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Acceptability, feasibility and preliminary evaluation of the WHO caregiver skills training for children with developmental disabilities in rural and urban Kenya

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ABSTRACT

Background Interventions to improve the developmental outcomes of children with developmental disabilities (DDs) in low-resourced settings such as Kenya are limited. The WHO caregiver skills training (CST) was developed to address social and communication needs of children with DDs through caregiver-mediated engagement strategies. This study investigated CST's acceptability, feasibility and evaluated its effect on behavioural, communication and quality of life outcomes for children with DDs and their caregivers in Kenya.

Methods The settings were rural Kilifi and Korogocho informal settlement in Nairobi, Kenya. A sequential mixed-methods design consisting of three phases. First, CST materials translation to Swahili, stakeholder consultations and pretesting the adapted CST with caregivers. A pilot with 90 caregivers randomly assigned to the CST or non-CST arm followed. Postintervention discussions with caregivers explored CST's acceptability. Quantitative data were analysed using descriptive statistics and tests of associations. Qualitative data were analysed using thematic analysis.

Results The adapted Swahili CST materials were found acceptable. Stakeholders reflected on the appropriateness, potential barriers and recommended approaches to improve CST. CST's perceived benefits were increased awareness of DDs and support resources, and stigma management. Overall, 86% of caregivers attended two-thirds of CST sessions, though non-attendance was mostly recorded in informal settings. CST's preliminary evaluation suggested improved scores on child and caregiver outcomes.

Conclusion WHO CST is a 'promising' intervention that needs adaptations and serves the needs of families of children with DDs in Kenya. Future studies evaluating CST's efficacy and feasibility for scale-up in health, education and community-based systems are needed.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ In 2016, the WHO caregiver skills training (CST) was launched to address the needs of children with developmental delays and disabilities, in low-resourced settings where specialist services are lacking.

WHAT THIS STUDY ADDS

⇒ This study was among the earlier global field studies to evaluate the acceptability and feasibility of the CST, in rural and urban Kenya settings, delivered using trained non-specialist facilitators.

⇒ CST adaptations process in Kenya involved the review of materials by a diverse stakeholder group, pretesting the CST with literate and low literacy caregivers and preliminary evaluation of the CST in a pilot, to assess the effect on child and caregiver outcomes.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The CST is a 'promising' intervention, with adaptation, that has the potential for scalability in health, education and community-based settings.

INTRODUCTION

The global burden of disability study and the WHO 2023 report estimates 52.9 million children have a developmental disability (DD) worldwide.[1 2] Sub-Saharan Africa estimates are particularly concerning, with the number of children with disabilities increasing at least threefold to 14.7 million between 1990 and 2016.[1] There is a growing concern regarding the quality of life of these children, which stems from the fact that there are limited services and professionals to address the needs of children with DDs.[3] Behavioural and communication problems occur in over half of the children with DDs.[4] Caregivers of children with DDs experience stigma,[5] parenting difficulties[4] and poor health,[6] adding to the increased socioeconomic burden for families.

Interventions to improve the behaviour and communication of children with DDs are available in resource-rich settings for

conditions such as autism and are intensive, requiring time to administer and train specialists/therapists.[7] There are limited studies conducted in low-resource settings on trialled interventions intended to improve behaviour and communication in children with DDs, and ultimately improve their quality of life.[8 9] As part of the WHO Mental Health Gap Action Programme, the caregiver skills training (CST) is a recommended caregiver-mediated intervention for children with developmental delays and disabilities.[10] CST has two distinct features. First, the intervention takes a task-sharing approach where trained and supervised non-specialists including social workers, nurses, teachers, community volunteers and experienced caregivers/parents can deliver the intervention.[11] Second, through a transdiagnostic approach, it addresses a range of DDs and a diagnosis from an expert/doctor is not required.[10]

Following the launch of the CST field test version in 2016, there was a call for field studies across the globe to assess its feasibility and acceptability in diverse geographical settings. In the Ethiopian pilot, caregivers and stakeholders recommended adaptations to the CST field test materials,[12] recorded excellent participation (100%) and retention (90%),[13] and found CST feasible and acceptable to implement.[12] Studies in Hong Kong,[14] India,[15] Italy,[16 17] Pakistan,[18] Serbia[19] and Taiwan[20] provide initial evidence that with recommended adaptations,[21] the CST may provide relatively less costly and scalable interventions for families of children with DDs in low-resource settings.

Building on the evidence base on CST's potential utility, this study set out to evaluate the extent to which CST could be implemented in rural and urban settings in Kenya. The aim was to investigate if a parental/caregiver-based intervention improves behaviour, communication and quality of life of children with DDs and their families. Specific objectives were to:

1. Adapt the WHO CST materials to make them contextually relevant in rural and urban settings of Kenya.
2. Examine the acceptability of implementing CST in rural and urban settings in Kenya.
3. Evaluate the preliminary efficacy and feasibility of CST.

METHODS

Study context

This study was conducted in two Kenyan settings between 2017 and 2018. Kilifi County is a rural region along the Kenyan Coast, and the fifth poorest county in Kenya.[22] Residents are predominantly the Mijikenda ethnic group, literacy levels are low (45%) and have the lowest socioeconomic status (55%), with an average per person monthly income of 700 Kenyan Shillings (US$7).[23] In Nairobi, the study was based in Korogocho informal settlement, where the African Population Health Research Center has an established demographic surveillance system.[24] Korogocho is the fourth largest informal settlement in Nairobi, approximately 12 km from the capital city, covering an area of 0.97 km^2, with over 250 dwelling units per hectare.[24 25]

Study design

A sequential mixed-methods study,[26] implemented in three phases (figure 1). Phase one included translation of CST materials, stakeholder consultations and prepilot with the aim of making context-relevant modifications. Phase two was a preliminary evaluation of the Kenyan adaptation of CST through a pilot. Phase three was a qualitative evaluation of the CST to assess its feasibility, acceptability and relevance. Data were collected between 2017 and 2018. The study adheres to the Consolidated Standards of Reporting Trials 2010 checklist for reporting a pilot or feasibility trial (online supplemental file 1).

Sampling and data collection procedures

Phase one: CST material adaptation

CST materials translation

Seven bilingual research members translated the English CST facilitator and participant guides to Swahili. The translation process followed the recommended WHO CST adaptation and implementation guide.[21] Due to the content-heavy nature of the CST facilitator and participant guides, we only conducted a forward translation

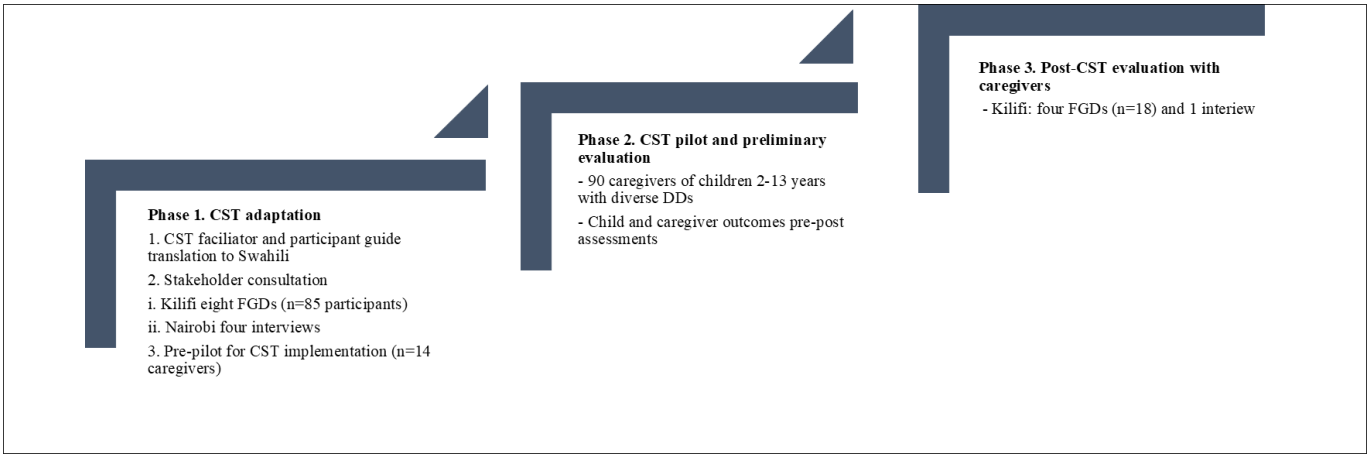

Figure 1 Sequential mixed-methods approach.

from English to Swahili and supplemented it with a rigorous expert panel review and harmonisation process. The expert panel included psychologists, special education professionals, clinicians and the original translation team and used a consensus-based approach in the harmonisation of translated materials to ensure accuracy and contextual relevance. The entire translation phase was supervised by the first author (AA).

Stakeholder consultations

Stakeholders were engaged to review CST translated materials and provide feedback on its feasibility, acceptability and contextual relevance for Kenya. In Kilifi, eight focus group discussions (FGDs) were conducted with a total of 85 participants. These included six caregiver FGDs (n=51) and two stakeholder FGDs (n=34), each comprising six to eight participants. In Nairobi, four in-depth interviews (IDIs) were conducted due to the challenges of mobilising stakeholders for an FGD.

The 51 caregivers who participated in the FGDs had children aged 2–13 years with various developmental disabilities (DDs), all with prior formal diagnosis. They were selected using simple random sampling from special schools, KEMRI/Wellcome Trust study databases and through non-governmental organisations registries (Nairobi only). The 34 stakeholders were recruited using snowballing techniques and represented special schools, health facilities, local administrative offices and higher educational institutions.

CST team preparedness and CST prepilot

A WHO CST international trainer (LP) conducted a 5-day training in Kilifi for eight Kenya team members prior to CST implementation. The team included four non-specialist facilitators (NSFs) and four research staff, with backgrounds in nursing, education, development studies and prior working experience in disabilities. A competency assessment for NSFs while delivering CST followed.

14 caregivers of children with prior formal diagnoses of DDs were invited to participate in the CST prepilot. Based on feedback from stakeholder consultations, these caregivers were placed in two groups (literate and low literacy in the language of instruction). After every CST session, caregivers provided qualitative feedback on CST sessions and CST materials' comprehensibility and appropriateness for caregivers with low literacy. This phase served as an additional validation step, using participants' feedback to identify and refine any unclear or culturally inappropriate content.

Phase two: CST pilot and preliminary evaluation

A stratified random sampling approach was used. The inclusion criteria required that participants be caregivers of a child with DD and reside in the same household during CST intervention. As this was a pilot study, no formal sample size calculations were performed, but the number of participants was guided by earlier studies. A sample size of 28 was deemed suitable to record effects on child behaviour outcomes.[27] A review on Triple P positive parenting programme efficacy reported an average sample of 31 in the included studies.[27] With this consideration, we settled for a sample of 100 (50 per arm) to account for attrition and generate information for future research.

Using existing databases from studies conducted in Kilifi and Nairobi, children were stratified by type of DDs and each stratum comprising 10 families. A computer-generated simple randomisation method was used to allocate participants to study arms. For logistical considerations, families in Kilifi were allocated to CST groups closest to their residence postrandomisation. Families received three home visits and attended nine group sessions held in a central community location.

Study measures and data collection procedures

Pre–post assessment measures included caregiver-reported measures on children's communication ability and behavioural patterns, and caregiver self-report measures assessing caregivers' mental health, quality of life and functioning.

The *Child Behaviour Checklist (CBCL)*[28] is a widely used parent report measure for detecting emotional, social and behavioural problems in children, and validated for use in Kilifi.[29] *The Patient Health Questionnaire-9 (PHQ-9)* is a severity measure for depression in adults and validated for use in the Kenyan context.[30] The 9-item tool has a 4-point scale from 0=not at all to 3=almost every day, where parents report the extent to which each item has been a problem in the previous week. The *Pediatric Quality of Life* (*PedsQL*) Family Impact module[31] is a measure of the impact of paediatric chronic health outcomes on the family's physical, social, emotional and cognitive functioning, communication and worries. The *Parental Stress Index*[32] is a tool used to measure stress among parents. It is an 18-item tool on a 5-point scale ranging from 1=strongly disagree to 5=strongly agree, where caregivers are required to rate the extent of agreement with statements describing feelings about their parenting experiences.

Phase three: ost-CST qualitative evaluation

Caregiver interviews explored experiences with the intervention, a month after CST. 25 caregivers were contacted and 19 were available to participate in FGDs (n=3; 18 caregivers) and one interview. Data were primarily collected in Kilifi, and discussions were moderated by the first author (AA), with no prior contact with CST participants.

Data management and analysis

Data were collected electronically in tablets using the Research Electronic Data Capture platform. Quality checks included manual checks, double-entry and verification, and the cleaned data analysed in Stata. Frequency tables were used to summarise CST session attendance.

Descriptive statistics were used to compare characteristics of caregivers in the study arms. Tests of associations and per-protocol analysis were done to compare outcomes between study arms and time points.

Audio files were transcribed verbatim. A thematic analysis approach[33] was used to analyse qualitative data in study phases one and three and managed using NVivo software. The analysis included data familiarisation, codebook development (inductive and deductive approaches), coding, combining codes into categories and themes, interpretation and presentation of findings.

Patient and public involvement

Overall, 85 caregivers and stakeholders participated in various consultations that informed the further adaptation of the CST materials and provided insightful feedback on its implementation.

RESULTS

This section integrates findings from various study phases. First, an overarching summary of the Swahili CST adaptations is presented. This is followed by findings from the CST pilot and preliminary evaluation of outcomes studied in phase two. The last section features caregivers' experiences and perceived acceptability and feasibility of CST.

Stakeholders' consultations and recommended CST adaptations

General themes emerging from stakeholder consultations included CST's perceived importance, potential barriers and proposed approaches to enhance implementation.

The acceptability and relevance of the adapted CST

Stakeholders unanimously had a positive outlook towards the Kenyan adaptation of CST, reporting its relevance in addressing various challenges in the community surrounding children with disabilities, highlighting key benefits and endorsing it for families. CST was perceived to address pre-existing challenges. For instance, caregiver stress, care burden, stigma, poor parenting coping strategies, access to information on appropriate care, awareness and exposure to management and care of children with DDs, among others.

> Of course! They will find [CST] useful, and parents love their children! …People think that parents probably lock their children [with DDs] in the house…[and] they don't like them… They protect them. (NGO_Stakeholder_Nairobi)

Caregivers and stakeholders interviewed thought that receiving CST would result in better parenting practices, increased social support and awareness, improved developmental milestone achievement in children, reduced care burden, stigma and discrimination among families and the larger community.

> …Yes, it [CST] has great benefits because it will make the child achieve milestones… (Caregiver_Stakeholder_Nairobi)

Factors influencing CST implementation

Respondents highlighted areas that could potentially impede CST's implementation process. For instance, caregiver absenteeism, family dynamics, insecurity (poor neighbourhood security, child maltreatment), DD severity, caregiver's education/literacy levels, societal beliefs and cultural practices were cited as potential barriers.

There was consensus among respondents on how the CST programme was packaged regarding content, structure and mode of delivery. Suggestions were provided on ways to improve CST delivery. These included incorporating topics such as toilet training, physiotherapy, nutrition, economic empowerment and couples counselling, which were identified as issues caregivers lack in their community.

> …counselling for parents because most of these parents their marriages are broken and if you looked further into it, you realise it was because the child had a disability. (FGD2_Stakeholder_Kilifi)

Given the high dependence on written materials (CST Participants' Guide during sessions and written homework assignments), respondents felt there was a need to ensure considerations for caregivers' education/literacy levels, which may influence their acceptability, understanding and interpretation of the information disseminated.

> …you should get caregivers especially if she is a mother, she should be able to give back feedback to the father when she gets back home on what they have been trained…so I don't know if you are considering education level… (FGD7_Stakeholder_Kilifi)

Comprehensive knowledge of the cultural and societal norms by CST facilitators was highly recommended since the intervention involved long-term engagement with families in their natural settings.

> The people [local CST team] visiting homes should be aware of the customs for…the Mijikenda culture, because you might just go to their [homes] without greeting every person in the homestead then they stand against you…You go there [not presentable] and you expect to see the parents and talk to them, they will not. (FGD7_Stakeholder_Kilifi)

Table 1 Examples of Swahili CST adaptation after pretesting with caregivers

CST section references	Proposed change
Replacing case stories names with familiar local names	Replace session 3 'Shalini' with *'Sara'*; session 5 'Fernando' with '*Fred';* session 6 'Mimi' with *'Munira';* session 7 'Ling' with *'Betty';* session 8 'Maya' with *'Monica'.*
Placement of home practice review section in participant guide	Moved to come before 'what we will learn today' section.
Session 3: Shalini's story	Added the missing translated text in the facilitator guide from participant guide.
Session 5: Fernando's story	Added the missing translated text in the facilitator guide from participant guide.
Session 5: Demonstration part 2	Original text mentions child looking at a cup, but the adult picks a book. Dropped the cup and used the book example.
Session 6: Mimi's story	The story does not mention the target step Mimi starts with as asked in the review and discussion.
Addition of an information resource pack	Included an updated list based on a mapping activity for locally available resources for health, education, social services and protection, counselling needs for referral purposes.

CST, caregiver skills training.

Swahili CST pretest and feedback for CST implementation

CST administration to caregivers in the literate and low literacy groups had no difference, with regards to caregiver understanding and CST materials use. These observations were attributed to CST facilitators assisting caregivers with reading difficulties, and caregivers were encouraged to share materials with literate family members to improve acceptance and use of CST strategies by multiple family members. Proposed modifications included replacing names in case stories with local names, which is consistent with guidance from WHO field-test adaptation guidelines,[21] aligning contents in the translated participant and facilitator guides to allow ease of referencing and coordination during CST sessions—summary in table 1.

Two important adaptations were made. A live demonstration of CST strategies by facilitator pairs to caregivers in a group session was found problematic. First, facilitators' time to prepare and execute demonstrations was deemed lengthy, and some community venues were confined. The CST team suggested prerecording facilitator demonstrations to improve on time management. With the realisation video demonstrations took relatively short time, the team decided to record all demonstration sessions and deliver them in video format. Second, childcare support for caregivers was a challenge, partly due to lack of carers at home and cost for childcare. The CST team resorted to bringing along an extra staff member who provided childcare; a service offered to all caregivers accompanied by children to CST sessions.

Preliminary evaluation of the CST: pilot findings

Participant recruitment and sample description

Overall, 119 caregivers of children with DDs were approached, but 4 (3.4%) did not consent. At baseline, 115 (96.6%) consenting caregivers came for assessment then were randomised into study arms. 90 caregivers met trial eligibility and continued in the study, with 80 (88.9%) completing endline assessments (figure 2).

Participants' demographic characteristics

Caregivers' mean age was 33.57 years (SD 9.05) and socioeconomic status assessed using an asset index was 2.63 (SD 1.54). Most were females (98.8%) and married (70.0%). Over half (52.5%) had achieved primary school level education. Nearly one-fifth (23.75%) of the children had autism and intellectual disabilities, and almost half (47.5%) had cerebral palsy. There was no significance between group differences in the sample characteristics (table 2).

CST attendance

Over half (63%) of caregivers in the CST arm attended eight or nine sessions, with Kilifi (78.3%) recording better attendance than Nairobi (47.8%) (table 3). Factors influencing attendance are further discussed in the post-CST qualitative findings section.

Preliminary evaluation of CST on child–caregiver outcomes

This study was not powered to evaluate CST's efficacy. However, as part of evaluating its feasibility, we investigated differences between preintervention and postintervention scores in the study arms. The decrease in mean difference scores for all measures was greater in the CST group compared with non-CST group, but there was no significance ($p>0.05$), except for PedsQL average score and CBCL school age total score (see table 4 and online supplemental file 2).

Post-CST feedback and caregivers' experiences

Post-CST FGDs (with only Kilifi participants) generated feedback, which revolved around four themes: course content; mode of CST delivery; perceived outcomes from CST involvement; and CST attendance.

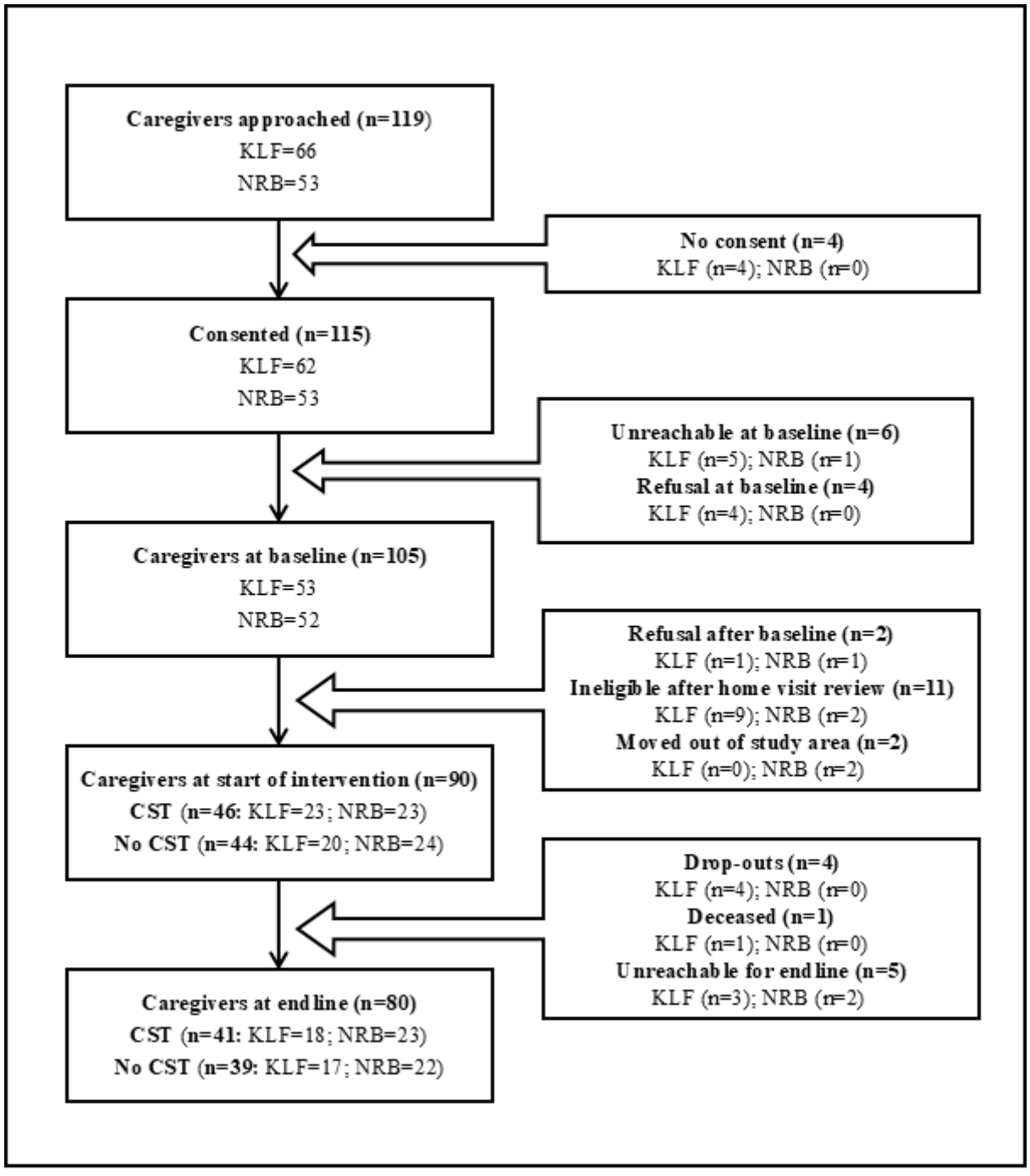

Figure 2 Pilot CST participant flowchart. CST, caregiver skills training.

Course content

Caregivers acknowledged the importance of the content delivered in all CST sessions and were found relatable to caregivers' living situations. CST content applicability further depended on the child's specific needs and disability type. Some caregivers expressed difficulty understanding the CST content at the training onset, attributing it to challenges of learning in a classroom set-up (adult learning). Similarly, some caregivers felt they found it tedious reading course content repeatedly to grasp information communicated. Progressively, grasping concepts became easier with time and improved in subsequent CST sessions.

Mode of CST delivery

Delivering CST in a 'peer-group' format was highly appreciated, as it enabled caregivers to learn from others' experiences (shared learning), encourage each other and cope with life stressors.

Table 2 Participant baseline characteristics stratified by intervention arm

	Total sample	Received CST (n=41)	Did not receive CST (n=39)	P value
Parent age, mean (SD)	33.57 (9.05)	32.95 (8.84)	34.18 (9.33)	0.555
SES, mean (SD)	2.63 (1.54)	2.51 (1.66)	2.74 (1.41)	0.505
Sex, n (%)				
Male	1 (1.25)	1 (100.0)	0 (0.00)	0.326
Female	79 (98.75)	40 (50.6)	39 (49.4)	
Conditions, n (%)				
Attention deficit hyperactivity disorder	7 (8.75)	3 (42.9)	4 (57.1)	0.143
Autism	12 (15.00)	3 (25.0)	9 (75.0)	
Cerebral palsy	38 (47.50)	19 (50.0)	19 (50.0)	
Epilepsy	8 (10.00)	5 (62.5)	3 (37.5)	
Intellectual disabilities	15 (18.75)	11 (73.3)	4 (26.7)	
Level of education n (%)				
None	9 (11.25)	4 (44.4)	5 (55.6)	0.293
Primary	42 (52.50)	19 (45.2)	23 (54.8)	
Secondary	8 (10.00)	3 (37.5)	5 (62.5)	
Tertiary	9 (11.25)	6 (66.7)	3 (33.3)	
Missing	12 (15.00)	9 (75.0)	3 (25.0)	
Marital status n (%)				
Never married	5 (6.25)	3 (60.0)	2 (40.0)	0.444
Married	56 (70.00)	30 (53.6)	26 (46.4)	
Separated	11 (13.75)	6 (54.6)	5 (45.4)	
Divorced	3 (3.75)	0 (0.0)	3 (100.0)	
Widowed	5 (6.25)	2 (40.0)	3 (60.0)	

CST, caregiver skills training; SES, socioeconomic status.

It is good when you are in a group setting because you will find that…there are some things you may not know and your colleagues will remind you, and you will be attentive… (FGD02_Caregiver_Kilifi)

Table 3 Total number of sessions attended by caregivers per site

Total CST sessions attended	Number of caregivers, n (%)		
	Both sites	Kilifi	Nairobi
9	18 (39.13)	14 (60.87)	4 (17.39)
8	11 (23.91)	4 (17.39)	7 (30.43)
7	3 (6.52)	1 (4.35)	2 (8.70)
6	8 (17.39)	2 (8.70)	6 (26.09)
5	2 (4.35)	1 (4.35)	1 (4.35)
4	3 (6.52)	–	3 (13.04)
3	–	–	–
2	–	–	–
1	1 (2.17)	1 (4.35)	–
Total	46 (100.00)	23 (100.00)	23 (100.00)

CST, caregiver skills training.

Perceived changes from CST involvement

Caregivers reported noticing progressive changes in their children and themselves since receiving the CST. They observed in their children improved awareness of self, ability to engage in daily activities, appropriate expression of needs and sharing engagement with others besides the caregiver.

…before, I could send the child [with DD] to get …a spoon they would bring me a plate… but we were told…when [a child] tries to say a word, even if they say it wrong, you are to pronounce it correctly. When you do that, you begin to see that they are starting to understand more… (IDI_Caregiver_Kilifi)

Based on self-report, caregivers noted changes in their attitudes and beliefs about their child's capabilities and discovering better ways to engage them in daily tasks and care. Participating in CST made caregivers feel less stressed during childcare, improved caregivers' understanding of their child's communication needs, increased caregiver confidence in teaching peers of children with DDs and enhanced knowledge on DDs. Similarly, caregivers noticed a change in attitude and support from

Table 4 Independent t-test for mean difference scores (endline–baseline overall)

Mean difference (endline–baseline)	Combined (80)		CST (41)		No CST (39)		
	Md (SD)	95% CI	Md (SD)	95% CI	Md (SD)	95% CI	P value
Sample	N=57		n=30		n=27		
CBCL school aged	−8.47 (24.21)	−14.90 to −2.05	−14.73 (19.35)	−21.96 to −7.51	−1.52 (27.37)	−12.35 to 9.31	**0.039***
Sample	N=20		n=11		n=9		
CBCL preschool	−8.1 (15.11)	−15.17 to −1.03	−9.64 (18.62)	−22.15 to 2.88	−6.22 (10.08)	−13.97 to 1.53	0.628
Sample	N=80		n=41		n=39		
PedsQL family impact total score	5.95 (16.61)	2.25 to 9.65	9.99 (14.75)	5.33 to 14.64	1.70 (17.56)	−3.99 to 7.44	**0.025***
PHQ-9 total score	−1.73 (5.10)	−2.86 to 0.59	−2.10 (5.62)	−3.87 to −0.32	−1.33 (4.52)	−2.80 to 0.13	0.506
PSI total score	−3.6 (10.12)	−5.85 to −1.35	−4.76 (8.59)	−7.47 to −2.05	−2.38 (11.51)	−6.12 to 1.35	0.298

*Significant.
CBCL, Child Behaviour Checklist; CST, caregiver skills training; Md, mean difference; PedsQL, Pediatric Quality of Life; PHQ-9, Patient Health Questionnaire-9; PSI, parent stress index.

other family members. That is, showing more support especially in childcare, and more accepting of the child's condition.

> …the [CST] training helped me…know that a child with disability can help themselves to do so many things…before I used to feel that I needed to do everything, bathing him, brushing his teeth. I used to feel that if I taught him, people would talk about me… (FGD3_ Caregiver _Kilifi)

Caregivers further mentioned gaining skills for appropriate childcare. Among the CST skills and strategies that they felt were useful included: 'breaking down activities into small steps'; 'show and say using words and gestures'; 'praising the child'; 'using mood thermometer'; and, 'removing distractions before starting an activity'.

> …the session about…trying to communicate with our children who do not know how to speak, when they say something. If he [child with DD] express they want something and shows you using gestures, [to] help them you must say what the object is so that they can say it properly. (FGD3_Caregiver_Kilifi)

CST participation created opportunities for empowering caregivers. For instance, caregivers reported having formed or joined social support groups and being aware of where to access services they needed to appropriately care for their children.

> My daughter, I didn't know where to start, even her education, I didn't know where to take her. But after they [CST team] came and told me of the place to take her for scan [assessment]…and they told me to take her to school. (IDI_Caregiver_Kilifi)

Barriers to CST involvement

Many caregivers mentioned limitations in their ability to attend some training sessions. Finding alternative childcare while the caregiver attended CST sessions, caregivers' working schedule and child illness were commonly cited barriers. In some instances, it led to older children missing school to look after their siblings.

> I used to leave the child [with DDs] with his siblings… they usually go [to school] but on those days when I come for the training, they stay home. (FGD3_Caregiver_Kilifi)

Disclosure to other family members regarding CST participation was mixed. While the CST guidelines encourage additional family members invited to sessions, some caregivers chose not to disclose their whereabouts, while others never involved their spouses. Other reasons surrounded discouraging community misconceptions about the implementing organisation.

> It's like the whole family…in their hearts it's like they do not want him [child with DD]. When I was told about it [CST training], his own father told me that if I attended, I would have to find someone even if they are not relatives and pay them to stay with the child. (FGD3_Caregiver_Kilifi)

DISCUSSION

This study evaluated the feasibility and acceptability of the WHO CST, one among the earlier global pilot studies, in poor rural and urban Kenya. Results from the Kenyan adaptation indicate the CST was acceptable, feasible to implement with trained NSFs and recorded high retention and participation by caregivers of children with DDs. Stakeholders and local researchers' participation

in the translation and adaptation of the CST materials ensured modifications aligned to the local context, while raising important programme considerations for the successful implementation of CST in low-resourced settings in Kenya. Below, we synthesise the key findings, while reflecting their implication for policy, practice and future research direction.

CST adaptation for the Kenyan context

The adapted CST materials were found comprehensible and culturally acceptable for implementation within rural and urban Kenya. Although CST is content-heavy with written materials, literate and low literacy caregivers were able to engage. With the amount of reading tasks during CST sessions and journaling/written exercise postsession, facilitators resorted to mostly reading the content, and caregivers were permitted to carry home and share materials with family members (eg, spouses and school-going children), which encouraged family engagement—a key retention strategy. This is important, given the varying literacy levels in urban and rural Kenyan households. Adaptations made in Ethiopia's CST pilot to accommodate low literacy caregivers include: removing written taught delivery approaches and replacing them with oral discussions aligning with Ethiopian oral tradition; and removing picture schedules, which were perceived as culturally inappropriate.[13] These findings underscore the importance of contextual adaptation and stakeholder participation, and the evidence generated was provided to the WHO, resulting in improvements to the final published version of the CST materials (updated 2022), with every written activity marked as potentially needing adaptation in settings with lower caregiver literacy.[21]

Using non-specialist facilitators in delivering caregiver-mediated interventions

In a context where mental health services gap is high and an overstretched health workforce characterised by very few specialists,[34] the inclusion of trained NSFs, who are indigenous and familiar with local community traditions/customs, was a valuable addition to the Kenya adaptation of CST. Evidence from other studies supports the use of NSFs comprising special education and allied health professionals to deliver the WHO CST with good/acceptable fidelity.[12 15 16 20]

Recent studies feature innovations of using trained caregivers as stand-alone facilitators or paired with specialists in delivering caregiver-mediated interventions with relatively good fidelity. For instance, a South African autism intervention[35] and Uganda's Baby Ubuntu programme for children with cerebral palsy[36] were co-delivered with caregivers. In Brazil, the congenital Zika syndrome parent group intervention used expert mothers as facilitators.[37] Caregiver-led interventions are growing in popularity, and through this innovation, they provide a potential sustainable solution, given their embeddedness in communities where they live and serve.

The 'promise' of CST for families of children with DDs

Our pilot findings are suggestive of improvements in caregiver outcomes, specifically family functioning (PedsQL) and mental health (PHQ-9), and improved child outcomes by examining their behavioural and communication functions (school aged CBCL), 3 months postintervention. While these findings corroborate with earlier CST evaluations delivered in-person or virtually in Hong Kong,[14] India,[15] Italy,[16] Serbia[19] and Taiwan,[20] the evidence is mixed for different age groups and developmental subdomains. Although our pilot was not powered to evaluate CST's efficacy, our qualitative data supports the progressive changes resulting from CST participation. For instance, parents reported improved knowledge, a better understanding of their child's condition and ability to learn, gaining confidence applying the acquired skills, thereby enhancing parenting skills. Furthermore, caregivers demonstrated gaining mastery in applying CST strategies such as shared engagement (teaching new skills in small steps), regulating challenging behaviour (mood thermometer) and using 'show and say' strategy, especially for minimally verbal children.

Caregivers' feedback signals their hopes and expectations of the CST intervention. They desired to have topics such as toilet training, psychosocial counselling and economic empowerment included in the training. The WHO CST content covers self-care and mental health support but does not feature toilet training, which is beyond the scope of CST.[10] The above concerns mirror the CST implementation context in Kenya: a high DD and motor comorbidities (47% with cerebral palsy) of the children studied with limited access to rehabilitative and therapy services; poverty and low-income households; and rising mental health needs due to societal stigma and caregiving burden. Future interventions could aim towards addressing these unique needs through broader multisectoral involvement.

CST implementation feasibility, contextual considerations and future research directions

Evidence from this pilot contributes to an improved understanding of potential barriers and facilitators to the CST implementation, and a glimpse into factors that may contribute to its sustainability. There was consensus that the Kenya CST was feasible to implement with 86% (n=40/46) completing two-thirds of CST sessions (50% as the WHO recommended threshold),[10] and drop-outs mostly from Nairobi's informal settlement. Factors contributing to non-attendance were childcare support, work engagements especially for urban caregivers working as casual labourers, frequent illness episodes for children with severe and comorbid conditions (eg, epilepsy, cerebral palsy and nutritional problems). Low male engagement was cited as a challenge, despite CST adaptation guidelines increasing numbers per family.[21] The above issues have been observed in the wider literature on parenting programmes within our context,[38 39] and in other CST evaluation studies.[13 16] These issues may

vary from context; however, it is important for implementing teams to reflect on how these could be incorporated in their implementation strategies, resources available and mechanisms to strengthen linkages with other service providers. It was encouraging to see the natural formation of support groups post-CST session and how these provided avenues for linkages with economic and livelihood programmes, which is a positive direction towards sustainability as observed in Bunning *et al*[23] study.

The availability of different CST delivery formats provides opportunities for its roll-out and penetration. Evidence suggests self-directed eLearning and virtual delivery of CST may be of potential value in places where group or individualised sessions are challenging to organise, especially as witnessed during the COVID-19 pandemic, or an add-on in clinical practice settings along with the provision of other psychoeducation.[40–43] More evidence is needed to evaluate the effectiveness of CST delivery in virtual or self-directed eLearning in low-resourced settings in Africa. Along with this, future research could investigate the scalability and integration of CST into existing health, education and community-based systems.

It was beyond the scope of this pilot to evaluate the fidelity of using NSFs. We recommend future research should investigate this further, by establishing evidence on prerequisite training for NSFs and competence level thresholds, as well as the potential effect on child–caregiver outcomes. Building on lessons from this pilot, our ongoing research aims to generate more evidence on CST's effectiveness through a multicountry trial in Ethiopia and Kenya.[44] This work will also explore the contextual determinants of CST implementation across diverse geographical settings.[45]

Study strengths and limitations

This study used a rigorous approach in the adaptation of CST materials by involving caregivers and professionals across health, education and social sectors. The heterogeneity in the patient population (children with diverse DDs and comorbidities) presents a 'real-world' scenario of the burden of disabilities in low-resourced settings. This relatively small pilot was sufficient to generate evidence on CST's acceptability, and we recommend future research to evaluate CST's effectiveness, with a diverse sample of DDs and caregiver gender.

CONCLUSION

The Kenya CST adaptation and its evaluation demonstrate this caregiver-mediated intervention delivered using NSFs is acceptable, feasible to implement and relevant to the needs of families of children with DDs. It may also add to the toolkit of interventions that could become available to address shortages of mental health and disability services in Kenya and other low- and middle-income countries, once the efficacy and effectiveness evidence is established. The evidence generated may inform other similar studies and ongoing global efforts to update the WHO CST adaptation guidelines. For instance, the provision of childcare and recording CST session demonstrations was beneficial adaptations in the Kenyan context, which may be relevant for other low-resourced settings.

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