0.48)	-5.44***	3.03 (0.77)	3.79 (0.41)	-4.77***
	12. Social, play & recreational activities with other pupils	2.97 (0.88)	3.97 (0.18)	-6.17***	3.00 (0.75)	3.86 (0.35)	-5.66***
	13. Moving around at school	3.45 (0.79)	3.97 (0.18)	-3.51***	3.55 (0.71)	4.00 (0)	-3.44**
	14. Using educational materials	3.18 (1.01)	3.97 (0.18)	-4.25***	3.39 (0.70)	3.90 (0.31)	-3.55***
	15. Communicating with pupils and adults	3.24 (0.90)	3.94 (0.25)	-4.13***	3.58 (0.71)	3.86 (0.44)	-1.88
Daily activities		61.36 (15.17)	78.87 (3.81)	-6.24***	64.85 (19.66)	92.76 (12.29)	-6.59***
	16. Household activities	2.36 (0.96)	3.71 (0.59)	-6.70***	2.48 (1.00)	3.59 (0.63)	-5.09***
	17. Shopping and managing money	1.81 (1.00)	3.52 (0.72)	-7.73***	1.94 (0.79)	3.48 (0.78)	-7.71***
	18. Managing daily activities	2.39 (0.90)	3.90 (0.40)	-8.59***	2.61 (0.97)	3.76 (0.64)	-5.47***
	19. Using transportation to get around	2.33 (1.11)	3.71 (0.69)	-5.91***	3.06 (0.93)	3.90 (0.31)	-4.60***
	20. School activities and responsibilities	2.67 (0.99)	3.90 (0.40)	-6.48***	2.88 (0.89)	3.83 (0.47)	-5.13***

***p<0.001, **p<0.01, *p<0.05

Children with disabilities generally scored lower on participation than their peers without disabilities. From the baseline before the *Obuntu bulamu* intervention to the endline following the intervention, it was seen that the overall participation scores had increased in children with disabilities. Participation scores in school significantly increased after the intervention in both children with disabilities and their peers. The baseline mean participation scores were 69.84 (SD 14.20), and the endline mean participation scores were 89.44 (SD 13.31), with a mean difference of -19.59 (95% CI: -24.45- -14.74) and p<0.001. The outcomes show that the intervention significantly improved the involvement scores of children with impairments. After the intervention, the scores generally rose, indicating that their levels of participation had improved.

DISCUSSION

Measuring the participation of children with impairments is a crucial first step in achieving their inclusion in all aspects of daily life. Since sociocultural contexts have an impact on participation and involvement, instruments used to measure children's participation should take culture into consideration. The instruments ought to have good psychometric validity. Even though most participation measurement tools developed in western cultural contexts are psychometrically valid, using them with African children may not be culturally appropriate. Many agree that culturally relevant participation assessment tools should be either created or adapted from tools developed in other cultures (Nampijja et al., 2010) (Gladstone et al., 2008). Adapting an existing tool is less expensive and more suitable to maintain construct validity of a tool across different settings.

The study addressed gaps in the literature concerning the lack of culturally appropriate Afrocentric tools to measure participation of children with disabilities. The translated and adapted CFFS and mainly the CASP measures participation of children with and without disabilities in the "*Obuntu bulamu*" study. Through peer-to-peer support, the "*Obuntu bulamu*" study sought to adapt the CFFS tool to the Ugandan setting to improve children with disabilities inclusion at school, family, community, and quality of life in Uganda.

Overall, there was evidence that the adapted tools were culturally appropriate, and reliable for measuring the extent to which children participate in home, school, community and daily activities compared to children of the same age as reported by their caregivers.

The CASE showed good levels of reliability in assessing children with disabilities environmental difficulties in Uganda, with good internal consistency and test-retest reliability. The authors previously found an internal consistence of 0.91 and an ICC of 0.75 for all items (Bedell & McDougall, 2015), not different from this study's results.

The study found that CASP accurately measures Ugandan children's social involvement as its initial objectives stated by the tool author. The study's results confirm the CAFI's reliability and validity for determining the type and degree of impairment in children with disabilities in Uganda.

There are some limitations of the study. First, the reliability and validity data reported are only preliminary given the limited sample size and unequal male-female parent distribution. To test these tools and generalize the results, a larger sample with roughly equal numbers of male and female parents is recommended. In addition, there was no child measure inform of a youth/child report tool which makes it hard to compare what parents report and what the children themselves think/say. What is presented in the findings is only what parents of these children think of participation of their children. A youth version of the CASP (CASP-Y) should be considered in the future research projects to gain children's perspectives about their own participation (McDougall, Bedell, & Wright, 2013). Much as parents are important observers of their children (Morrow, Hayen, Quine, Scheinberg, & Craig, 2012), the addition of supplement for an outside family member like a teacher or colleague or friend, to get a more comprehensive impression of the functioning of the child would be useful (Galvin, Froude, & McAleer, 2010).

There are several strengths of the study. The study followed recommendations for cultural adaptation in the literature. The use of bilingual social scientist to translate the tools from English to Luganda and, a commonly spoken language in the central Uganda where the study participants stayed was essential for clarifying confusing questions or response items. Also using an independent social scientist who had not seen the original questionnaire to translate it back into English was helpful in putting questions in context. This cultural understanding was necessary to produce valid and reliable measures. Testing the internal consistence and validity of the data on two time points also gives solid evidence of cultural appropriateness.

RECOMMENDATIONS

CFFS is a helpful tool to quantitatively measure participation from parents' perspectives. We recommend that in addition, teachers and children's tools are developed and combined with qualitative study methods to measure participation in our context. When studying the inclusion of children with disabilities, a mixed method design, integrating qualitative and quantitative information in form of drawings and Photo Voice is recommended to give voice to the different groups. Our pilot study used drawings, children's workshops, and Photo voice alongside the

CFFS. Children were given instant cameras to take photos and were followed up at home and in school by a member of the research team. The children received instructions for taking photos of their daily lives: what is important to them, what they enjoy, and what they dislike or find difficult. Results of this component of the study will be reported elsewhere.

CONCLUSION

From this study, it could be said, the CASE, CASP, and CAFI are reliable and useful tools for evaluating environmental issues faced by children with disabilities, measuring social participation in childhood, and determining the type and degree of impairment in children and young people with disabilities in the Ugandan context from a parent's perspective. The CCFS scores also showed the '*Obuntu bulamu*' intervention has the potential to improve participation in education. We recommend utilizing the tools in conjunction with qualitative data collection techniques such as use of drawings, children-friendly workshops, and Photo Voice that allow for children inclusion and cultural sensitivity.

DECLARATIONS

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Conflicts of Interest

The authors declare no conflict of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

Ethics approval and consent to participate

The Uganda Virus Research Institute Research Ethics Committee in Entebbe (GC/127/19/01/633) and the Ghent University Faculty of Psychology and Educational Sciences approved this research (Ref: Bannink/2017). Every adult participant gave written informed consent to the visual narrative drawing, photo, and film activities and the public dissemination of results. When possible, children assented and parents gave consent. The Uganda National Council for Science and Technology authorized the study. (HS SS 4557).

Authors' contributions

With assistance from the unit statisticians, CN created the study data capture tools, carried out the statistical analysis, and wrote the manuscript. ESK collected the data and participated in the manuscript's writing. JS took part in the planning of the study, the writing of the paper, and general support for the study's execution. The research was planned, implemented, and supported by FBM, who also helped with the data analysis and manuscript drafting processes. Drafts and the final manuscript were critically reviewed and approved by all authors.

Data Availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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