Co-creating a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda (CEBU)

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EKWFRA001

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Dedication

I dedicate this thesis to the doctors, nurses, occupational therapists, physiotherapists, speech and language therapists, caregivers, teachers, and community members who have embraced the vision for a society where children with brain injury have equal opportunity to participate in daily life cultural choices and involve in meaningful occupation with shared values for health and wellbeing.

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Abstract

Background

The Culturally Relevant Programme Enabling Participation of Children with Brain Injury in Uganda was co-created to address the occupational needs of children with brain injury aged four months to 17 years, as well as the well-being of their caregivers.

Aim and Purpose

The aim of this thesis was to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda and describe its co-creation process. The purpose was to improve children's activity functioning and survival following brain injury, and impact on caregivers' health.

Methods

Three studies were implemented in two phases following participatory action research design. Phase one explored the participants' thoughts, feelings, and perceptions of the usual intervention in Kampala-Wakiso Brain Injury Home Therapy Centre (KWB-HTC) Uganda. In phase two, a culturally relevant programme enabling participation of children with brain injury was co-created; its consequences and limitations described. Purposive selection of primary participants (eight brain injured children) and general participants (eleven health professionals and three caregivers) took place. Video data were collected from each primary participant in the usual intervention; action changes. Interview data were collected from general participants in group reflection and individual interview. Thematic analysis was used to analyse data collected.

Findings

Thematic analysis of data collected identified three main themes:

The first theme, *"an intervention that does not satisfy basic needs,"* linked to three sub-themes: *"ignorance of child's condition," "assessment that does not focus on functional issues,"* and *"unwitting goals."* The second theme, *"bridging basic needs and enablement,"* linked to three sub-themes: *"assessing child enablement contexts," "supporting caregivers to attain psychological health,"* and *"involving the child in daily life activities."* The third theme, *"diversifying daily life participation,"* linked to two sub-themes: *"forming community connectedness,"* and *"moderating caregiver constraints."*

Conclusion

In conclusion, every child with brain injury in Uganda deserves an intervention that satisfies basic needs, co-created as the Four-star Model for Enablement and Participation. To implement the Four-star Model, this thesis proposed Occupation Actualization (OA) philosophy which requires children with brain injury to be involved in daily life activities formed by occupation scale and occupation score. The Occupation Actualization philosophy assumes that there is a positive relationship between occupation scale, occupation score, and enablement within the guiding principles of the Four-star Model delivered through community connectedness at the African One Hospital. Further research is recommended to implement and evaluate the effectiveness of the Four-star Model in Uganda, and test the validity of the OA philosophy.

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Abbreviations

AA	Activity Actualization
AAC	Augmentative and Alternative Communication
ACEC	Assessing Child Enablement Contexts
AHPC	Allied Health Professionals Council
AO	Action Observation
BAI	Exploring Background Information
BBE	Bridging Basic Needs and Enablement
BCG	Bacillus Calmette-Guerin
BHRC	Brain Health and Rehabilitation in Communities
BI	Brain Injury
BMC	British Medical Council
BSB	Exploring Body Structures and Body Functions
CBI	Counseling Caregivers on Brain Injury
CDS	Child Development Services
CEBU	Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda
CECA	Child Enablement Contexts Assessment
CES	Exploring Child Environment Support System
CFCS	Communication Functional Classification System
CHC	Child Health Condition
COVID-19	Coronavirus Disease of 2019
CP	Cerebral Palsy
CPG	Core Participants Group
CRP	Culturally Relevant Programme
CRPD	Convention on the Rights of Persons with Disabilities
C2C	Carer-to-Carer
DBI	Diagnosing Brain Injury
DO	Dependent Occupation
DPT	Diphtheria Pertussis Tetanus
Dr	Doctor

EAC	East African Community
FFF	Feeding on Formulated Food
FMEP	Four-star Model for Enablement and Participation
GCS	Glasgow Coma Scale
GH	General Hospital
GMFCS	Gross Motor Functional Classification System
GPG	General Participants Group
HC	Health Centre
HPV	Human Papillomavirus
HREC	University of Cape Town Faculty of Health Sciences Human Research Ethics Committee
ICD	Involving the Child in Daily Life Activities
ICD-10	International Classification of Diseases Version 10
ICD-11	International Classification of Diseases Version 11
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth
ICU	Intensive Care Unit
IO	Independent Occupation
KCCA	Kampala Capital City Authority
KWB-HTC	Kampala-Wakiso Brain Injury Home Therapy Centre
MACS	Manual Ability Functional Classification System
MHREC	Mulago Hospital Research Ethics Committee
MJAP	Makerere University Joint AIDS Program
MMR	Measles, Mumps, and Rubella
MNRH	Mulago National Referral Hospital
NBA	Naming Basic Needs Activities
NDA	National Drug Authority
NIN	National Identification Number
NRH	National Referral Hospital
OBH	Oral-Body Hygiene

OSc	Occupation Scale
OSr	Occupation Score
OT	Occupational Therapy
OTs	Occupational Therapists
OTD	Occupational Therapy Department
OTD-M	Occupational Therapy Department - Mulago National Referral Hospital
PAR	Participatory Action Research
PEDI-UG	Uganda Version of Pediatric Evaluation of Disability Inventory
PEO	Person Environment Occupation
PGFO	Post Graduate Funding Office
PhD	Philosophy Doctor
PI	Principal Investigator
PJE	Posture and Joint Mobility Exercise
PN	Participation Number
PSC	Play-Social Relationship-Class
PT	Physiotherapy
PwD	People with Disabilities
RCoHE	Regional Center of Health Excellence
RCT	Randomized Controlled Trial
RDC	Resident District Commissioner
RDM	Research Data Management
RRH	Regional Referral Hospital
SCAP-H	Supporting Caregivers to Achieve Psychological Health
SICA	Sharing Information about individual Child health condition and Activity fit
SLT	Speech-Language Therapy
SOPs	Standard Operating Procedures
TBI	Traumatic Brain Injury
UATM	Using Assistive Technology or Medicine
UBoS	Uganda Bureau of Statistics
UCT	University of Cape Town
UN	United Nations

UMDPC	Uganda Medical and Dental Practitioners Council
UNCST	Uganda National Council for Science and Technology
UNICEF	United Nations International Children's Emergency Fund
UNMC	Uganda Nurses and Midwives Council
VHT	Village Health Team
WHO	World Health Organization
WMA	World Medical Association
VRA	Video Record Assessment
VRAS	Video Record Assessment Scores
ZCCS	Zimbabwean Caregiver Constraint Scale

Operational Definitions

Body function – refers to the physiological and psychological functions of body systems (World Health Organization, 2007).

Brain Injury – refers to brain damage which includes traumatic brain injury, cerebral palsy, and stroke among others (World Health Organization, 2018).

Cerebral Palsy – this is a form of brain injury described by ICD 11 as a child with a permanent, but not unchanging, disorder of movement and/or posture and of motor function, which is due to a non-progressive interference, lesion, or abnormality of the developing/immature brain (World Health Organization, 2018).

Child's activity – refers to what a child does or is expected to do in a specified time space or setting (Schulze, 2015).

Co-create – means spaces created through a social model to change a lack of inclusive attitudes and develop actions geared towards barriers to inclusion and participation of children with brain injury at both family and society level (Thompson, Elliott, Willis, Ward, & Falkmer et al., 2016).

Disability – in children, disability can be viewed as the degree to which adult caregivers play a larger role in the accomplishment of daily activities than what would be expected at a certain age (Saloojee, Ekwan, Andrews, Damiano, Kakooza-Mwesige, & Forssberg, 2021).

Functional limitation – means a child's ability to perform normal activities of daily living is restricted and requires caregiver's assistance and more time to perform such activities (Schulze, 2015).

Hydrocephalus – refers to abnormal build-up of cerebrospinal fluid (CSF) deep within the brain; this excess fluid causes the ventricles (cavities) within the brain to widen, putting harmful pressure on the brain tissues (National Institute of Neurological Disorders, 2025).

Impairment – means a child has limitation or abnormality in anatomical, physiological, or psychological processes (World Health Organization, 2007).

Occupation – refers to the activities that people do as families in families and with communities to occupy time and bring meaning and purpose to life, occupations include things people need to, want to, and are expected to do (World Federation of Occupational Therapists, 2012).

Participation – means the involvement of a person in a situation that may include playing a role in society (World Health Organization, 2007).

Stroke – refers to a form of brain injury where normal blood flow within the brain is disrupted following rupture or blockage of blood vessel, a disabling condition, with cerebrovascular diseases

noted to be the leading cause of disability in many countries around the world (Quinn, Dawson, Walters, & Lees, 2009).

Traumatic Brain Injury – refers to a form of brain injury caused by direct trauma to the head such as a fall, road traffic accident, and non-accidental injuries (Hawley, Ward, Long, Owen, & Magnay, 2003).

Preface

The idea for this thesis evolved from my earlier role as an occupational therapist working alongside a pediatric services multi-disciplinary team, comprised of doctors, nurses, physiotherapists, speech therapists, and occupational therapists, in MNRH between 2018 and 2021. MNRH is Uganda's complex national referral hospital. In this thesis, MNRH is referred to as African One Hospital. While providing child development services (CDS) in African One Hospital, as an occupational therapist, I first saw that the number of children with brain injury needing occupational therapy was alarming; about four to six new cases were referred by doctors for occupational therapy in the CDS every Thursday clinic day.

Second, I noted that all the children with brain injury referred for occupational therapy had more than three body-activity functional challenges; for example, poor postural control, joint contracture, hand function limitation, seizures, spasticity, and mobility limitation, among others; this was the time I saw the usefulness of the World Health Organization International Classification of Functioning, Disability and Health (WHO, ICF) (2001) and the World Health Organization International Classification of Functioning, Disability and Health for Children and Youth (WHO, ICF-CY) (2007). Then, I started to use the WHO, ICF and WHO, ICF-CY in describing the multifactorial body issues experienced by children with brain injury. Multifactorial body issues are body structural challenges that limit the activity involvement of children with brain injury in daily life contexts; for instance, joint contracture and muscle spasticity limit the child's mobility in different spaces, such as the home environment.

Third, I noted that, despite these multifactorial body issues, there was no clear intervention strategy for children with brain injury referred for occupational therapy in the CDS clinic. I therefore began to look at the body issues of children with brain injury as compounded by their daily life culture. Thus, as an occupational therapist who values earlier research into the therapeutic power of occupation (for example, Kielhofner, 2008; Townsend and Polatajko, 2007), I wanted to know more about daily life cultures of children with brain injury in their different contexts. This led me to my first research idea about assessing children with brain injury using the Uganda version of the Pediatric Evaluation of Disability Inventory (PEDI-UG). The PEDI-UG is a standardized assessment tool, adapted from the PEDI-US to evaluate the functional capacity of children with or without disability, aged 6 months to 7.5 years, in the self-care, mobility and social domains

(Kakooza-Mwesige, Tumwine, Forssberg, & Eliasson, 2018; Amer, Kakooza-Mwesige, Jarl, Tumwine, Forssberg, Eliasson, & Hermansson, 2018).

I held a personal belief that children with brain injury deserve an effective home intervention programme. While I maintained a keen eye on what children with brain injury were going through in diverse cultural situations, such as activities happening in the home environment, I realized that they experienced multifactorial body issues that limited their daily occupation or daily life cultures in all cultural situations, especially in the home environment. This led me to want to change the situation by providing answers to the multifactorial body issues which impacted negatively on the participation ability of children with brain injury in Ugandan cultural contexts. My first question was how to detect the daily life cultural limitations or daily occupational limitations because of multifactorial body issues of children with brain injury. I decided to explore health professionals' experiences with the PEDI-UG (Ekwan, Satink, Kamwesiga, & Schulze, 2022). However, health professionals' experiences with PEDI-UG weakened the position of its use in diverse cultural contexts. The issues were that the PEDI-UG needed translating into different Ugandan languages and that health professionals need training on its use and value for children with disabilities (Ekwan et al., 2022).

This led me on to explore two further issues. The first was the reasons why, despite existing solutions, children with brain injury continued to experience multifactorial body issues, daily life cultural issues, and dependence issues that restricted their participation or involvement in diverse cultural situations. The second was the mechanisms by which different interventions have contributed solutions to the multifactorial body issues, daily life cultural issues, and dependence issues of children with brain injury. Based on the philosophy of enabling children with brain injury, I was keen to make theoretical linkages between children's body issues and daily life cultures or daily life occupation and participation. My theoretical interest focused on the involvement of children with brain injury in diverse daily life situations. To structure my thinking, I used principles of occupation that looked at daily life cultures within three domains: the person experiencing multifactorial body issues; the environment within which daily cultural issues were observed (environment), and the occupations that formed the daily life cultures happening within the cultural context (Law, Cooper, Strong, Stewart, Rigby, & Letts, 1996).

My original PhD topic was to test the validity of my ideas about usual interventions for children with brain injury in KWB-HTC Uganda. The KWB-HTC stands for Kampala-Wakiso Brain Injury Home Therapy Center. This was a center that brought together health professionals with a common goal of enabling the participation of children with brain injury. I recognized that children with brain injury were dependent on their daily life cultures and that all treatment started at the KWB-HTC needed to have its effectiveness tested: this was to be the focus of my PhD studies. However, after an initial discussion with my supervisor, I realized that my idea of testing the effectiveness of the usual interventions in KWB-HTC was unrealistic, due to lack of research evidence to support the usual intervention as a developed practice framework. After several supervision sessions and discussions, my supervisor and I agreed that, rather than testing the effectiveness of my personal ideas about usual interventions in KWB-HTC Uganda, my PhD study would aim to co-create a culturally relevant programme that would enable the children's participation in diverse cultural contexts.

This happened at a time when I was practicing occupational therapy in KWB-HTC Uganda. The KWB-HTC was established under occupational therapy department (OTD) in the African One Hospital. I decided to gain more familiarity with the cultural situations of children with brain injury and to explore the different perspectives of stakeholders that had shaped my understanding of the cultural life challenges and contextual issues which impacted on the involvement of the children in diverse daily life situations. In order to meet these goals, I chose to interact with 14 children with brain injury, and the KWB-HTC team: three C2C caregivers, two occupational therapists, one physiotherapist, one speech and language therapist, five nurses, and three doctors who were key contributors in KWB-HTC Uganda. Through these interactions, it became clear that change was required for children with brain injury to be enabled to participate more fully. However, I found it difficult to work out what kind of change was required and how to create that required change. When I shared the challenge with my supervisor, we decided that we could find out what kind of change was wanted by asking the stakeholders and research team via participatory action research (Kemmis & McTaggart, 1988).

I then carried out a review of the literature on children with brain injury in Uganda and found two relevant studies: Akwenda (Saloojee, Ekwan, Andrews, Damiano, Kakooza-Mwesige, and Forssberg, 2021) and ABAaNA EIP (Nampijja, Webb, & Nanyunja et al., 2019). Akwenda refers

to an intervention programme for children and youth with cerebral palsy in a low-resource setting in sub-Saharan Africa (Saloojee, Ekwan, Andrews, Damiano, Kakooza-Mwesige, and Forssberg, 2021); ABAaNA EIP refers to an intervention programme for young infants with neurodevelopmental impairment in Uganda (Nampijja, Webb, & Nanyunja et al., 2019). Both studies focused more on the caregivers' contexts than the child's contexts (Saloojee et al., 2021; Nampijja et al., 2019). In addition, the two studies were based on intervention philosophies imported from other countries, which may have limited relevance in the Ugandan context (Nampijja et al., 2019; Saloojee, & Bezuidenhout, 2020).

Following the literature review, I affirmed that there was a knowledge gap about what would constitute a culturally relevant programme for enabling the participation of children with brain injury in Uganda. To address this gap, I planned my study in four stages: 1. developing a proposal; 2. ethics approval; 3. collecting and analyzing data; 4. writing thesis. For the first stage of the study, developing a proposal, I worked with 14 children with brain injury in KWB-HTC, and consulted the KWB-HTC team. I then realized that all children with brain injury were not happy during exercise, feeding, self-care, assistive technology and medicine use in KWB-HTC as part of their daily cultures. This was the time I visualized partnership with diverse groups of health professionals and caregivers to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda.

One of the challenges faced in developing the new programme was that Uganda was grappling with the COVID-19 pandemic and, later Ebola epidemics cropped in the country. I had to develop standard operating procedures (SOPs) to control and prevent the spread of COVID-19 and Ebola among study participants. These SOPs involved use of the home setting (KWB-HTC) for weekly interactions between children with brain injury, caregivers, and health professionals.

For the second stage, ethics approval was received from the University of Cape Town and the Uganda National Council for Science and Technology to have this research conducted in Uganda. At this point, I had to consider changing my job to avoid role conflict with my researcher role and to adhere to UCT funding policy. I decided to change from being an occupational therapy practitioner in KWB-HTC Uganda to being a full-time researcher in UCT.

For the third stage, collecting and analyzing data, I struggled to maintain a role shift because there were moments when I found myself part of the team providing weekly interactional sessions with children with brain injury. Because of increased academic demands, I later found it impossible to juggle between two roles; then, I proceeded to focus on research and academic roles. Practically, this was managed by re-allocating my former roles as an Occupational therapist in KWB-HTC Uganda to another Occupational therapist who was not part of the study but was involved in the KWB-HTC usual intervention. This created more time for me to stick to roles involving research and academic undertaking; for example, coordinating research team and research participants, collecting data, storing data, analyzing data, and reporting about the study findings.

One exciting experience as a researcher in the University of cape Town involved in a study to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda was about the choice of research topic; this was a challenge because, I never had in mind own research paradigm and yet this thesis required me to come up with own research paradigm. I managed to maneuver over this challenge with direct guidance and involvement of my thesis supervisor whose main role was to create an environment of academic challenge and later critique my actions and response to assigned task; in this case, the assigned task was to read widely on the focused topic and come up with own research paradigm informed by ontological and epistemological philosophical stance.

Dealing with diverse groups of health professionals involved in the management of children with brain injury in KWB-HTC Uganda, caregivers and children with brain injury formed another worthwhile experience for me as a researcher. Initially, getting these groups together required constant updates about the usual intervention in KWB-HTC Uganda and what the study adds to the practice that every stakeholder needed for involvement. As part of the change aspiration, I experienced the use of PAR approach following the 12 research processes to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda (fig 5).

For the fourth stage, writing thesis, I experienced the rigor involved in thesis writing that was centered on me as the writer with support from the supervisors and at some point, with support from fellow PhD students involved in the writing circle. I initially thought that this thesis writing would take between three and four months (September 2023 to December 2023). This was not the

case, it took me about eight months just learning about my thesis, getting together my thesis findings in an easy-to-read text format (September 2023 to April 2024). This thesis writing was supervised by two thesis supervisors via monthly supervision meetings and written feedback. I later spent four months, putting together the first four chapters of my thesis (introduction, literature review, methods, and findings) (May 2024 to September 2024). Upon putting together, the first four chapters of my thesis, I started to receive more intensive supervision in form of weekly feedback on my shared thesis document via google drive; this significantly increased my chances for thesis writing completion and submission for examination within the agreed time not exceeding February 2025.

One thing that helped me during the thesis writing was working in a small group of 10 students from the University of Cape Town, Faculty of Health Sciences who were desirous of completing PhD thesis writing and submitting for examination by July 2024. The thesis writing programme was designed for three months as an intensive daily writing engagement with other PhD students who had reached the final stage of their thesis writing. Each student writer came up with monthly, weekly, and daily personal writing goals and worked towards achieving the personal writing goals.

The writing programme started in March 2024 and ended in June 2024. All students involved in the writing programme including myself were determined to complete their thesis writing and submit for examination by the end of programme in June 2024. Notwithstanding the different stages each writer joined the thesis writing programme, by the end of the thesis writing programme, only one out of ten writers had completed and submitted the thesis for examination. The remaining nine writers including myself acknowledged the challenge with academic writing that made it hard to determine the actual date of thesis completion. Nevertheless, the remaining nine thesis writers (PhD students) re-committed to complete thesis writing and submit for examination no later than February 2025. The use of the thesis writing circle kept me focused and motivated to complete the thesis writing within a set time frame. In addition, it was one useful way to receive feedback from fellow PhD students other than feedback from supervisors only; this created some form of peer pressure that culminated in my steady thesis writing progress.

The latest supervision meetings held between thesis supervisors and myself were so instrumental in getting me to the thesis writing finishing line as I learnt to distinguish the essence of telling

exactly what happened as opposed to reporting about the findings. This was one of my weaknesses in thesis writing that I struggled to admit because the feedback created enormous work in the thesis writing process. I can attest that after this latest feedback, I started to package and communicate my ideas and findings correctly especially looking at the CEBU co-creation process by telling my readers exactly what happened and my roles as the researcher at each stage of the co-creation process contrary to what I initially did, reporting about what happened during the CEBU co-creation process. Thus, I strongly believe that I have reached the highest level of knowledge and understanding in my chosen research topic: CEBU. I have also gained vast experience in academic research that can allow me work as an independent researcher in future, I am ready to apply relevant principles, theoretical framework, and model of practice in the real-life practice situation. I am now capable of making research-based choices and decisions informed by my own philosophical stance and theoretical lens that can culminate in effective practice. I can now communicate scientific findings to inform the scientific community in acceptable ways. I have reached a point in my research career when I can track the progress of my scientific work, communicate about the progress, and conclude the study in meaningful ways by providing recommendations to inform policy and practice. With all these, I am confident that I have successfully completed my PhD studies, and I am happy to present this thesis for examination.

Moving forward, I plan to further develop my research career in the field of PAR while incorporating the use of randomized controlled trial (RCT) to test the effectiveness of the findings of this thesis; the intention is to create lasting impact for Ugandan children with brain injury who have suffered multifactorial body issues in diverse cultural situations for long. Thus, I look forward to a future where every child with brain injury has equal opportunity to participate in daily life cultural choices and involve in meaningful occupation with shared values for health and wellbeing.

Chapter one: Introduction

1.0 Introduction

1.1 Background

Brain injury is a major source of health loss and disability among children worldwide (Williamson and Rajajee, 2024); it's a consequence of a trauma of some kind, such as a road traffic accident or assault, and can be caused by other issues such as encephalitis, loss of oxygen to the brain or a stroke (Clark-Wilson & Holloway, 2019; Holloway, Orr, & Clark-Wilson, 2019). Brain injury can result in complex presentation of fatigue, pain, sensory and physical impairments, language difficulties, cognitive and emotional disorders, and personality changes, slowness in processing information, difficulty in concentration, recalling information, problem solving, and decision making, and behavior changes, all together or singularly restrict participation in society (Clark-Wilson & Holloway, 2019; Holloway, Orr, & Clark-Wilson, 2019). According to Huang (2023), brain injury impairment relates to the area of the brain injured as described below:

Frontal lobe injury – a person may lose the ability to solve problems, plan and initiate actions involving movement; if the back part of frontal lobe gets injured, a person may experience difficulty with performing voluntary movement; if the middle part of the frontal lobe gets injured, a person may become apathetic, inattentive, unmotivated, thought process may be slowed; if the middle back part of the left frontal lobe (Broca area) is injured, a person may experience difficulty expressing self in words; if the front part of the frontal lobe is injured, a person may experience difficulty holding information available for processing referred to as working memory, reduced fluency of speech, apathy (lack of emotion, interest, and concern), inattentiveness, delayed response to questions, striking lack of inhibition, and exhibiting socially inappropriate behavior.

Parietal lobe injury – a person may lose the ability to interpret sensory information from the rest of the body, combine impression of form or texture or weight into general perceptions, influence mathematical skills and language comprehension, store spatial memories that enables orientation in space (where a person is), maintain a sense of direction (where a person is going), process information that helps a person to know the position of different body parts; if the front part of the parietal lobe is injured on one side , a person may experience numbness and impaired sensation on the opposite side of the body; affected person may have difficulty locating sensations such as pain, heat, cold, vibration, and may have difficulty recognizing objects by touch especially looking at texture and shape; if the middle part of the parietal lobe is injured, a person may experience

difficulty doing simple tasks such as combing hairs or dressing; this is described as apraxia; in addition, a person may have trouble understanding how objects relate to each other in space, as a result, the person may have trouble drawing and constructing things, and may get lost in own neighborhood; the person may neglect the body side opposite the brain injured side; parietal lobe injury may result in a form of touch disorder referred to as somatosensory agnosia, a condition where a person have difficulty identifying a familiar object (for example, key) placed in the hand; however on sight, the person recognizes the object

Temporal lobe injury - a person may lose the ability to generate memory and emotions, process immediate events into recent and long term memory, store and retrieve long term memories, comprehend sounds and images, integrate hearing and speech; for most people, part of the left temporal lobe controls language comprehension; if injured, memory for words may be drastically impaired resulting in impaired ability to understand language, an impairment referred to as Wernicke (receptive) aphasia; if certain areas of the right temporal lobe are damaged, memory for sounds and music may be impaired, as a consequence, a person may have trouble with singing; temporal lobe injury may result in three different forms of agnosia: Hearing (auditory agnosia), a condition where a person cannot identify objects based on sound; taste (gustatory agnosia), a condition where a person cannot identify taste even though provided with opportunity to experience it; smell (olfactory agnosia), a condition where a person cannot identify odors even though provided with opportunity to experience it.

Occipital lobe injury – a person may lose the ability to process and interpret vision form and memories; integrate visual perceptions with the spatial information provided by the adjacent parietal lobes; if both sides of the occipital lobe are damaged or injured, a person cannot recognize object by sight, even if the eyes are normally functioning; this is referred to as cortical blindness; however, if a person with cortical blindness reports false claims of seeing objects (for example, making up descriptions of objects seen), this would be referred to as confabulation, a disorder described “Anton syndrome;” occipital lobe injury may result in a form of sight disorder described as visual agnosia, a condition where a person cannot recognize objects for daily routine such as a spoon even though presented to the sight; however, the person immediately recognizes the object when offered the opportunity to touch the object initially presented to the sight.

Brain injury has been reported internationally as a leading cause of disability and death among children (Centre for Disease Control & Prevention, 2013). It is more likely that every child with brain injury would lose the ability to participate in activities (Singam, Ytterberg, Tham, & von Koch, 2015). However, each child with brain injury presents differently and at the same time brain injury influences the child's development differently depending on the nature of injury, severity, and age (Fink, Stagnitti, & Galvin, 2012).

For children with brain injury to participate in activities that they and their caregivers most value, rehabilitation goals should be in line with the cultural values of the child and the family (Cott, Wiles, & Devitt, 2007). In this way, rehabilitation goals have to focus on child support; however, little is often done to support children with brain injury (de Weerd, Rutgers, Groenier, & van der Meer, 2011). Without focused rehabilitation goals, enabling child's participation following brain injury would be a challenge in daily life situations such as enjoying mealtime, playing with others, getting to school, visiting health facility, and caring for own health (Andrews, Namaganda, Imms, Eliasson, Asige, & Wanjala et al., 2023). It is not surprising that children with brain injury have suffered from participation restriction than their peers in different settings (Shikako-Thomas, Majnemer, Law, & Lach, 2008). This could be because previous studies did not focus on understanding the rehabilitation goals of children with brain injury but instead focused on body organs and functions (Abdel Malek, Rosenbaum, & Gorter, 2020).

In the current study, important lessons were drawn from the participation contexts: Kampala-Wakiso Brain Injury Home Therapy Centre (KWB-HTC), children with brain injury, usual intervention, and consequences. The KWB-HTC was started as a home therapy programme for children with brain injury living in Kampala-Wakiso districts of Uganda at the time when the COVID-19 pandemic restricted movement of patients to occupational therapy unit situated in African One Hospital. Because of the COVID-19 movement restriction, it was necessary to have a home therapy programme as part of the solution. This culminated in children with brain injury receiving the usual intervention in home environment described as usual interactional actions which included: assessment and management of children's functional issues via play, exercise, feeding, self-care, assistive technology, and medicine use; involvement of caregivers and health professionals.

The usual intervention did not go well because the involved children with brain injury felt that they were denied the culturally relevant care. For example, the children's voices and cultural values were ignored in planning and implementing the usual interactional actions. With the growing reservation on the usual intervention, the researcher in partnership with caregivers and health professionals (doctors, nurses, and therapists) decided to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda; what would later replace the usual intervention programme. The researcher together with partners further noted that several studies showed support for interventions that include the voices and cultural values of children with brain injury as a way to minimize activity functional loss, regress in life satisfaction, and caregivers experience of poor health outcomes (Bergstrom, von Koch, Andersson, Tham, & Eriksson, 2015; Egan, Davis, Dubouloz, Kessler, & Kubina, 2014; Singam, Ytterberg, Tham, & von Koch, 2015). At this point, the only valid idea was to have CEBU in place of the usual intervention programme at the KWB-HTC.

CEBU stands for Culturally relevant programme Enabling participation of children with Brain injury in Uganda. This study, therefore, aimed to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda and describe its co-creation process. The researcher believed that by using a culturally relevant programme, caregivers, health professionals, and other community members may become aware about how to enable participation of children with brain injury in diverse cultural situations including home environment. In line with the researcher's belief, it was collectively assumed that CEBU would resolve the perceived occupational misfit of children with brain injury in Uganda. In this case, occupational misfit refers to a child with brain injury (person) who fails to achieve participation goals (occupation) because of using a culturally irrelevant programme (usual intervention). Thus, this study needed to change the culturally irrelevant programme known as the usual intervention by co-creating a culturally relevant programme known as CEBU based on the person, environment, and occupation theoretical lens that visualized human occupation as occurring within person and environmental parameters described as "fit" (Law, Cooper, Strong, Stewart, Rigby, P., & Letts, 1996).

1.2 Uganda contextual issues

Uganda is known as the pearl of Africa and a member of East African Community; it's bordered by Sudan to the North, Kenya to the East, Tanzania, and Rwanda to the South, and Democratic Republic of Congo to the West. The East African Community (EAC) comprises eight partner states which ascribe to the EAC treaty: The Republic of Kenya, the Republic of Uganda, the United Republic of Tanzania, the Republic of Burundi, the Republic of Rwanda, the Democratic Republic of Congo, the Federal Republic of Somalia, and the Republic of South Sudan (East African Community, 2024).

The EAC treaty was signed in November 1999 and Uganda ascribed as an active member in July 2000 (East African Community, 2024). The treaty allows free movement of EAC Health Professionals to and fro EAC member states based on six Regional Centers of Health Excellence (RCoHE) which include:

I. East African Center of Excellence for Nephrology and Urology in the Republic of Kenya
II. East African Center of Excellence for Cardiovascular Health Sciences in the United Republic of Tanzania
III. East African Center of Excellence for Oncology in the Republic of Uganda
IV. East African Center of Excellence in Biomedical Engineering, eHealth, and Health Rehabilitation in the Republic of Rwanda
V. East African Center of Excellence for Vaccines, Immunization, and Health Supply Chain Management in the Republic of Rwanda
VI. East African Center of Excellence for Nutritional Sciences in the Republic of Burundi (East African Community, 2024).

The East African Community, RCoHE, has a missing link in Brain Health Sciences that this study could motivate as part of an effort to work towards a society where every child with brain injury has equal opportunity to participate in daily life cultural choices and involve in meaningful occupation for health and wellbeing.

Figure 1. Map Showing the Location of Uganda in the East African Community

Note. Figure 1 = East African Community Map (2024), showing the location of Uganda in the East African Community; = East African Community States; = Uganda

Uganda has a fast-growing population growth rate of 3.3 per year and fertility rate of 4.3 births per woman in 2024 (World Population Review, 2024). The population of Uganda as of June, 2024 was estimated to be 49,842,991 with the largest group (48.47%) being children in the 0-14 year-old age group; the second largest group (28.34%) being adults in 25-64 year-old age group; the third largest group (21.16%) being a mix of children and youth in 15-24 year-old age group; lastly, the smallest group (2.04%) being older people in 65 year or older age group (World Population Review, 2024).

Uganda, has more than 56 tribes which all practice different beliefs, norms, values and speak different languages (Uganda Safaris, 2024); the nine top tribes of Uganda are easy to distinguish among others in their linguistic ethnic categories and values. The bulk of Uganda's tribal group are the Bantu speaking group in central, southern, and western regions; the non-Bantu speaking group are mainly in eastern, northern, and northwest regions. English is the official language spoken by all tribes in Uganda (Focus East Africa Tours, 2024).

The first top tribal group in Uganda are the Baganda, constitutes more than one-fourth of all tribes in Uganda and speak Luganda, one of the Bantu languages; the Baganda tribe values their cultural dance, “Kiganda" where participants shake their lower body parts in time to match the beat of the drum; the Baganda are sometimes referred to as King’s men because of roles played by their Monarch, the Kabaka, in their political, social, and cultural institutions; the majority of Baganda are Christian; matooke, a plantain boiled, steamed, and served with groundnut is a typical meal of Baganda people; the Baganda people live on the north and western coasts of Lake Victoria (Focus East Africa Tours, 2024).

The second top tribal group in Uganda are the Banyankole, speak Runyakitara, one of the Bantu languages; King Mugabe, according to history ruled the Banyankole with absolute power; for example, he claimed ownership of all the livestock in the nation; the Banyankole are ranked high in pastoralism and low in crop farming; the Bairu are the Banyankole crop farmers who also keep goats and sheep; the Bahima are the cow herders; the Banyankole children are taught moral behavior through legends and stories; Christians make up the majority of the Banyankole who strictly observe Christmas and Easter; the Banyankole dress differently based on ranks and gender; for example, the chiefs dress on lengthy cow skin robes; the average person carries a tiny piece of cow hide over the shoulders; however, the Banyankole have in recent years changed to modern way of living paying little values to historical Kingship leadership; Bahima tribe ingest mainly milk, butter, fresh blood from their animals, and beef; the Banyankole people live in south west Uganda (Focus East Africa Tours, 2024).

The third top tribal group in Uganda are the Basoga, speak Lusoga, one of the Bantu languages; the Basoga are proud to have the source of Nile river on their land; the Basoga for long held the idea that there was a spirit world and the supreme being referred to as Lubaale; the other cultural practices in Basoga are similar to that in Buganda; its kingdom headed by the Kyabazinga; the Basoga people neighbor Baganda to the east (Focus East Africa Tours, 2024).

The fourth top tribal group in Uganda are the Bakiga, speak Rukiga, one of the Bantu languages; the Bakiga tribe go by the names “Kiga” or “Chiga;” the Bakiga people still adhere to many of its ancient customs such as leaders were not permitted to wed someone from another tribe; the Bakiga

had faith in Ruhanga, the all-powerful creator and the Nyabindi cult, which worshiped the ghost of a revered rainmaker; the Bakiga are primarily farmers growing sorghum, peas, millets, sweet potatoes, vegetables and beans; the Bakiga mostly use sorghum for making beer creating a community where the most valued social activity is drinking alcohol; the Bakiga people live in south west Uganda and others live in Rwanda (Focus East Africa Tours, 2024).

The fifth top tribal group in Uganda are the Iteso, speak Ateso language; the Iteso, according to history migrated from Abyssinia in Ethiopia; finger millet and sorghum are the two main food crops of the Iteso; the Iteso had three different birth types: Single birth, twin birth, and spiritual birth; spiritual birth, took the form of air or water; the clan performs ceremonial act to welcome the new born into the family; the Iteso did not view death as a natural happening but a result of witchcraft and ancestor spirits calling the living to join the world of the dead; the Iteso people live in Eastern Uganda (Focus East Africa Tours, 2024).

The sixth top tribal group in Uganda are the Langi, speak Lango, one of the Luo languages; the Rhino is valued by the Langi people as their tribe's emblem, it signifies courage and determination; before British colonization of Uganda, the Langi people had their government that is why the colonial masters found it difficult to colonize Langi people but eventually had to use influence from other tribes which were already colonized especially the Baganda tribe to subdue the Langi people to accept colonization; the Langi, were the first tribal group in Uganda to rise against British colonialism led by one of their son, Dr Apollo Milton Obote (the first elected leader of the Republic of Uganda: 1962 to 1966 as Prime Minister, 1966 to 1971 as President, and 1980 to 1985 as President); Langi children were taught morality, manners, and how to treat their family members and other people with love and respect; male children learned from their fathers or other male relatives and female children learned from their mothers or other female relatives; the Langi people emphasized games, myths, proverbs, and riddles; the Langi people live in Northern Uganda (Focus East Africa Tours, 2024).

The seventh top tribal group in Uganda are the Acholi, speak Acholi, one of the Luo languages; the Acholi tribe, according to history migrated from Bahr el Ghazal in South Sudan; the Acholi practiced both animal and crop farming; raising cattle, sheep, and goats; the natural birth and the spiritual birth, "Jok Anywala" are the two different birth rituals that the Acholi recognized; the

Acholi had faith in spirit, “Jok” as a supreme being capable of giving women children through birth; the Acholi valued communicating about historical situations via songs and dance; the elephant is the Acholi’s emblem, it signifies loyalty and power; the Acholi people live in Northern Uganda (Focus East Africa Tours, 2024).

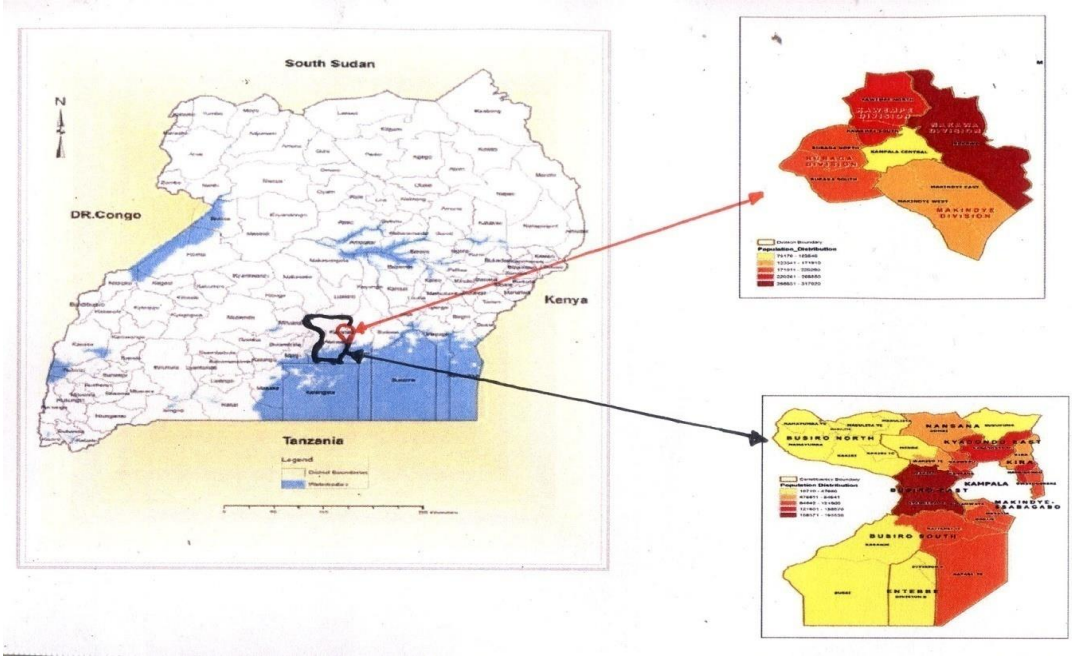
The eighth top tribal group in Uganda are the Bagisu, speak Massaba language; the Bagisu tribe has no migration history, they claim that Mundu and Sera were the names of their ancestors; male circumcision is the main and most distinctive social rite of the Bagisu people; the Bagisu culture does not allow uncircumcised men to wed Bagisu women; the Bagisu people live in Eastern Uganda, mainly concentrated near Mount Elgon (Focus East Africa Tours, 2024).

The ninth top tribal group in Uganda are the Lugbara, speak Lugbara, one of the Central Sudanic languages; the Lugbara are settled farmers who culturally value shifting-hoe farming for their livelihood; the Lugbara’s emblem is the leopard, it signifies independence and power; the preferred traditional food is cassava eaten as mingled cassava flour which is locally known as “Anara;” the Lugbara people are well known for their marriage cultural value that requires high price dowry in form of cows, material items, and money from the man’s family in exchange of a woman; the Lugbara people live in West Nile Region of Uganda and others live in the Democratic Republic of Congo (Focus East Africa Tours, 2024).

1.3 The Kampala-Wakiso contextual issues

CEBU study took place in Kampala and Wakiso districts of Uganda. Kampala being the capital city of Uganda had the second highest population (1,680,600 people), and Wakiso, one of the new city in Uganda had the highest population (2,915,200 people) (International Growth Centre, 2021; Uganda Bureau of Statistics, 2020).

Figure 2. Map Showing the Location of Kampala and Wakiso Districts in Uganda



Note. Figure 2 = Map of Uganda adapted from Uganda Bureau of Statistics (2017), showing the location of Kampala and Wakiso Districts in Uganda; ←→ = Kampala; ←→ = Wakiso

The administrative system in Kampala is centrally managed by Kampala Capital City Authority (KCCA) with five divisions: Central, Nakawa, Makindye, Rubaga, and Kawempe (Uganda Bureau of Statistics, 2020). On the other hand, the political demarcations of Kampala comprises eight constituencies: Kampala Central, Kawempe North, Kawempe South, Makindye East, Makindye West, Rubaga North, Rubaga South, and Nakawa (Uganda Bureau of Statistics, 2020).

Wakiso encircles Kampala as shown in the map; its administrative system comprises Entebbe municipality, Kyadondo, and Busiro counties (Uganda Bureau of Statistics, 2020). The political demarcations of Wakiso comprises eight constituencies: Kira, Entebbe, Makindye-Ssabagabo, Nansana, Kyadondo East, Busiro South, Busiro North, and Busiro East (Uganda Bureau of Statistics, 2020).

1.4 The Uganda health care system

Uganda has one of the most robust health structures in Africa in a decentralized government; this is provided for in its local government's Act (cap. 243) (1997) (Uganda Local Government, 2020); the Act provides for city, municipal, division/town, ward, and cell councils in urban settings;

district councils, counties (which are administrative units without a council), sub-county councils, parish councils, and village councils in rural settings. For intergovernmental relations, the President of Uganda, appoints the Resident District Commissioner (RDC) to represent national government and coordinate the administration of government services in the district. The RDC is the main contact person between local and national government system; for example, at the lowest ward/village level, the RDC provides support for basic computer skills such as the use of spreadsheets to maintain records for planning and management purposes (Uganda Local Government, 2020).

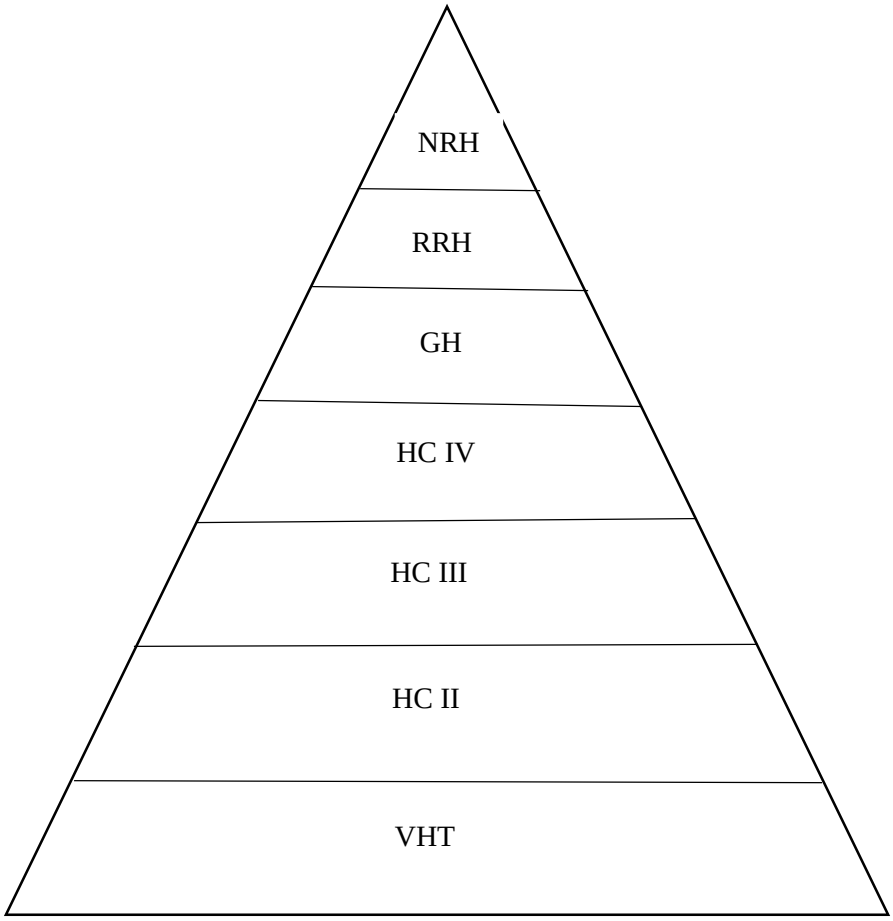
Under section 35(3) of the local government's Act (cap 243) (1997), district councils are mandated to prepare a comprehensive and integrated development plan incorporating plans of sub-counties and municipal councils for submission to the national planning authority. On the same line, sub-counties and municipal councils must prepare plans incorporating the plans of parish/ward councils, and village/cell councils in their respective area of jurisdiction. This planning activity is coordinated by the district technical planning committee and by the sub-county planning and budget desk based in the planning unit. The plans which include health services are submitted to the respective councils for consideration in accordance with section 37 (4) of the local government's Act (Uganda Local Government, 2020).

The health services are delivered according to disease complexity. This starts at the village or community level, village health team (VHT) to the national level, national referral hospital (NRH); there are Regional Referral Hospital (RRH), General Hospital (GH), and Health Center (HC): IV, III, and II between NRH and VHT (Nampala, 2018).

The NRH, RRH, GH, and HC are statutory health facilities; this means, services in those health facilities are state financed (Nampala, 2018). Meanwhile, the VHT are non-statutory community structures; this means, VHT services are not state financed; the VHT are elected by the community members as part of the local council to voluntarily serve the community (Nampala, 2018).
The management of a disease condition in Uganda, therefore, starts at the VHT level and follows through the referral pathway to HC II, HC III, HC IV, GH, RRH, and NRH depending on the complexity of the patient's health condition and the capacity of the health facility. If the health facility has capacity to manage the patient's health condition, the referral stops; however, if the

health facility does not have capacity to manage the patient's health condition, the referral proceeds to a higher health facility (Nampala, 2018); the structure of health system in Uganda is as shown below (Figure 3).

Figure 3. The Uganda Health Care Structure and Referral System



Note. Figure 3 = Seven tiered hierarchical levels of Uganda health care structure adapted from Nampala (2018); VHT = Village Health Team; HC II = Health Center Two; HC III = Health Center Three; HC IV = Health Center Four; GH = General Hospital; RRH = Regional Referral Hospital; NRH = National Referral Hospital

The Uganda health care system, however, does not restrict self-referred patients who bypass the referral system put in place by government. The self-referred patients usually justify their decisions based on distance and service availability. In terms of distance, a patient living in the neighborhood of a NRH may argue for no need to seek for referral to the NRH. More so, service availability is

often guaranteed in higher health facilities like RRH and NRH than lower health facilities like HCII, HCIII, and HCIV.

The proposed CEBU fits within all the health care structure and referral system in Uganda through community connectedness at the African One Hospital. The NRH will be the center for community connectedness to implement CEBU in selected communities (for example, RRH, GH, HCIV, HCIII, HCII, and VHT). The community connectedness approach builds on the original idea for the KWB-HTC usual intervention where doctors, nurses, and therapists from the African One Hospital work with a group of children with brain injury and caregivers in a community home center as described below.

1.5 The KWB-HTC usual intervention

The KWB-HTC usual intervention was implemented every first four Saturdays of each month; three C2C caregivers implemented the usual intervention on the first Saturday; three therapists on the second Saturday; five nurses on the third Saturday; and three doctors on the fourth Saturday. Each Saturday had 14-18 children with brain injury and 14-18 caregivers in attendance.

Three C2C caregivers were trained by OTD-M on how to handle children with brain injury; the training was based on the C2C principles which include getting the child's body ready, play and communication, postural management, and safe feeding practices among others (Saloojee et al., 2021; Saloojee & Bezuidenhout, 2020). Other GPG members (doctors, nurses, and therapists) were not trained by OTD-M because they already had enough expertise in handling children with brain injury based on their previous work experience in African One Hospital.

The KWB-HTC was open between 8am and 5pm Kampala time. Each group, 4-6 children with brain injury attended the center in three hour shifts i.e., 08h00, 11h00, and 14h00. The caregivers together with the children arrived at the KWB-HTC reception desk and started registration at 8am Kampala time. The first child to arrive received registration number one and the last child to arrive received registration number ranging from 14 to 18 depending on the total number of children with brain injury on a specific day.

The KWB-HTC usual intervention would start with a body hygiene session for 25-30 minutes in the hygiene room. The second, exercise session for 20 minutes in the exercise room. The third, dressing and play session for 25-30 minutes in the dressing and playroom. The fourth, feeding, medicine and assistive technology use session for 30-35 minutes in the feeding, medicine, and assistive technology room. After the fourth session, children and caregivers were allowed to go back home via the reception desk.

1.6 The start of the CEBU study in the KWB-HTC usual intervention

GPG members partnered with the researcher in the CEBU study which involved eight children; this started at 8:30am Kampala time and ended for children at 1pm Kampala time. The researcher then invited the GPG members for collective reflection which started at 2pm Kampala time and ended at 5pm Kampala time on the same day for action-observation. Tea break was allocated 30 minutes between 10:30am and 11am Kampala time. Lunch break was allocated 45-minutes between 1pm and 1:45pm Kampala time. The collective reflection was described as self-observation and individual reflections leading to re-analysis of the significance of the usual interactional actions (de-la-Cueva-Ariza, Delgado-Hito, Martinez-Estalella, Via-Clavero, Lluch-Canut, & Romero-Garcia, 2018).

Table 1. GPG Members Involved in the Action-Observation at the KWB-HTC (n= 8)

Dates	GPG	PN1	PN2	PN3	PN4	PN5	PN6	PN7	PN8
7 Jan 2023	C2C Caregivers	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4
14 Jan 2023	Therapists	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4
21 Jan 2023	Doctors	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4
28 Jan 2023	Nurses	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4	AO1-4

Note. GPG = General Participants Group; PN1 = Atin; PN2 = Omwa; PN3 = Dazo; PN4 = Amol; PN5 = Mera; PN6 = Omol; PN7 = Abil; PN8 = Bade; AO1-4 = Action-Observation Room Number One to Four; Jan = January

1.7 Problem statement

Children with brain injury in Uganda have suffered disability and participation restriction in diverse cultural contexts for long because there has been no culturally relevant programme coupled with limited context specific information to guide stake holders' collaborative work (Mehmood, Zia, Hoe, Kobusingye, Ssenyojo, and Hyder, 1018). A culturally relevant programme should address some of the context specific information gaps such as patients' demographics, pre-hospital and hospital assessment and care, brain injury causes, brain injury severity, and treatment outcomes (Mehmood, Zia, Hoe, Kobusingye, Ssenyojo, and Hyder, 1018). The absence of a culturally relevant programme undermines the stakeholders' agenda to reduce deaths and disabilities from brain injury in Uganda. The World Health Organization (2007) described the contributors of participation restriction as lack of inclusive or care attitude among family members, health professionals, teachers, and community members. In this case, every Ugandan child with brain injury would require meaningful occupation shaped by their own voices and cultural values under the auspice of caregivers and health professionals to overcome participation restriction (Saloojee et al., 2021).

From other studies, the researcher noted that without meaningful occupation that includes the voices and cultural values of children with brain injury, many Ugandan children with brain injury may die or continue to suffer from activity functional loss, regress in life satisfaction, and their caregivers may experience poor health outcomes as a consequence of stress from seeing and caring for their struggling children (Bergstrom, von Koch, Andersson, Tham, & Eriksson, 2015; Egan, Davis, Dubouloz, Kessler, & Kubina, 2014; Singam, Ytterberg, Tham, & von Koch, 2015).

The cry of children with brain injury in KWB-HTC Uganda, therefore, reminded us about the urgent need for a Culturally relevant programme for Enabling participation of children with Brain injury in Uganda (CEBU). In this context, CEBU means an intervention programme that bridges basic needs and enablement based on children's voices and cultural values.

1.7.1 *Rationale*

All children from different socio-economic backgrounds, children from marginalized groups, and children with disabilities including those with brain injury should have the same right to participate in society (United Nations, 2018). The principle of 'leaving no one behind' pronounced during the

UN Decade of Persons with Disabilities (1983-1992) remains the conscious force for driving a focus on enabling participation for all human beings (United Nations, 1982). In addition, the recent disability ideology 'nothing about us without us' supports a vision for participation (Brown and Stoffel, 2011); this is embedded in the principle of independent living (Ratzka, 2012; Hasler, 2003). Independent living, according to Ratzka (2012) means freedom, choice, control, and equality in daily life within a given context. This research, therefore, assumed that CEBU ideology, is ingrained in the principle of independent living through collective voices for leaving no child behind and treating every child as valued and respected members of society. The CEBU co-creation process embodied the United Nations (2018) disability ideology; "nothing about us without us" for involving children with brain injury and their caregivers during the co-creation process.

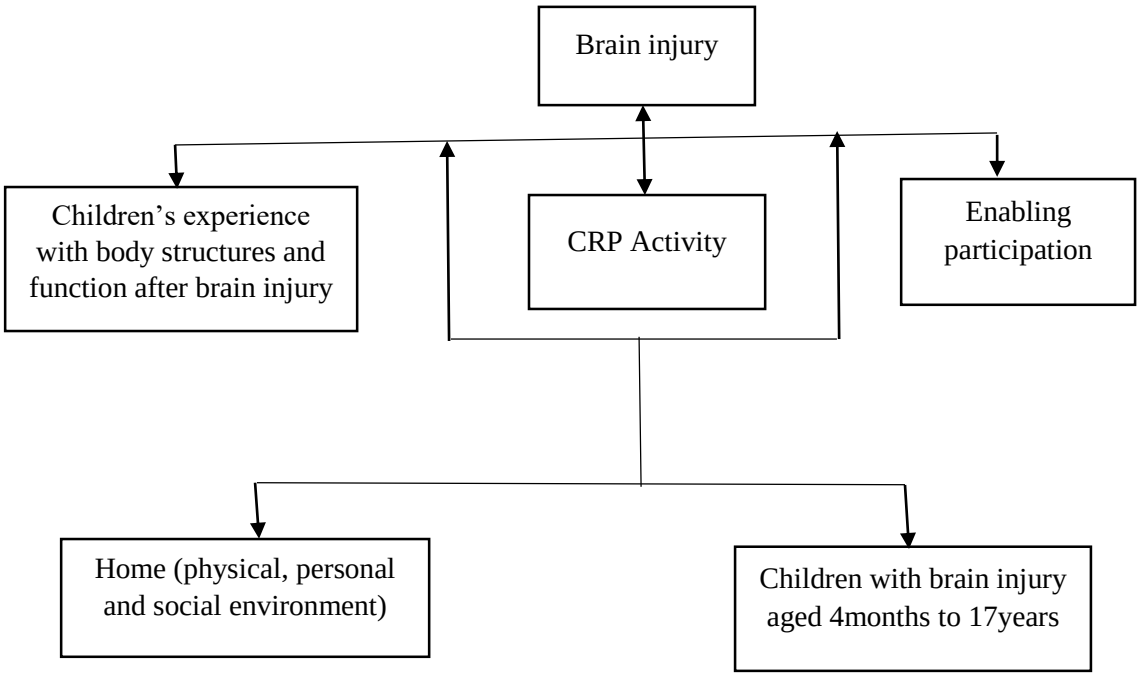
Taking a leaf from the principle of independent living (Hasler, 2003; Ratzka, 2012), CEBU should focus on the needs of children with brain injury. In this way, all concerned stakeholders should be aware about the ethics of care for children with brain injury particularly looking on how to enable their participation in society. The stake holders should be encouraged to implement what fits the needs of children with brain injury in diverse cultural contexts: first, by removing all barriers such as a lack of inclusive or care attitude among family members, health professionals, teachers and community members (World Health Organization, 2007).

This study findings, therefore, will motivate caregivers, health professionals, and different community members to embrace the vision for a society where every child with brain injury have equal opportunity to participate in daily life cultural choices and involve in meaningful occupation for health and wellbeing.

1.8 Conceptual framework

The CEBU study was conceptualized by contextualizing the World Health Organization's International Classification of Functioning, Disability and Health (WHO ICF) (2001) as shown below (Figure 4).

Figure 4. The ICF Contextualized Conceptual Framework Used to Guide the CEBU Study



Note. Figure 4 = Contextualized ICF (World Health Organization, 2001) used to guide the CEBU study; CRP = Culturally Relevant Programme

1.9 Philosophical and theoretical perspectives

The philosophical stance of the researcher in this study was a constructivism paradigm which rejects any possible single representation of reality (Charmaz, 2016) and emphasizes a belief in multiple realities that are linked to the diverse experiences of individuals which are formed through different interpretations, meanings, and intentions (Crotty, 2020; Charmaz, 2000). A constructivist perspective foregrounds that reality is shaped by our interpretations or constructions of our experiences, and while experiences may appear to be standard or similar they are open to many interpretations and any of those explanations or all of which may be correct (Jaccard & Jacoby,

2010). Conversely, this study recognized the limitation of constructivism; for instance, potential for subjective interpretations that limits generalizability or broader patterns (Charmaz, 2016).

The researcher focused on the development of an intervention programme which supports the occupational engagement of all children with brain injury in meaningful and culturally relevant ways. This thesis was drawn to the ways in which constructivism allows the researcher to explore multiple realities of engagement as experienced by each child and their families. With the understanding of multiple realities, the researcher valued constructivism as it encouraged open mindedness in exploring cultural values via different perspectives of the other people, the researcher partnered with to develop the CEBU.

The choice of a constructivist research paradigm informed the researcher's ontological stance of a culturally relevant programme (CRP) based on the underlying philosophies of occupational therapy and occupational science (for example, Law et al., 1996), which shaped the researcher's belief about the CRP as being a form of occupation with multiple realities that include what each child needs and does in the context that may lower the risk of disability or functional loss. The justification for the choice of a constructivism research paradigm was a belief that constructivist perspective offers flexibility in the use of strategies and principles which allows the researcher to adhere to the chosen methodology using a PAR approach instead of being prescriptive (Charmaz, 2014). Within occupational therapy practice, constructivism may be seen as linked to client-centeredness, the understanding of individual experiences of occupation, and the social and cultural contexts of participation through the use of Person-Environment-Occupation (PEO) model (Law et al., 1996).

From the epistemological perspective, the researcher desired to know about "enablement and participation" in a Uganda home context guided by the Person-Environment-Occupation (PEO) model (Law et al., 1996). In this research, the PEO model by Law and friends (1996) was used to trigger debate and reflections between the researcher and participants concerning their thoughts about CEBU. The use of constructivist perspectives (Charmaz, 2016) helped the researcher to shape thinking about the practical use of the PEO model (Law et al., 1996); facilitating discussions about daily life experiences of caregivers and health professionals involved in the care of children with brain injury in Uganda. In doing this, the researcher wanted to know more about realities

concerning the usual intervention programme at the KWB-HTC, and which would support action changes. The realities were sought from multiple sources (doctors, nurses, therapists, caregivers, and children with brain injury) with a focus on enablement and participation; this affirmed the contextual relevance of constructivism in this study which applied the PAR principles of knowledge co-creation (Kemmis & McTaggart, 1988), 2014), grounded on the use of PEO model (Law et al., 1996), and guided by constructivism philosophy (Charmaz, 2016).

1.10 Research question

The overall research question of this thesis: How do the participants co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda (CEBU) and describe its co-creation process?

1.11 Aim of thesis

The aim was to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda (CEBU) and describe its co-creation process.

1.11.1 *Specific objectives*

The specific objectives of this thesis were:

(i) To explore the participants' thoughts, feelings, and perceptions of the usual intervention programme in KWB-HTC Uganda (study one).

(ii) To generate a culturally relevant programme enabling participation of children with brain injury in KWB-HTC Uganda (study two).

(iii) To describe the consequences and limitations of the culturally relevant programme enabling participation of children with brain injury in Uganda (study three).

1.12 Research assumptions

- CEBU ideology is ingrained in the principle of independent living through collective voices for leaving no child behind and treating every child as valued and respected members of society.
- CEBU involves a shift in attitude, perceptions, and support system within established environmental contexts restricting participation of children with brain injury in Uganda.

- CEBU applies the principle of occupational performance coaching (Graham, Rodger, and Ziviani, 2009) to influence occupational therapy practice for children with brain injury in Uganda.
- CEBU co-creation process requires a participatory action research (PAR) design (Kemmis and McTaggart, 1988) to engage multi-level participants as evidenced from other studies (de-la-Cueva-Ariza et al., 2018).
- The Uganda health care structures operating at seven levels (Nampala, 2018) can use the CEBU practice framework in all the seven levels to uphold the cultural values and voices of every Ugandan child with brain injury.
- The implementation of CEBU practice framework requires partnership between caregivers and different health professionals (for example, therapists: occupational therapist, physiotherapist, speech and language therapist; doctors: neurosurgeon, physician, psychiatrist, pediatrician, general practitioners; nurses: nutrition nurse, pediatric nurse, neuro-surgical nurse, and psychiatric nurse).

Chapter two: Literature Review

2.0 Literature Review

2.1 Introduction

In this study, the researcher conducted several literature searches between July 2021 and September 2021 to present an in-depth description of the participation challenges of children with brain injury and rehabilitation services. There was an intentional focus on what had been written about the cultural relevant programmes for children with brain injury. The following search terms were used:

> Children with brain injury OR brain injured children OR children with traumatic brain injury
>
> AND culturally relevant intervention OR culturally relevant rehabilitation OR culturally relevant programme, AND occupational engagement OR participation OR inclusion.

The data sources included: EBSCOhost MEDLINE Complete, EBSCOhost web CINAHL, EBSCOhost Research Databases, PubMed Central, and DOAJ (Directory of Open Access Journals). Only peer reviewed literature published between 2000 up to 2021 were selected and reviewed. Exceptions were made for literature about brain injury theories and models of practice to include those published from 1970 up to 2021. In addition, the literature review followed the PRISMA (2020) method (Page, McKenzie, and Bossuyt et al., 2021); as detailed in (appendix, nine). Using the PRISMA method, the researcher identified 5014 records from different data bases; 802 duplicate records were removed before screening, 1121 records were removed through computer automation, 26 records were removed for other reasons; 3062 records were screened; 673 records were excluded after screening; 801 records were sought for retrieval; 224 records were not retrieved; 586 records were assessed for eligibility; 109 records were excluded because no information on brain injury was found in those records, 88 records were excluded because the studies were conducted on adult population, 46 records were excluded because of clarity issues; 343 new studies were included; 104 reports of new studies included; total studies included in review (new studies, previous version of review, and studies via other sources) were 374; reports of total studies included (new studies, previous version of review, and studies via other sources) were 119; the details in (appendix 9). An updated literature review was conducted between August 2023 and December 2024; this included a total of 81 studies reviewed, and 23 studies reported on.

No literature related to culturally relevant programme enabling participation of children with brain injury was located, justifying the current research topic.

2.2 Background literatures

The World Health Organization (2011) estimated one billion people with disabilities (PwD) in the world and 80% reside in low-income countries. In addition, the World Health Organization (WHO) estimated that in 2011, only 3% of individuals world-wide received adequate rehabilitation requirements (World Health Organization, 2011). Following the international standards and a normative framework for disability, the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), provides for a paradigm shift in attitude and approaches to people with disability, especially viewing them as active contributing members of society with equal rights (United Nations, 2006).

Available literature points that several children with brain injury in developing countries are poor and experience difficulties in accessing basic health services, including rehabilitation services (Bhatia & Joseph, 2000). For example, most African countries including Uganda, often place efforts in improving acute care services with little or nothing for post-acute care services such as rehabilitation (Lemogoum, Degaute, & Bovet, 2005; Ogungbo, Ogun, Ushewokunze, Mendelow, Walker, & Rodgers, 2005; Tuakli-Wosornu & Haig, 2014; World Health Organization, 2004).

2.3 Brain injury

The World Health Organization, International Classification of Diseases 11th Revision (ICD-11) includes diseases, disorders, and injuries (World Health Organization, 2018). Both the ICD-11 and ICF-CY complement each other to diagnose diseases, disorders, and injuries (World Health Organization, 2007, 2018). The ICD-11 supposed that children with brain injury fall under different forms of disorders or diseases such as stroke, cerebral palsy, traumatic brain injury and so on; these are specific diagnoses meant to guide decisions on the culturally relevant programme (CRP) that fit the heterogeneous nature of functional challenges associated with the disorder or disease (Galvin, Froude, & McAleer, 2010).

From a severity perspective, a Glasgow Coma Scale (GCS) score which is a global neurologic measure is often used to evaluate the functional challenges of children with brain injury based on

eye opening, motor, and verbal responses to various level of stimuli especially during early stages of onset of injury (Teasdale & Jennett, 1974). The GCS score nine to 12, means moderate brain injury; GCS score three to eight means severe brain injury; GCS score 14 to 15 means no significant brain injury (Teasdale & Jennett, 1974).

For a child who sustains moderate to severe brain injury, there can be long term physical, cognitive, emotional, behavioral, or social impairments with resultant problems in development, socialization, and independent living (Eker, Schalen, Asgeirsson, Grande, Ranstam, & Nordstrom, 2000; Ommaya, Goldsmith, & Thibault, 2002). However, the challenging aspect of brain injury is that each brain injured child presents differently and at the same time brain injury may influence the child's development differently depending on the nature of injury, severity, and age (Fink, Stagnitti, & Galvin, 2012). According to Galvin and friends, recovery from brain injury can be unpredictable and the predictability depends on the severity and age (Galvin, Froude, & McAleer, 2010). Different studies showed that children who sustain moderate to severe brain injury diagnosed according to GCS are more likely to remain dependent on others to achieve daily living activities (Blosser & DePompei, 1996; Teasell, Bayona, Marshall, Cullen, Bayley, & Chundamala et al., 2007).

In the literature reviewed about brain injury, no literature was found connecting brain injury or children with brain injury and culturally relevant programme; the researcher had to look at this as a knowledge gap in relation to CEBU.

2.4 The impact of brain injury on the occupational engagement of children in form of body functioning and activity functioning

The World Health Organization (2007) describes functioning and disability as a complex interaction between the individual's health condition and the contextual factors of the environment and personal factors. As such, the health condition of an individual affects body and activity functioning leading to participation restriction (World Health Organization, 2001, 2007). The concept of body functioning refers to physiological and psychological functions of body systems; this involves body structures, the anatomical parts such as organs, limbs, and their components (World Health Organization, 2007). The concept activity functioning refers to the child's ability to perform normal activities of daily living such as play, dressing, feeding, and so on (Schulze,

2015). Because of brain injury, a child may experience mobility and activity limitations that restrict participation in daily occupations within home contexts, community, and the broader society (Donkervoort, Wiegerink, van Meeteren, Stam, & Roebroeck, 2009).

The World Health Organization, ICF-CY (2007) further supports the relationship between body function and body structures, activity, and participation. For example, if a child with brain injury can move the limb efficiently, their range of activities expands and engaging in diverse activities may enable fulfillment of participation (Dunkervoort, Wiegerink, van Meeteren, Stam, & Roebroeck, 2009). In this case, the degree of function in finger movement, activities, and gross mobility affects participation in leisure (Dunkervoort, Wiegerink, van Meeteren, Stam, & Roebroeck, 2009). The degree of functional limitation at body or activity level not only affects participation but also affects a person's overall health condition (Okumura, Hersh, Hilton, & Lotstein, 2013).

Other studies have found out that children with brain injury often experience feeding challenges due to limited engagement which led to malnutrition (Kakooza-Mwesige, Tumwine, & Eliasson et al., 2015). To increase the child's level of activity engagement, efforts are needed to address the contextual issues restricting participation (Darrah, Law, Pollock, Wilson, Russell, & Walter et al., 2011). The body functioning issues, and activity functioning issues are two contextual issues that this study recognized as important aspects to guide decisions about a culturally relevant programme enabling participation of children with brain injury in Uganda. For example, Schulze (2015) reported that children with brain injury often require caregiver's assistance and more time to perform different activities because of body functioning issues; in addition, Schulze (2015) argued that activity, body functioning, and participation are inseparable. Several studies have shown that children who experience body functional challenges may find difficulty in performing daily living tasks and in the end may experience participation restriction concerning getting ready and functioning in outdoor activities (Bundy, 1995; Cordier, Bundy, Hocking, & Einfeld, 2009; Rowe, 2008).

Other studies attest that children with activity limitations often miss the play time because it takes them too long to get ready, as such delay and functional limitations in activities of daily living can be barriers to participation in family life, school, and society in general (Cairney, Hay, Faught,

Wade, Corna, & Flouris, 2005; Mandich, Polatajko, & Rodger, 2003; Ostensjø, Carlberg, & Vøllestad, 2003).

No literature was found referring to the impact of brain injury on children's occupational engagement in line with a culturally relevant programme. The researcher had to look at this as a knowledge gap in relation to CEBU.

2.5 Cultural relevance in programmes for children with brain injury

CEBU brings together five different concepts: culture, relevance, programme, enablement, and participation. From the study ontology, the concept culture means the usual patterns of behavior that influence health through its established environmental parameters to which individuals must respond (Gannotti & Handwerker, 2002); the concept relevance means cultures shaped by the dimensions and severity of a particular condition or disease through the socially constructed meaning of the condition or impairment to the individual, to other social actors in the individual's life (for children this would mean their parents, siblings, teachers, therapists, and friends), and the presence of barriers to independence within the physical and cultural environment (Gannotti & Handwerker, 2002); and the concept programme means attitudes, perceptions, and support systems present or not present in families and communities that impede or enable the ability of children with disabilities to reach their maximum potential (Albrecht & Higgins, 1977; Edgerton, 1988).

From the epistemological standpoint, the concept enablement means the positive aspects of the interaction between an individual with a health condition and that individual's contextual factors (environmental and personal factors) (World Health Organization, 2001); then, the concept participation means involvement in a life situation (World Health Organization, 2001). In this study, CEBU was defined as changes enacted in the environment through the socially constructed meaning to the individual and/or social actors in the life of a child with brain injury aimed at enabling participation of children with brain injury in diverse cultural contexts.

The World Health Organization (2007) highlighted several activities which in principle may mean culturally relevant activities associated with maintenance of one's health, moving around, transportation, acceptance, recreation and leisure, and relationships (World Health Organization, 2007). In line with the maintenance of health, it is further argued that a lack of activity involvement

of a person experiencing functional restrictions can lead to the development of secondary disabilities, and other serious health problems (Davison, Maguire, McLaughlin, & Simms, 2022). The current study argued that children with brain injury may be enabled to participate in society by getting involved in relevant disability preventive activities such as daily exercises. One way of doing this is to encourage assisted or active mobility. The World Health Organization (2007) further supports the idea that individuals with disability need to move around with or without equipment or caregivers' assistance to maintain health and wellbeing.

Among other things, children with brain injury should participate in activities with their peers to promote their growth and development (Bjorquist, Nordmark, & Hallstrom, 2015). One way of doing this is to address the issue of transportation; the World Health Organization (2007) emphasized the use of appropriate means of transport to encourage participation in daily activities.

Available literature points out modifying tasks and environment to assist children with brain injury reach desired level of activity participation (Foo, Galvin, & Olsen, 2012). Environmental modification is applied through the principle of 'context therapy,' where efforts are directed in making changes within the child's environment without attempting to remediate the impairments (Darrah, Law, Pollock, Wilson, Russell, & Walter et al., 2011). Although this approach has yielded promising results in brain injury studies particularly focusing on cerebral palsy, its use in different interventions may be controversial because of cultural diversity associated with new contexts. With those controversies about context therapy, more evidence may be required to support the use of context therapy in diverse contexts.

One study has so far described context therapy as the most effective intervention for improving participation of children with brain injury especially those with cerebral palsy (Novak, McIntyre, Morgan, Campbell, Dark, & Morton et al., 2013). In contrast, other studies have suggested that the main problem of context therapy is about its appropriateness across different settings, and different brain injury conditions occurring in children (Thompson, Elliott, Willis, Ward, & Falkmer et al., 2016). This kind of controversy, risk use of context therapy across diverse cultural spaces because brain injury conditions present diverse barriers unique to the environment and person (Thompson, Elliott, Willis, Ward, & Falkmer et al., 2016). To minimize such unique environmental barriers, for example, cost of accessing services and geographical location, a family-centered approach to

practice has been commended by parents (Andrews, Falkmer, & Girdlers, 2014). In using the family centered approach, therapists who are skilled in activity grading and adaptation that meet the specific needs of children with brain injury, should work in a collaborative manner with parents/caregivers to build their capacity, and tackle barriers happening in the environment with a goal to enable participation of children with brain injury (Thompson, Elliott, Willis, Ward, & Falkmer et al., 2016).

This understanding that a family centered approach addresses barriers in the environment to enable participation of children with brain injury, may be traced from what Pachter and Harwood (1996) stated; the family, when supported may socially construct themes for enhancing the cultural life of its members; to achieve this, the family requires understanding, emotions, attitudes, and pattern of behaviors concerning children with disability. However, the likely benefit and cultural appropriateness of family centered approach are not defined in connection with a specific model of care for children with brain injury.

From these diverse viewpoints, it can be noted that the central element in enabling participation of children with brain injury are the parents/caregivers. Therefore, the use of occupational performance coaching which aims to empower parents may be perceived as a culturally relevant approach (Graham, Rodger, & Ziviani, 2009). In addition, another important approach termed solution-focused therapy that strengthens parent's capability for problem solving and developing a positive vision for the future have been linked to context therapy in terms of positive effects in meeting the child's goals (Graham, Rodger, & Ziviani, 2009). What is not clear is the evidence to support these ideologies: context therapy, family centered approach, occupational performance coaching, and solution focused intervention as a culturally relevant programme.

From a social model of disability, an important assumption was drawn that a social model of disability recognizes the impact of impairment, identifies constraints in social environment which often are the most significant barriers to participation of children with brain injury (Dempsey & Nankervis, 2005; Finkelstein, 1991). Thus, in using the social model, spaces can be created to change a lack of inclusive attitudes and develop actions geared towards barriers to inclusion and participation of children with brain injury at both family and society level (Thompson, Elliott, Willis, Ward, & Falkmer et al., 2016). With a lack of inclusive attitude, major barriers exist in

community programmes (Willis, Girdler, Thompson, Rosenberg, Reid, & Elliott, 2017). Therefore, to change that lack of inclusive attitude, a public awareness campaign is recommended as part of a successful programme for enabling participation of children with brain injury in diverse contexts (Heah, Case, McGuire, & Law, 2007). This adds to the conception that public awareness should form part of the CEBU ideology linked to the occupational perspective of health and wellbeing (Wilcock, 1998).

From the extensive literature reviewed about cultural relevance programmes for children with brain injury, it cannot be concluded what kind of intervention would form a culturally relevant programme for children with brain injury, making the CEBU a knowledge gap.

2.6 Home as physical, personal, and social environment

The home encompasses physical, social, and personal home (Sixsmith, 1986). The physical home refers to the structures and its spatial layout and arrangement of furniture. On the other hand, the social home enables opportunities for occupational engagement which are daily activities happening in social spaces (Angus, Kontos, Dyck, McKeever, & Poland, 2005). The home can be perceived as the center of social relations and interactions referred to as gathering, entertainment, and enjoying others' company (Sixsmith, 1986).

From another viewpoint, Moore (2000) argued that the emotional, social, physical, and symbolic embodiment of the home environment are products of social relations. In contrast, Sixsmith (1986) reported that the meaningfulness of home changes whenever people connected to unpleasant feelings are present. In this case, the personal home according to Marcus (1995) refers to choice of decoration, furniture, possession which together can be a place of self-impression and expression in material surrounding as well as a reference point for security and belonging in context. Several studies have reported that the use of home spaces, objects such as furniture and devices can enable functioning within home spaces (Molony, 2010; Rowles & Chaudhury, 2005; Sherman & Dacher, 2005; Twigger-Ross & Uzzell, 1996; Williams, 2002). With all these, the home can evoke self-reflection about life situations, choices, as well as representations using objects and/or material experiences (Sherman & Dacher, 2005; Twigg, 1999).

The unique personal attribute of an individual, the context of physical and socio-cultural environment, and specific components of the activity collectively determine successes or failures in a chosen activity of daily living (Gannotti & Handwerker, 2002; Holsbeeke, Ketelaar, Schoemaker, & Govter, 2009). Therefore, children's participation in daily living activities are often affected differently by contextual factors, and such differences should be considered when discussing possible action steps to enable participation given the established functional limitations (Kielhofner, 2016). Based on the understanding of the home, Weisner (1984), reported that the home is a key contextual setting for enabling participation of children with functional difficulties. For example, children who learn to eat by themselves are more familiar with the context in which the eating activity is being implemented to address functional limitation and gain mastery of required skills for daily living (Weisner, 1984). Therefore, it is important to consider both the child's functional limitations and contextual restrictions bearing on the activity (Haley, Coster, & Binda-Sundberg, 1994; Smits, Gorter, Ketelaar, Van Schie, Dallmeijer, Lindeman, & Jongmans, 2010; Young, Williams, Yoshida, Bombardier, & Wright, 1996).

From this extensive literature about the home, it is believed that the experience of children with brain injury can be formed in home spaces through sustained exposure to diverse cultural life situations that enable their choice of valued life situations and develop representation using home objects and spaces. In this way, the experiences of children with brain injury as with family members need to match the changing nature of the personal, physical, and social environment (Meijering, Nanninga, & Lettinga, 2016). Thus, enabling participation of children with brain injury at home requires critical changes or improvement to achieve a fit between the home environment, occupation, and child with brain injury. This ideology resonates with the person-environment-occupation (PEO) model often used in Occupational therapy by Occupational therapists (Law et al., 1996).

The literature reviewed about the home as personal, physical, and social environment drew the researcher closer to connecting with a culturally relevant programme from a contextual perspective but this did not bring out any specific model or programme applied in context as a culturally relevant programme; as such, the researcher continued to stress that CEBU was a knowledge gap.

2.7 Enabling participation of children with brain injury

The World Health Organization (2007) defines participation as a person's involvement in a situation that may include playing a role in society. In early childhood development, participation in leisure and recreation activities provides children with the opportunity to explore their own personal interests, grow as individuals and most importantly to enjoy life (Case-Smith, 2010; Simpkins, Ripke, Huston, & Eccles, 2005; World Health Organization, 2007). Available literature points to children with moderate and severe brain injury as experiencing significant participation restrictions in social and community-based leisure activities (Galvin, Froude, & McAleer, 2010). As a result of participation restriction at community level, most children with brain injury tend to participate more in their home environment with family members than with friends (Galvin, Froude, & McAleer, 2010).

The World Health Organization captures the dynamic interaction between health conditions (impairments), child's activity (carrying out an action or completing a task) and participation (involvement in daily life situations); inclusive of environmental and personal factors (World Health Organization, 2001, 2007). The ICF-CY relates facilitators or enablers to increased participation; while barriers to restricted participation (World Health Organization, 2007).

Within the immediate family, parents may serve as primary enablers for children's participation; for example, by being available to provide individualized support (Barr & Shields, 2011; Galvin, Froude, & McAleer, 2010; Oates, Bebbington, Bourke, Girdler, & Leonard, 2011). Further to this, Bar and Shields (2011) argued that friendship can motivate a child with a disability to participate in physical activity, sports, and general play. Conversely, a lack of friendship or difficulty making friends due to communication impairments may act as barriers to participation (Galvin, Froude, & McAleer, 2010). Other contextual issues such as environmental factors (e.g. physical geography and socio-economic status) have been identified as barriers or enablers to participation for children with disability in general (Imms, Reilly, Carlin, & Dodd, 2009; Oates, Bebbington, Bourke, Girdler, & Leonard, 2011). According to Barr and Shields (2011) societal attitudes may restrict participation of children with disability in physical activities. As such, Barr and Shields (2011) argued that most services, systems, and policies claim to be inclusive but in actual sense there is a lack of such services that enable the inclusion of children with disability in family and society life.

The problem of children with brain injury is often compounded by mainstream programmes that are unwilling or unable to be inclusive (Barr & Shields, 2011). With this point in mind, other studies reported strong enablers which include peers and community activity organizers who accept children with brain injury (Imms, Reilly, Carlin, & Dodd, 2009).

The literature reviewed about enabling participation of children with brain injury did not bring out any information about a culturally relevant programme for children with brain injury; this concluded the literature search, and the researcher concluded that CEBU was a knowledge gap.

Chapter three: Methods – Study Approach and Design

3.0 Methods – Study Approach and Design

This study was framed within a constructivist stance and a qualitative approach. More specifically, the researcher used a participatory action research design to explore multiple perspectives from a wide sample of participants which were then drawn on to guide a collaborative process to co-create the CEBU (Kemmis & McTaggart, 1988). With the constructivist paradigm, researchers nesting their worldview in constructivism believe in the collective construction of knowledge (Guba & Lincoln, 1989). The researcher believed that varied perspectives were required to underpin and support the process of developing CEBU, providing each participant the opportunity to share perspectives, discuss and then negotiate a consensus on how the CEBU should be composed and implemented (Guba & Lincoln, 2005).

The use of participatory action research facilitated a creative, iterative, and collaborative process of developing the CEBU with a specific intention to impact body functioning and activity functioning for children's participation in daily life cultural activities. Thus, it required a creative process whereby participants took steps to identify and change the identified contextual issues limiting body function and activity function for successful participation of children with brain injury in KWB-HTC Uganda. To achieve this, a co-creation process where participants did action planning, action observation, collective reflection, and re-analysis of action leading to action re-planning, action change observation, collective reflection of action change, and re-analysis of action change to have CEBU.

This followed similar previous PAR study work of de-la-Cueva-Ariza and friends (2018) in the study of patterned knowledge actions and improvement actions for nursing care of critical patient's family in a Tertiary Hospital, ICU in Barcelona (Spain). The CEBU co-creation process was a collaboration between the general participants' group (GPG) members (doctors, nurses, therapists, and caregivers), children with brain injury, and the researcher assisted by two research assistants. The study relied on the de-la-Cueva-Ariza et al. (2018) because there was no reported study for Uganda that utilized a PAR approach for this study to rely on about the practical use of PAR approach in related health research.

3.1 Participants

The researcher, 14 GPG members between 28 and 62 years (Table 2), and eight children with brain injury between two years and 14years (Table 3) participated in this study that took place in a home therapy center connected to African One Hospital, located in Kampala, the capital city of Uganda. Four participant's categories: three doctors, five nurses, three therapists, and three C2C caregivers formed the general participant groups (GPG); two members from each GPG with more years of experience in handling children with brain injury took part in the core participant group (CPG) meeting to discuss and approve GPG recommendations (de-la-Cueva-Ariza et al., 2018). Participants who met the inclusion criteria were purposively selected to take part in the study.

Table 2. Characteristics of GPG Members Involved in the CEBU Co-creation Process (n= 14)

Pseudonyms	SINo	Gender	Age (Yr)	Title	years of practice
Onit	D1	F	41	Neurosurgeon	05
Fiti	D2	F	30	Psychiatrist	02
Twil	D3	F	44	Pediatrics doctor	08
Ono	N1	F	62	Pediatrics nurse	32
Twi	N2	F	59	Pediatrics nurse	29
Throg	N3	F	47	Neurosurgical nurse	17
Fout	N4	F	40	Pediatrics nurse	14
Fivi	N5	F	48	Nutrition nurse	21
Onivo	T1	M	42	Physiotherapist	14
Twori	T2	M	28	Occupational therapist	07
Twiti	T3	F	35	Speech-language therapist	11
Onup	C1	F	61	C2C Caregiver	05
Twic	C2	F	29	C2C Caregiver	04
Logu	C3	F	40	C2C Caregiver	05

Note. SINo = Study Identification Number; Yr = years

3.1.1 *Recruitment and Sampling of Study Population*

A list of 84 children diagnosed with brain injury at the CDS Mulago and their caregivers were obtained from the Occupational Therapy Department (OTD), Mulago. From this list, the researcher identified 12 caregivers and 12 children with brain injury who were monthly attendees of the KWB-HTC. A total of three caregivers from the monthly attendees were purposively selected in line with the inclusion criteria described below to participate in the general participants' group (GPG) (de-la-cueva-Ariza et al., 2018). From the sampled caregivers, again a further purposive sampling was carried out to select two caregivers who acted as core participants' group (CPG) members. In addition, the researcher assessed all the 12 children who were coming monthly to the KWB-HTC. The assessment was carried out to get the children's sociodemographic baseline data, medical history, Glasgow Coma Scale (GCS) score, Gross Motor Function Classification (GMFCS), Manual Ability Classification (MACS), and Communication Function Classification (CFCS) as part of their selection process. A total of eight children with brain injury were purposively selected from among a group of 12 children with brain injury assessed, selection was based on age, medical history, GCS, GMFCS, MACS, and CFCS (Saloojee & Bezuidenhout, 2020; Hidecker, Paneth, Rosenbaum, et al., 2011; Palisano, Rosenbaum, Bartlett, and Livingston, 2008; Eliasson, Krumlinde-Sundholm, Rosblad, et al., 2006; Teasdale and Jannett, 1974).

A second group of general participants (three therapists) were purposively selected from among the 14 therapists (eight OTs, four PTs, and two SLTs) who completed a quality management system training organized by the Occupational Therapy Department, MNRH. The selection was based on the history of involvement in the KWB-HTC. From the sampled therapists, again a further purposive sampling was carried out to select two therapists who acted as core participants' group members.

A third group of general participants (five nurses) were purposively selected from among the 11 nurses (four Neurosurgery, four Pediatrics, and three Psychiatry) working at the MNRH in 2021/2022 financial year. The selection was based on the history of involvement in the KWB-HTC. From the sampled nurses, again a further purposive sampling was carried out to select two nurses to act as core participants' group members.

A fourth group of participants (three doctors) were purposively selected from among the 10 doctors (four Neurosurgery, three Pediatrics, and three Psychiatry) working at the MNRH in 2021/2022 financial year. The selection was based on the history of involvement in the KWB-HTC. From the sampled doctors, again a further purposive sampling was carried out to select two doctors to act as core participants' group members.

Using the contact details obtained from OTD, phone calls were made to the selected caregivers and therapists followed by physical visits to deliver invitation letters to them. The contact details for nurses, and doctors selected for the study were obtained from their respective heads of department at MNRH, phone calls were made to each of them followed by physical visit to deliver invitation letters.

3.1.2 *Inclusion and exclusion criteria*

The health professionals and caregivers who participated in the CEBU co-creation process were included or excluded based on six criteria:

- Age (health professionals and caregivers aged between 25 and 65 years were included; those aged below 25 and above 65 years were excluded).
- Language (health professionals and caregivers fluent in English were included; those not fluent in English were excluded).
- Origin (health professionals and caregivers who are Ugandan were included; non-Ugandan were excluded).
- Training (caregivers trained on C2C were included alongside health professionals who had at least two years working experience in handling children with brain injury in African One Hospital; those without this background were excluded).
- Commitment (health professionals and caregivers who committed 5-6 months for the study were included; those who did not commit the specified months were excluded).
- Registration (health professionals with up-to-date registration status with the AHPC or UMDPC or UNMC were included; those without any background were excluded).

The children with brain injury who participated in the CEBU co-creation process were included or excluded based on five criteria:

- Age and diagnosis (Saloojee and Bezuidenhout, 2020) (children aged two to 17 years diagnosed with brain injury condition were included; those below two and above 17 years were excluded).
- Gross Motor Function Classification (GMFCS) (Palisano, Rosenbaum, Bartlett, and Livingston, 2008) (children with GMFCS level two to five were included; those with GMFCS level one were excluded).
- Manual Ability Function Classification (MACS) (Eliasson, Krumlinde-Sundholm, and Rosblad, et al., 2006) (children with MACS level two to five were included; those with MACS level one were excluded).
- Communication Function Classification (CFCS) (Hidecker, Paneth, and Rosenbaum, et al., 2011) (children with CFCS level one to four were included; those with CFCS level five were excluded).
- Glasgow Coma Scale (GCS) (Teasdale and Jennett, 1974) (children with GCS level nine to 15 were included looking at their improved physical abilities and less dependence on caregivers that increased their chances for meaningful engagement; those with GCS level three to eight were excluded).

Table 3. Characteristics of the Children in the Study (n= 8)

Pseudonyms	SINo	Gender	Age (Yr)	Schooling	Diagnosis	GMFCS	MACS	CFCS	GCS
Atin	PN1	F	5	X0	CP	4	4	3	15
Omwa	PN2	F	11	X0	Hydro	3	2	1	15
Dazo	PN3	F	5	X0	CP	4	4	4	12
Amol	PN4	F	2	X0	CP	4	3	4	12
Mera	PN5	M	8	X1	TBI	5	3	2	15
Omol	PN6	M	14	X0	Stroke	2	2	2	15
Abil	PN7	F	3	X0	TBI	5	4	4	9
Bade	PN8	M	4	X0	Stroke	3	3	4	12

Note. SINo = Study Identification Number; Yr = years; GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System; CFCS = Communication Function Classification System; GCS = Glasgow Coma Scale; CP = Cerebral Palsy; Hydro = Hydrocephalus; TBI = Traumatic Brain Injury; X1 = Child Attending School; X0 = Child not Attending School.

The researcher adopted an active role in the knowledge co-creation process acting as both facilitator and participant during research engagements (Kemmis & McTaggart, 1988). This took place in parallel to observing and reflecting about the research process (Arieli, Friedman, & Agbaria, 2009). Examples of the roles assumed in the research process are presented below:

The researcher not only facilitated and participated in the GPG meetings but was also involved in coordinating activities about involvement of children with brain injury and GPG members during interactional actions in different KWB-HTC action rooms.

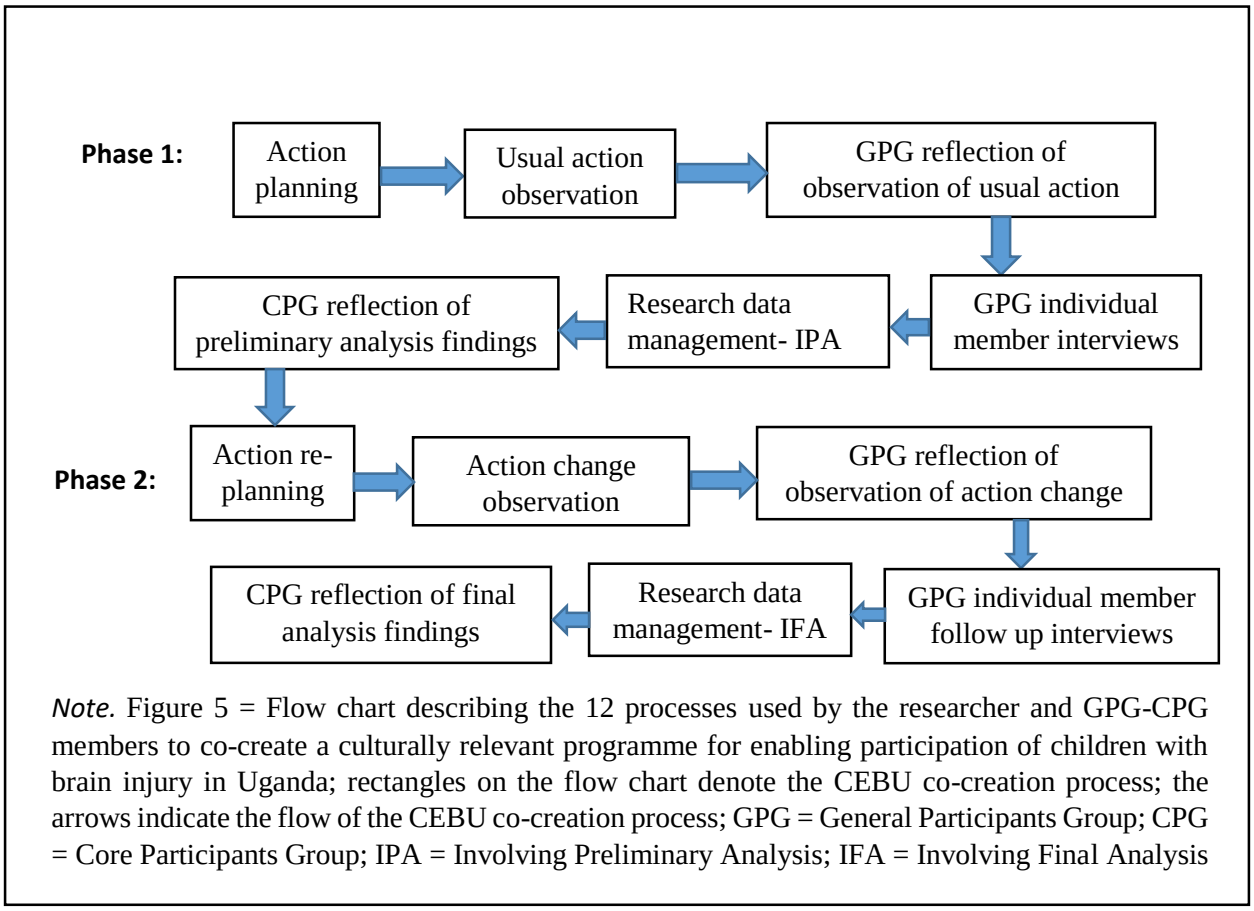
The researcher encouraged each GPG member to remain involved from 8:30am to 5pm Kampala time; children with brain injury together with their caregivers to remain involved from 8:30am to 1pm Kampala time.

The researcher provided feedback to GPG members on interactional actions that did not work based on the observed responses of children with brain injury to justify the need for action change.

3.2 The research process for co-creating CEBU

The research process for co-creating CEBU started in January 2023 with action planning and ended in August 2023 with CPG reflection of final analysis findings. This was conducted in two phases and 12 processes as shown below (figure 5) and described in the text.

Figure 5. The Research Process for Co-creating a Culturally Relevant Programme Enabling Participation of Children with Brain Injury in Uganda (CEBU)



Note. Figure 5 = Flow chart describing the 12 processes used by the researcher and GPG-CPG members to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda; rectangles on the flow chart denote the CEBU co-creation process; the arrows indicate the flow of the CEBU co-creation process; GPG = General Participants Group; CPG = Core Participants Group; IPA = Involving Preliminary Analysis; IFA = Involving Final Analysis

The GPG members in their different groups (doctors, nurses, therapists, and caregivers) participated in two phases of research undertaking for co-creating CEBU similar to the PAR work of de-la-Cueva-Ariza and friends which emphasised multi-level participants involvement that used three principles: self-observation, individual reflections, and collective reflections, leading to the re-analysis of the significance of the usual interactional actions and as a justification for change of actions in phase two (de-la-Cueva-Ariza et al., 2018); this is detailed below:

3.2.1 *Action planning (January 2023)*

Action planning was the first process for co-creating CEBU. In action planning, the researcher invited the research assistant and GPG members, and the researcher outlined the details for study participation. In addition, clarified on the roles of GPG members (three doctors, five nurses, three therapists, and three C2C caregivers) and research assistants. The GPG members and research

assistants participated in a training that took place in the African One Hospital focused on human subject protection, brain injury, PAR, data collection and monitoring, COVID-19 and Ebola prevention. In the training, eight children with brain injury were represented by their caregivers.

It was agreed what procedure would be required to guide the implementation of the usual action observation (Table 4).

Table 4. Procedure to Guide the Implementation of the Usual Action Observation

PN	Action plan
One:	The usual action observation would involve eight children with brain injury, three C2C caregivers, three doctors, three therapists, five nurses, two research assistants, and researcher.
Two:	The usual interactional action observation would be described as getting children with brain injury involved in oral and body hygiene, exercise, dressing and play, feeding, assistive technology and medicine use as it has been happening before the study.
Three:	The researcher would ensure adherence to set procedures which require each child with brain injury (numbered one to eight) to participate in each of the interactional action room.
Four:	A system of entry and exit would allow a child to enter from room one or three and exit from room four or two.
Five:	The usual interactional action would take four hours, allowing each child 16 minutes in each interactional action room; three minutes for getting the child ready, 10 minutes for interactional action, three minutes for winding up and moving to the next room or exiting if finished.
Six:	The second child would be stationed and waiting in the next room to avoid time waste during the wind-up time.
Seven:	Each GPG member would record individual reflections in participation file during usual interactional action.
Eight:	The researcher or research assistant would record a five-minute video clip for each child involved in each interactional action room.
Nine:	The term systematic video recording would be used to mean the video recording should be performed for each child from entry to exit before starting on a new child.
Ten:	The researcher would coordinate the procedures One to Nine above.

Note. PN = Procedure Number

3.2.2 *Usual action observation (January 2023)*

Usual action observation was the second process for co-creating CEBU. The action observed was interactional in nature. The GPG members agreed on the procedure for implementing the usual action observation detailed above. Action was interactional in nature. At the start of the usual interactional action observation process, the researcher invited child number one and two, their caregivers, and the GPG members to action observation room one and action observation room three. The action observation room two and four were kept vacant to receive the first two children (number one and two).

Once the child in action observation room one reached action observation room four and the child in action observation room three reached action observation room two; the researcher invited two children with brain injury, child number three and child number four to interactional action observation room one and three which were already vacated. This was the time when all four action observation rooms were occupied. The researcher waited for all the four children with brain injury to exit before inviting another set of children; this was referred to as first action observation round.

The researcher invited child number five and six to action observation room one and three to start the second round of action observation. Finally, child number seven and eight were invited by the researcher to interactional action observation room one and three when the two rooms were vacated with child number five and six in action observation room number four and two respectively.

The GPG members did interactional action observation for each child with brain injury in each action observation room for 10 minutes before moving to the next room with a child in waiting; each child spent 16 minutes in each interactional action observation room. Altogether, the interactional actions with eight children with brain injury utilized four hours (first round, two hours; second round, two hours). There was a 30-minute tea break between the first round and second round of interactional action.

3.2.3 *GPG reflection of observation of usual action (January 2023)*

GPG reflection of observation of usual action was the third process for co-creating CEBU. The researcher invited the GPG members to reflect about the usual interactional action for each of the eight children with brain injury. Each GPG member shared their self-reflection recorded in the

participation file. The GPG reflection adopted valued shared self-reflection, discussed, and agreed as proposal for action change. The proposal for action change if rejected by the GPG reflection meeting was not taken forward as a culturally relevant programme for enabling participation of children with brain injury. Thus, the CPG meeting did not have to approve any usual action rejected by the GPG meeting.

At the start of the GPG reflection about observation of usual interactional action, members complained about spending the entire day at the study site.

> ”Fiti” (Psychiatrist) felt that the research work was too much: “I did not expect to spend my entire day in the KWB-HTC.... I had some private clients to attend to.... now it is too late...so I must cancel their appointment.”

Aware of the time constraints, the researcher highlighted the structure of the GPG reflection as follows: hearing submissions from each GPG individual member during their group meeting (doctors, therapists, C2C caregivers, and nurses).

The GPG - doctors, therapists, and C2C caregivers had five submissions per category for collective reflection: the first three submissions were based on the doctor’s or therapist’s or C2C caregiver’s individual self-reflection of the usual interactional action observation of children with brain injury. The fourth submission was based on the five minutes video recording of each child observed from each action room by the research assistant; this was supplemented by the fifth submission from the researcher.

For the GPG - nurses, the structure had seven submissions for collective reflection: the first five submissions were based on the nurse’s individual self-reflection of the usual interactional action observation of children with brain injury. The sixth submission was based on five minutes video recording of each child observed from each action room by the research assistant; this was supplemented by the seventh submission from the researcher.
The researcher facilitated the GPG discussion on each submission for about 20-30 minutes before the next submission.

3.2.4 *GPG individual member interviews (January 2023)*

GPG individual member interviews was the fourth process for co-creating CEBU. The researcher invited the GPG individual members for interviews on the fourth and fifth day after the GPG reflection. Each GPG member was interviewed on the appointment date and time at the research office in African One Hospital using structured interview questions (Appendix 10). The interviews generated additional data to supplement the GPG reflection. The researcher used open ended questions, encouraged flexible, and open communication during interviews (Gallacher & Gallagher, 2008). Open communication helped the GPG members to provide a broader picture about the problem associated with the usual intervention for children with brain injury in KWB-HTC Uganda. The researcher expanded the interview questions to explore challenges of children with brain injury in other contexts such as individual homes, government and private health facilities, government and private schools among others.

Each GPG member shared ideas about changes that would make a culturally relevant programme for children with brain injury in Uganda. For example, several participants were not happy for Government not supporting children with brain injury.

> "Logu" (C2C caregiver number three) explained how the Government of Uganda has let down children with brain injury: "I am not happy because the Government of Uganda does not prioritize the health and education of children with brain injury."

Finally, the researcher interviewed each GPG member about what would be the likely consequences and limitations of implementing the suggested changes depicted as CEBU.

3.2.5 *Research data management - involving preliminary analysis (January to March 2023)*

Research data management - involving preliminary analysis was the fifth process for co-creating CEBU. Research data management (RDM) refers to the documentation and organization of data within the research processes (http://www.digitalservices.lib.uct.ac.za/dls/services/rdm. The RDM includes: data collection, data capture, analysis, collaboration, and publishing (http://www.digitalservices.lib.uct.ac.za/dls/services/rdm.

The researcher audio recorded the GPG reflection and GPG individual interviews. In addition, the researcher and research assistant video recorded the usual action observation using video clips based on video record assessment (VRA).

Overall, data collected comprised: 120 video clips, four audio recordings for GPG reflection, 14 audio recordings for GPG individual member interviews, 14 participation files for GPG members' self-reflections, four sets of researcher's field notes, and one researcher's journal.

The researcher watched the video clips to cross check that the video data matched the audio data extracted from the videos during the GPG discussion (for example, audio data about interaction between the child, health professionals, and caregivers during usual action were extracted from the video recorded, and triangulated by checking video against audio to confirm action-interaction match; for instance, child cry was taken to mean discomfort and disapproval of action where the video data was taken), listened to the audio recordings, read through the self-reflections for each GPG member in the participation files; read the researcher's field notes and journals, and asked a few clarifying questions to specific GPG member on phone.

Preliminary analysis of data collected followed six steps process for thematic analysis (Braun & Clarke, 2006). As part of a justification, thematic analysis offers an accessible and theoretically flexible approach to analyzing qualitative data; formed by themes or patterns in relation to different epistemological and ontological positions. Other participatory action research projects have previously used thematic analysis to co-create knowledge about the development of outdoor play area for children (Nah & Lee, 2016). The researcher initially wanted to use narrative analysis to analyze the data collected but this could not work because some of the data collected did not fit narrative analysis; stories and their details (Ntinda, 2018), (for example, data concerning toy selection, skin care, ingestion, and medical prescription).

The researcher used the preliminary analysis findings to inform the CPG meeting and the second study cycle. From the preliminary analysis findings, the researcher generated six themes and 36 sub themes (two themes and nine sub themes for study one, two themes and 14 sub themes for study two, two themes and 13 sub themes for study three).

The researcher shared the preliminary analysis findings with the supervisors and the data monitoring team (senior consultant neurosurgeon in African One Hospital and research assistants) for feedback purposes. The research supervisors' feedback indicated weak coherence between the themes and data elements. The researcher addressed the issue of coherence as part of an ongoing revision to the preliminary analysis findings. Feedback received from the senior consultant neurosurgeon indicated gaps in actions for psychological health of caregivers. The researcher shared the identified gaps with the CPG members for collective response.

Finally, feedback from the research assistants emphasized systematic data recording that was earlier addressed during interactional usual action observation.

The CPG members, selected from among GPG members were involved in validating or generating themes through their involvement in the CPG meeting that discussed the preliminary analysis findings as described below.

3.2.6 *CPG reflection of preliminary analysis findings (March 2023)*

CPG reflection of preliminary analysis findings was the sixth process for co-creating CEBU. The researcher invited the CPG members to the CPG meeting to collate, make additional inputs, and approve the preliminary analysis findings of study phase one. The CPG meeting took place in the African One Hospital.

The researcher introduced the purpose of the CPG meeting and invited each of the eight representatives for the GPG members to make their group submissions.

The researcher allocated each representative five minutes to make submissions and ten minutes for CPG discussion. Because there were two representatives per GPG, the five minutes was allocated to the pair.

Overall, the GPG representatives made presentations for one hour. Then, the researcher made presentation of the preliminary analysis findings incorporating emerging views from the GPG representatives. The researcher structured the presentation based on six themes; the themes and subthemes highlighted the data elements.

The researcher's presentation took one hour; then, CPG members discussed the preliminary analysis findings; the discussion took another one hour.

The CPG meeting ended when each GPG representative was clear about plan for study phase two:

- Using CECA tool to assess child enablement contexts for the eight children with brain injury; the usual intervention programme had missed the enablement contexts.
- Counselling caregivers on brain injury to ease psychological pain; the usual intervention did not support constrained caregivers.
- Sharing information among health professionals and caregivers about child health condition and activity fit; the usual intervention did not share information on child's activity fit.
- Using step by step procedures described as AT7M7 action steps, OH4BH10 action steps, P4JE8 action steps, FFF6 action steps, and P3S2C3 action steps (Appendix 8) to implement basic needs; the usual intervention did not use step-by-step procedure but instead used unfocused goals.
- Allocating 20 minutes for each basic needs; the usual intervention allocated 16 minutes for each basic needs.
- Creating five interactional action rooms (an extra one room for play and social relationship in class); the usual interactional action had four action rooms.

3.2.7 *Action re-planning (April 2023)*

Action re-planning was the seventh process for co-creating CEBU*;* this was conducted as the first step of phase two for co-creating CEBU. As part of action re-planning, the first GPG meeting was held to disseminate the plan for study phase two based on the CPG approved interactional action change from study phase one.

In the GPG meeting, the researcher invited the CPG representatives to take the GPG members through the CPG approved interactional action change from study phase one. This meeting took place in the KWB-HTC action room one. At the end of the presentation from the CPG representatives, members were invited to ask questions. The GPG members questioned why the CPG meeting did not address the previous issue raised that the GPG reflection should stop at 4pm as opposed to 5pm.

"Onivo" (Physiotherapist) expressed dissatisfaction about the end time for GPG reflection meeting: "I think the GPG reflection meeting should stop at 4pm not 5pm as previously experienced.....this will help us dodge the Kampala road traffic jam which starts at around 5pm every day."

In the GPG meeting, members agreed - GPG reflection would stop at 4pm and that they would use new procedures to guide the implementation of the action change observation (Table 5). As part of the change process, eight children with brain injury were assessed using the CECA tool on the same day after the GPG meeting. Two additional actions happened after assessment:

1. Caregivers counselling to ease psychological pain
2. Sharing information among health professionals and caregivers about individual child health condition and activity fit.

Table 5. The New Procedure to Guide the Implementation of the Action Change Observation

PN	Action plan
One:	The action change would involve eight children with brain injury, three C2C caregivers, three doctors, three therapists, five nurses, two research assistants, and researcher.
Two:	The interactional action change observation would be described as getting children with brain injury involved in AT7M7 action steps, OH4BH10 action steps, P4JE8 action steps, FFF6 action steps, and P3S2C3 action steps.
Three:	The researcher would ensure all participants adhere to set action changes, including the creation of additional action room, movement between rooms (entry/exit) and ending GPG reflection at 4pm Kampala time; the children's numbered arrangement would remain unaltered.
Four:	A system of entry and exit would change to include: child entry room one or three and exit room five or two.
Five:	The interactional action would change to take five hours, allowing each child 20 minutes in each interactional action room; three minutes for getting the child ready, 15 minutes for interactional action change, two minutes for winding up and moving to the next room or exiting if finished.
Six:	The second child would be stationed and waiting in the next room to avoid time waste during the wind-up time.
Seven:	Each GPG member would record individual reflections in participation file during interactional action change.
Eight:	The researcher or research assistant would continue with the role of recording a five-minute video clip for each child involved in each interactional action change room.
Nine:	The description of systematic video recording would remain unaltered; the video recording performed for each child from entry to exit before starting on a new child.
Ten:	The researcher's role would remain unaltered; to coordinate the procedures One to Nine.

Note. PN = Procedure Number

3.2.8 *Action change observation (April 2023)*

Action change observation was the eighth process for co-creating CEBU. The action change was interactional in nature. The implementation of interactional action change involved the researcher, GPG members, children with brain injury and their caregivers in KWB-HTC five interactional action rooms. The researcher reminded the GPG members about the new set of procedures focused on the step-by-step basic needs implementation in different action change rooms.

> "Ono" (nurse number one) whose son was wedding did not participate fully during action change implementation: "my son is wedding today....I can participate in the study up to 11am and leave....I will abide by whatever my colleague nurses decide from the GPG reflection meeting, and I can provide my written reflection as well."

At the start of the interactional action change observation process, the researcher invited the child number one and two, their caregivers, and the GPG members to the action observation room one and action observation room three. The action observation room two, four, and five were kept vacant to receive the first two children (number one and two).

Once the child in action observation room one reached action observation room five and the child in action observation room three reached action observation room two; the researcher invited two children with brain injury; child number three and child number four to interactional action change observation room one and three which were already vacated. This was the time when four action observation rooms were occupied except room four. The researcher then waited for all the four children with brain injury to exit before inviting another set of children; this was referred to as first action change observation round.

The researcher invited child number five and six to action observation room one and three to start the second round of action change observation. Finally, child number seven and eight were invited by the researcher to interactional action change observation room one and three when the two rooms were vacated with child number five and six in action observation room number five and two respectively.

The GPG members did interactional action change observation for each child with brain injury in each action observation room for 15 minutes before moving to the next room with a child in

waiting; each child spent 20 minutes in each interactional action change observation room. Altogether, the interactional actions with eight children with brain injury utilized five hours (first round, two and half hours; second round, two and half hours). There was a 30-minute tea break between the first round and second round of interactional action change.

The GPG members expressed satisfaction with the children's positive responses in the interactional action change observation.

> "Onup" (C2C Caregiver number one) was excited about the positive results of action change: "I am so happy.....no child is crying following the action change.....previously, with the usual actions children were crying a lot."

3.2.9 *GPG reflection of observation of action change (April 2023)*

GPG reflection of observation of action change was the ninth process for co-creating CEBU. The researcher invited the GPG members to reflect about the interactional action change for each of the eight children with brain injury.

The GPG reflection adopted shared valued self-reflection, discussed to reach consensus about the outcome of the action change observed during the interactional action. Any action change that met the expectation of the GPG members was reflected as shared positive self-reflection; this was recommended to the CPG meeting for inclusion in the final culturally relevant programme for enabling participation of children with brain injury in Uganda. If the action change did not meet the expectation of the GPG members, it was reflected as negative self-reflection and was not recommended for inclusion in the final culturally relevant programme for children with brain injury in Uganda.

> "Onit" (Neurosurgeon) did not fully participate in the GPG reflection because of other engagements: "I have an emergency in the hospital....so I must leave the reflection meeting at 3:30pm....other doctors...my colleagues here can continue and if there are additional changes to the programme....I would like to get that feedback."

The researcher allowed "Onit" to share her own individual reflection and leave at 3:30pm; other GPG members continued to share their reflections up to 4pm Kampala time. The presentations started after the researcher highlighted the structure of the GPG reflection which members had to follow. The structure of reflection included hearing submissions from each GPG member.

The GPG - doctors, therapists, and C2C caregivers had five submissions per category for collective reflection: the first three submissions were based on the doctor's or therapist's or C2C caregiver's individual self-reflection of the interactional action change observation of children with brain injury. The fourth submission was based on the five minutes video recording of each child observed from each action room by the research assistant; this was supplemented by the fifth submission from the researcher.

For the GPG - nurses, the structure had seven submissions for collective reflection: the first five submissions were based on the nurse's individual self-reflection of the interactional action change observation of children with brain injury. The sixth submission was based on five minutes video recording of each child observed from each action room by the research assistant; this was supplemented by the seventh submission from the researcher.
The researcher facilitated the GPG discussion on each submission for about 20 minutes before the next submission.

3.2.10 *GPG individual member follow up interviews (April 2023)*

GPG individual member follow up interviews was the 10th process for co-creating CEBU. The researcher invited each GPG member for follow-up interviews on the fourth and fifth day after the GPG reflection day. Each GPG member physically attended the follow-up interviews on the appointment date and time at the research office in African One Hospital.

The follow up interviews generated additional data for the CEBU; consequences and limitation of the CEBU. In the follow up interviews, the researcher used open ended questions and encouraged each GPG member to maintain open communication (Gallacher & Gallagher, 2008).

The GPG members shared a broad picture of the CEBU and its consequences because the researcher expanded the follow up interview questions to include the challenges faced by children with brain injury in diverse contexts such as individual homes, government health facilities, private health facilities, government schools, and private schools among others.

Each GPG member shared positive aspects of action change that had to form the culturally relevant programme for children with brain injury in Uganda; the consequences and limitations of CEBU.

3.2.11 *Research data management- involving final analysis (April to August 2023)*

Research data management - involving final analysis was the 11th process for co-creating CEBU. In this process, the researcher audio recorded the GPG reflection, GPG individual follow up interviews; in addition, the researcher and research assistant video recorded the action change observation in five minute video clips for each observation made based on the video record assessment (VRA). The researcher took field notes about observed action change of research interest. The researcher also maintained a clear and complete account of action change in the research journal and field notes. Each GPG member recorded self-reflection of action change observation in their participation files.

The researcher watched the video clips to cross check that the video data matched the audio data extracted from the video during the GPG discussion (for example, audio data about interaction between the child, health professionals, and caregivers during action change were extracted from the video recorded, and triangulated by checking video against audio to confirm action-interaction match; for instance, child cry was taken to mean discomfort and disapproval of action where the video data was taken), listened to the audio recordings, read the self-reflections of action change observation made by each GPG member in their participation files; read the researcher's field notes and journals, and asked additional clarifying questions to specific GPG member on phone especially concerning any part of the participation file recording of the GPG member's self-reflection that appeared confusing or unclear.

In the final analysis, data was examined in a relational manner (study phase one and study phase two). The data included, 120 video clips for study phase one and 150 video clips for study phase two; four audio recordings of GPG reflection in study phase one and four audio recordings of GPG reflection in study phase two; 14 audio recordings of GPG individual member interviews and 14 audio recordings of GPG individual member follow up interviews; 14 participation files for self-reflections of the GPG members; eight sets of researcher's field notes, one researcher's journal.

Data was analyzed following six steps process for thematic analysis (Braun & Clarke, 2006). As part of a justification, thematic analysis offers an accessible and theoretically flexible approach to analyzing qualitative data; formed by themes or patterns in relation to different epistemological

and ontological positions. Other participatory action research projects have previously used thematic analysis to co-create knowledge about the development of outdoor play area for children (Nah & Lee, 2016). The researcher initially wanted to use narrative analysis to analyze the data collected but this could not work because some of the data elements did not fit narrative analysis; stories and their details (Ntinda, 2018), (for example, data concerning contexts assessment, occupation scale, and occupation score).

The researcher used the final analysis findings to inform the CPG meeting, write the thesis for examination, and end the study.

From the final analysis findings, the researcher generated a total of three themes and 19 sub themes (one theme and six sub themes for study one, one theme and seven sub themes for study two, one theme and six sub themes for study three).

The researcher then shared the final analysis findings of study phase two with the research supervisors and data monitoring team members for their feedback prior CPG approval.

The supervisors' feedback indicated that more work was required to collapse and tighten the sub-themes, relate the study themes to sub-themes; shorten data elements, and relate the three studies; this feedback helped the researcher to collapse the sub-themes to three sub-themes for study one; three sub-themes for study two; two sub-themes for study three. The relational component was addressed by the researcher as part of an ongoing process of thesis writing and continuous improvement that created linkages between the themes, subthemes, data elements, and the three studies.

Feedback from the senior consultant neurosurgeon showed that the issue earlier raised about the psychological health of caregivers was fully addressed and there was no additional comments.

Feedback from the research assistants confirmed adherence to systematic data recording with no additional comments.

The CPG members, selected from among GPG members were involved in validating or generating themes through their involvement in the CPG meeting that discussed the final analysis findings as described below.

3.2.12 *CPG reflection of final analysis findings (August 2023)*

The CPG reflection of final analysis findings was the 12th process for co-creating CEBU. The researcher invited the CPG members for the final CPG meeting in the African One Hospital. The CPG members collated, made their last inputs, and approved the final analysis findings.

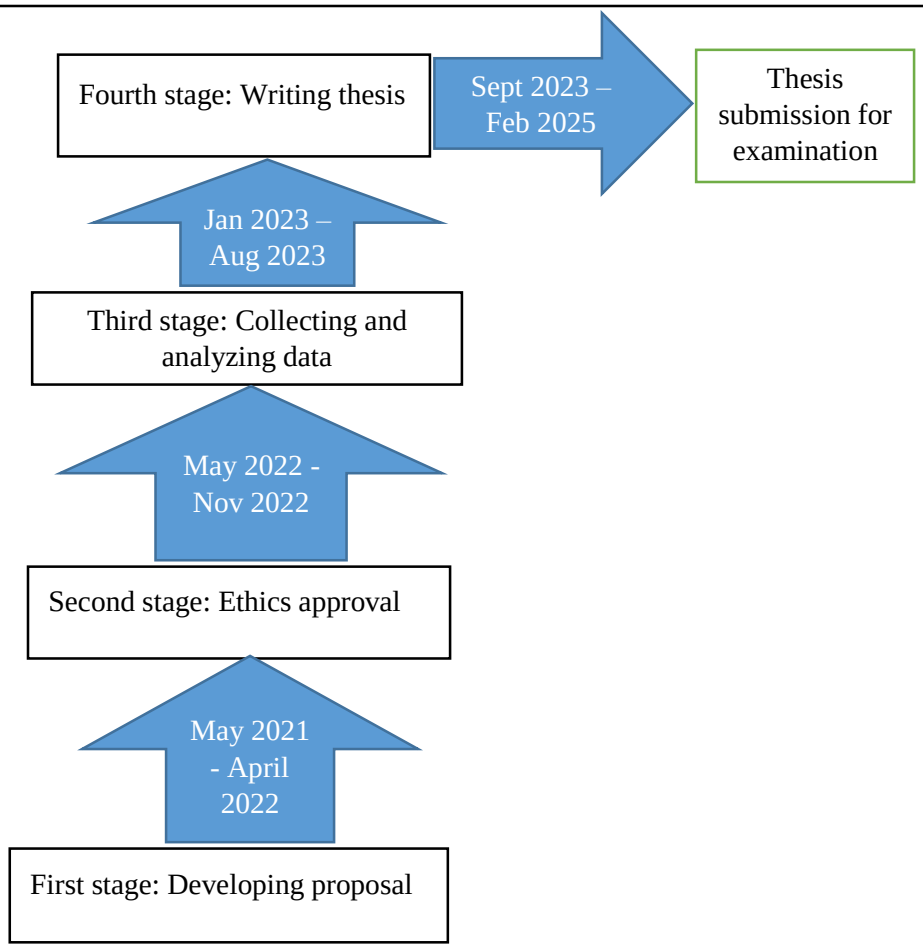
The CPG reflection started with CEBU co-creation process highlighted by the researcher; this included credibility issues such as data quality and completeness. The researcher allowed member's submissions, approval and rejection of submissions with justification; the submission was approved if evidence existed for children's positive response during the interactional action change. On the other hand, the submission was rejected if no evidence existed for children's positive response during the interactional action change.

Five minutes were allocated for each CPG representative to present about their GPG members' recommendations for CEBU, consequences, and limitations; one hour 30 minutes for the researcher to present about final analysis findings.
Ten minutes were allocated for discussing the presentation made by each CPG member; two hours for discussing the presentation made by the researcher.

The Four-star-Model for Enablement and Participation of children with brain injury was generated as CEBU from the CEBU conceptual framework; this was done during the CPG reflection.

Moving forward, the researcher and CPG members agreed to launch the CEBU as a Four-star Model for Enablement and Participation of children with brain injury in Uganda.

Figure 6. Project Milestone and Timeline



Note. Figure 6 = Flow chart showing the project milestone and time used to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda; rectangles denote the project milestone; the arrows indicate time used; Feb = February; Aug = August; Nov = November.

3.3 Trustworthiness

The researcher ensured trustworthiness of the study by following the research process being proposed and align the research question, methodology, method, analysis, and results of the study (Coughlan, Cronin, & Ryan, 2007).

Credibility was ensured by presenting clear data concerning a culturally relevant programme (CRP) for enabling participation of children with brain injury in the KWB-HTC to the CPG meeting, data monitoring team, and supervisors after analysis, allowing member checking and collaborative interpretation of themes (Shenton, 2004). To do this, a thematic analysis process was

used (Braun and Clarke, 2006), achieving a level of clarity in the result interpretation to ensure dependability (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004).

Dependability was supported by maintaining a structured analytical process using Braun and Clarke's six phase thematic analysis (Braun and Clarke, 2006), with feedback from supervisors and co-researchers guiding refinement of themes. The researcher kept the reflective journal to ensure confirmability of research findings (Shenton, 2004).

Confirmability was promoted through peer inputs and by documenting analytic decisions and reflections in a researcher journal. Although generalizability was not the aim, the researcher adhered to the study protocol as approved by the research governing body in South Africa and Uganda aimed to create possibility for transferability of the study in other settings different from that being proposed (Coughlan, Cronin, & Ryan, 2007).

Transferability was dually supported; protocol and detailed description of participants' roles and engagement process. The participatory nature of the study helped to address the dialogic and catalytic validity, ensuring that knowledge production was shared and that finding were action oriented in nature, resulting in the Four-star Model for Enablement and Participation of Children with Brain Injury in Uganda.

3.4 Ethical considerations

The World Medical Association (WMA) declaration of Helsinki (2013) principles for medical research involving human subjects was used as a basis for ethical considerations for this thesis (https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/.

Ethics approval was obtained from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (HREC) (UCT, HREC REF: 313/2022); the approval was granted based on the research compliance to the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee Standard Operating Procedure (www.health.uct.ac.za/fhs/research/humanethics/sop. In addition, ethics approval was also

obtained from Mulago Hospital Research Ethics Committee (MHREC, 2340), and Uganda National Council for Science and Technology (UNCST) (HS2509ES).

Each GPG member signed confidentiality agreement form, and informed consent form before involvement in the study. Each child with brain injury aged eight years and above who had ability to read written information or listen to verbal communication signed assent form. The caregivers consented for children with brain injury, eight years and above who were unable to read written information or understand verbal information, and those below eight years.

Informed consent was received from each GPG member: three doctors, five nurses, three therapists, and three C2C caregivers for them to participate in co-creating CEBU. Assents were received from two children with brain injury; six caregivers consented on behalf of their children with brain injury who were either below eight years or lacking ability to read or understand verbal information. Because the study involved vulnerable children with brain injury, in addition to addressing all the prescribed ethical requirements, additional efforts were made by the researcher to select only children with the physical abilities to fully participate in the study i.e., children with brain injury who scored GCS 9-15 were described as physically capable of participating in the study and were included.

Each participant was informed that their involvement in the study was not mandatory and that they were free to withdraw from taking part in the study at any time without fear of consequences. In addition, participants were informed about the risk of COVID-19 and Ebola in the study. To address this risk, the researcher generated and shared SOPs for the control and prevention of Ebola (Appendix 15) and COVID-19 (Appendix 16); all participants acknowledged in writing to confirm that they were fully aware about the risk of Ebola and COVID-19.

GPG members signed their consent form three week to the study start date. Two children with brain injury signed their assent form two weeks to the study start date; six children with brain injury who were unable to assent had their caregivers' consent two weeks to the study start date. The researcher updated the GPG members, children with brain injury, and caregivers about the research participation dates and other issues represented in the informed consent for the day's session; this was in line with the recommendations for updating participants' involvement in

studies utilizing emerging research designs such as participatory action research (Heath, Charles, Crow, & Wiles, 2007).

One important success worth mentioning here is that throughout the entire span of the study, none of the GPG members and children with brain injury withdrew participation. Each research assistant signed confidentiality agreement form prior involvement. In addition, power dynamics was fully addressed in this study: Doctors had their separate GPG meeting arrangement and date, and the same with nurses, therapists and caregivers. Thus, power dominance did not influence the direction of the study findings in any way.

Chapter four: Findings

4.0 Findings

The overall aim for this thesis was to co-create a culturally relevant programme for enabling participation of children with brain injury in KWB-HTC Uganda (CEBU) and describe its co-creation process. Three main themes (Table 6) were derived from data collected during the CEBU co-creation process.

Table 6. Main Themes Derived from Data Collected During the CEBU Co-creation Process

Main Themes	Names
Theme one:	An intervention that does not satisfy basic needs
Theme two:	Bridging basic needs and enablement
Theme three:	Diversifying daily life participation

4.1 Theme one: An intervention that does not satisfy basic needs (study one)

Theme one, described the participants' thoughts, feelings, and perceptions of the usual intervention programme in KWB-HTC Uganda as "*an intervention that does not satisfy basic needs.*"

The participants expressed their concerns that the usual intervention was not inclusive of activities that were well suited to address the child's specific and unique needs. In this case, the participants noted that the health professionals and caregivers' actions ignored the child's condition, and assessments that did not focus on functional issues which led to rule deviation or unfocused activities described as unwitting goals. The summary of the thematic findings from study one is provided below (Table 7).

Table 7. Summary of Thematic Findings from Study One

Main Theme	Sub Themes
An intervention that does not satisfy basic needs	(a) Ignorance of child's condition (b) Assessment that does not focus on functional issues (c) Unwitting goals

Caregivers and health professionals did not appear to have the necessary knowledge about the child's condition that would guide them to select activities that could support their engagement in their occupations. In several instances caregivers and health professionals' actions ignored the child's condition which compromised the activity fit and this led to the child becoming irritated during sessions.

> "Twori" (28 years old, occupational therapist) mentioned several instances where caregivers did not display appropriate knowledge, citing that "caregivers were lacking knowledge about brain injury condition, and children's involvement process in activities of daily living such as body hygiene, feeding, and play." Other GPG members agreed, describing children's experiences as "irritating" and "limiting in terms of activity involvement."

Caregivers were not guided by health professionals to discern how much help to give their children and this meant they were not skilled in creating opportunities for their children to decrease their level of dependence on their caregivers.

> "Ono" (62 years old, pediatric nurse) stated that "caregivers try to do everything to help their children with brain injury feed or perform different activities of daily living as they want not as the child wants." The GPG members agreed, and singled out health professionals as responsible for guiding caregivers. The GPG members described health professionals as "disinterested" and "unwilling to help caregivers deal with issues of child involvement in daily life activities."

With unclear assessment criteria (for example, using toys to assess mobility, vision, touch, and hearing ability) several functional issues such as body structures and body functions were not reported on.

> "Twiti" (35 years old, speech and language therapist) mentioned some of the issues that weakened the use of toys as a form of assessment and cited that "toys limit assessments to play situation." The GPG members agreed, and cited this form of assessment as "missing vital details such as body structures, body functions, and activity functional difficulties of the child."

The problem of unclear assessment was compounded by unwitting goals where the caregiver or health professional decided on what to take as the child's basic needs. This further compromised the child's involvement in daily activities.

> "Twil" (44 years old, pediatric doctor) mentioned certain instances where the participation process for children with brain injury involved in daily activities were compromised (for example, "caregivers and health professionals disregarded what the child wanted as part of daily activities." This was further validated by GPG members who emphasized that "health professionals have a role to play in guiding caregivers and children's participation in meaningful ways."

Ignorance of child's condition

The first sub-theme for study one, ***Ignorance of child's condition,*** describes the irritated responses and often inappropriate child handling observed in the caregivers and health professionals when engaging with the children.

> "Logu" (40 years old, caregiver) mentioned the names of some caregivers who did not notice that their children had mouth soars including feelings like "the children were irritated during tooth brushing, did not even love the feeding activity, and could not even spit during tooth brushing ending up swallowing back everything." In addition, "Onit" (41 years old, neurosurgeon) expressed dissatisfaction about the children's feeding mode by their caregivers citing that "caregivers did not give their children enough time to feed, there were those caregivers who just poured feeds in their children's mouth." The GPG members agreed, and recommended that "children with brain injury should be fed on feeds that do not cause irritation and chocking."

The participants thought that the dominant factors linked to the child's subjective irritation were the caregivers.

> "Twic" (29 years old, caregiver) reported that several caregivers experienced psychological pain because of having a child with brain injury including feelings like "caregivers were so distressed with themselves and were not able to take good care of themselves and their kids." The GPG members agreed, and also added that "caregivers should be encouraged to form an association that can support their mental health and wellbeing including information sharing with one another."

The participants felt that the caregivers had lost hope about their children getting any better because of psychological distress. It was therefore perceived that some caregivers never wanted to associate with their brain injured children.

> "Onup" (61 years old, caregiver) described the caregivers' feelings as "hopelessness" and "tiredness" because of having a child with brain injury whose health condition was not improving but instead getting worse. The GPG members agreed, and emphasized the relevance of reduced stress among caregivers describing it as "purposefulness" in terms of daily interactions with the brain injured child.

The participants discussed and agreed that positioning a child in a specific child space for activity should be the responsibility of the caregiver or any involved health professional. To the contrary, the participants perceived adult space was used to position the children. This action affected the children's potential to engage in meaningful activity choice without causing child irritation.

> "Twori" (28 years old, occupational therapist) mentioned some of the difficulties with using adult spaces for positioning a child with brain injury, including perception that "getting a child with brain injury to do tooth brushing or body hygiene or any other daily activity may be a struggle in an adult space such as chair or bed." "Onivo" (42 years old, physiotherapist) added that the act of using adult spaces may limit activity engagement described as "irritating to the child." The GPG members agreed, and emphasized the need to use special pediatric chair for getting a child with brain injury in upright sitting position described as "comfortable to participate in meaningful daily living activities."

Participants also perceived child's bodily damage such as genital injury from the repeated use of diapers.

> "Onit" (41 years old, neurosurgeon) reported that all babies observed were on diapers and cited that "the skin rushes and genital wound was a consequence of using diapers." This prompted the GPG members to point out clear guideline for using diaper "children with brain injury should not use diapers during day time except nighttime to keep the bed dry."

As part of an emotive response, some participants thought that the caregivers should have been warned about irritating their children using inappropriate language.

"Ono" (62 years old, pediatric nurse) emphasized the need for caregivers to avoid negative talks in the child's presence, for instance using words like "I am tired of you," "for how long will I suffer with you," "if you do not want to feed leave." The GPG members supported this by stating that the caregivers should be "helped to come to term with reality."

Assessment that does not focus on functional issues

The second sub-theme for study one, ***Assessment that does not focus on functional issues,*** described unclear assessment criteria such as using toys. Participants felt that while the use of toys was of benefit to assess play engagement, an assessment tool was needed to assess the child's body structures, body functions, and other activities such as feeding, exercise, body hygiene, and assistive technology use.

"Fiti" (30 years old, psychiatrist) emphasized the need to use an assessment tool that focuses on body functional issues, citing that "we need to have an assessment tool that can explore the body structural and body functional problem of the children with brain injury." "Twil" (44 years old, pediatric doctor) added that "the activity and participation issues should be resolved based on assessment findings." The GPG members agreed, and added that "clear goals should be generated for enablement and participation based on functional issues identified using an assessment tool."

Even with play, there were disagreements among participants on the use of toys for child assessment and that further consideration of color, sound, movement nature, shape, and size could be applied to guide the selection of toys used.

"Logu" (40 years old, caregiver) mentioned some of the applicable toy selection criteria such as "color brightness," "sound greatness," "movement nature," "shape and size," and "clear limit for specific toy utilization." Twic (29 years old, caregiver) added that "a particular toy that is appropriate today may not be appropriate at all time for the same child."

The extended use of toys and the appropriate use of toys with respect to the child's developmental stage and abilities was recommended.

"Fiti" (30 years old, psychiatrist) emphasized the need to use appropriate toys, including feelings like "I love to see children with brain injury involved in symbolic play which are

appropriate to their age and nature of brain injury." "Throg" (47 years old, neurosurgical nurse) added that "play depends on the child's perception and expectations from the play objects." Further to this, "Twiti" (35 years old, speech and language therapist) referred to most play objects used in the usual intervention programme as "meaningless" and "irrelevant." The GPG members agreed, and were prompted to endorse the understanding that "for children with brain injury to participate in play depends on body function, age, and environment." Similarly, "Fout" (40 years old, pediatric nurse) was keen to add that "a child may be a five year old and operates physically at the level of a five year old but in his life the child has never seen a toy car made from plastic making its use meaningless." This context was further strengthened by "Twori" (28 years old, occupational therapist) who described meaningful play objects as "those object the child knows."

Unwitting goals

The third sub-theme for study one, ***Unwitting goals,*** described unfocused activities or rule deviation in the child's daily life.

"Fivi" (48 years old, nutrition nurse) mentioned some instances where caregivers did harmful medicine practices on their brain injured children, describing it as "deviation from medicine prescription," "under dosing the children by mixing medicine with water and sieving the medicine particles out before administering it." "Twi" (59 years old, pediatric nurse) added that the child whose mother sieved medicines showed signs of "increased seizures." The GPG members agreed, and emphasized the need for caregivers to change their practice concerning "sieving medicines." "Fout" (40 years old, pediatric nurse) reported "inconsistent use of medicine," in form of scattered nature of medicine administration, perceived as "children who were required to take medicines in the morning and evening; took medicine in the morning or evening only or spent days without taking medicines."

The inconsistencies in medicine administration posed great possibilities for health risks associated with poor response to medicine use.

"Twil" (44 years old, pediatric doctor) mentioned some of the reasons why medicines should not be administered in unmonitored, and unmeasured food, including perception like "a child with brain injury experiencing seizures was made to take undefined medicine

dose in food depending on whether the child finished the food or failed to finish the food." Similarly, "Onit" (41 years old, neurosurgeon) cited food temperature as "destructive," leading to "reduced drug potency," and "child's poor response to medicine use."

Participants thought that for consistency to be attained in the child-activity involvement, children should be given opportunity to do what they want to do, using appropriate procedure, at an appropriate time. To achieve this, participants felt that clear goals should be set and followed to ease the child's participation process.

"Twori" (28 years old, occupational therapist) mentioned some of the reasons why children with brain injury should do what they wanted to do, and referred to this as "chosen time of the child," and "help required by the child." "Fiti" (30 years old, psychiatrist) emphasized the need to respect the participation process of the child, looking at it as "doing an activity with the child and the child is not complaining." The GPG members agreed, and endorsed child interest in activity participation as "absence of cry," and "use of child centered goal."

The child's skin health was taken by participants as a goal area. For example, participants expressed their feelings that the child's skin requires proper care in terms of cleanliness, dryness, oiliness, and daily management of skin rushes.

"Onit" (41 years old, neurosurgeon) mentioned several elements concerning the child's skin care, looking at "cleaning," "oiling," and "avoiding skin rushes." The GPG members agreed, and endorsed child skin care as a "goal area."

Another issue sensed by participants was about the use of unhealthy diet as daily feeds for children with brain injury. For instance, participants thought that feeding a child with brain injury on protein or carbohydrate only was a form of unhealthy feeding. In this case, participants noted the need to set goals for balanced diet that could address the requirement for feeding children with brain injury on vitamin rich foods in addition to protein and carbohydrate rich foods.

"Twil" (44 years old, pediatric doctor) mentioned some of the unhealthy feeding practices that risked the lives of children with brain injury, and shared about one lived experience from a caregiver who said: "I always feed my child on egg white," another caregiver, added: "my child prefers milk and yoghurt for breakfast, lunch, and supper." With such

unhealthy feeding among children with brain injury, the GPG members agreed, and endorsed feeding as a "goal area."

The participants perceived that the health professionals and caregivers did not have a sense of child safety for children in participation contexts. This was perceived to be a form of goal disorientation. In their report, the participants explained how caregivers and health professionals were seen walking over exercise mat and did not wash hands between sessions with different children.

> "Throg" (47 years old, neurosurgical nurse) mentioned some of the caregivers and health professionals who never did hand washing between sessions, expressing fear that such actions may contribute "infection spread." "Fivi" (48 years old, nutrition nurse) emphasized the need to take hand washing as a core component of "goal orientation in activity participation context." To guarantee child safety, the GPG members discussed and agreed on the principle of infection control that included "disinfection of therapy surfaces using sanitizers," and "hand washing with soap and water."

Conclusion

Theme one, suggests that the usual intervention programme in KWB-HTC Uganda did not satisfy the basic needs because the caregivers and health professionals actions were not aligned with the child's condition and their needs, assessments were not used optimally to guide interventions which supported engagement in occupations and actions taken were unwitting and often in contravention to what had been prescribed and/or advised.

4.2 Theme two: Bridging basic needs and enablement (study two)

Theme two, described the culturally relevant programme for enabling participation of children with brain injury in Uganda as "*bridging basic needs and enablement.*" This was framed as a complex interaction between the child's enablement context, activity, and involvement. This complex interaction was termed CEBU conceptual framework (Figure 8). The summary of the thematic findings from study two is provided below (Table 8).

Table 8. Summary of Thematic Findings from Study Two

Main Theme	Sub Themes
Bridging basic needs and enablement	(a) Assessing child enablement contexts
	(b) Supporting caregivers to attain psychological health
	(c) Involving the child in daily life activities

Bridging basic needs and enablement

The main theme for study two, ***bridging basic needs and enablement,*** the third arm of CEBU symbolized green star (Figure 9), for which all the three sub themes established refers. Using the participants' ideology, bridging basic needs and enablement refers to activity fit in the child's contexts. Where child's contexts refers to situation involving a child with brain injury, caregiver, health professional, and any other relevant person. The reality nature of body-activity culture of children with brain injury involved appropriate help.

> "Onivo" (42 years old, physiotherapist) mentioned about sticking to the prescribed cultural activity for the child as a "culturally relevant way to attain child enablement." "Twori" (28 years old, occupational therapist) added that enablement may include "appropriate support from caregiver, health professional, and any other person deemed relevant."

This PAR study supported the idea that children with brain injury who experienced action change in activity choices and enablement participated more in diverse cultural contexts in KWB-HTC Uganda. The action change focused on sharing information among health professionals and caregivers about individual child health condition and activity fit.

> "Logu" (40 years old, caregiver) cited useful action changes, including "knowledge about the child's body-activity function to make meaningful activity choices and goals." The GPG members acknowledged that the action changes should be related to caregivers' psychological health described as "attainment of psychological pain freedom." Similarly, "Twil" (44 years old, pediatric doctor) acknowledged the relevant nature of action changes that included child involvement in daily life activities described as "the child's 24-hour time space at home or in the community."

Assessing child enablement contexts

The first sub-theme for study two, ***assessing child enablement contexts,*** the first arm of CEBU symbolized yellow star (figure 9). This is based on the principle of child enablement contexts assessment.

> GPG members viewed brain injury as affecting the child's health differently, including "health and participation"

The enablement contexts described by GPG members which require assessment include:

1. Exploring background information

Background information focused on child's age, date of birth, gender, tribe, language, date of assessment, participation number, contact details, national identification number (NIN), immunization, therapy sources, date of therapy initiation, and complex health care needs among others.

> "Onit" (41 years old, neurosurgeon) emphasized the importance of generating background information including "the duration that the child has been on therapy treatment," and "the point of initiation of therapy treatment." Furthermore, "Fiti" (30 years old, psychiatrist) added that knowing the tribe and the language of each involved child and caregiver may contribute "relevant information sharing because of cultural sensitiveness."

2. Exploring child environment support system

The environment support system was noted as the attitude of people in the child's space.

> "Ono" (62 years old, pediatric nurse) related environmental support system to "funding," and "attitude." As part of the environmental support system, the GPG members agreed that the care of a child with brain injury may be affected if the caregiver or health professional or any other community member has negative attitude.

Following the submissions from GPG members, brain injury was taken to be a health condition that requires involvement of different health professionals and other support teams such as health clinics, school, and homes.

> "Fiti" (30 years old, psychiatrist) listed support teams including "schools," "hospitals," "homes," and "different community structures such as rehabilitation centers."

3. Exploring body structures and body functions

Body structures and body functions included appearance of different body parts and their functionality based on the applicable ICF-CY coded items.

> "Onivo" (42 years old, physiotherapist) shared about the use of ICF-CY coded items to define relevant concepts, describing "body structures," and "body functions."

Because of diversity in religious beliefs, participants did not agree to include assessment of blood drug level as part of the body structures and body functions. However, the participants referred to blood drug level as an essential component of body health contexts connected to prolonged medicine use.

> "Onit" (41 years old, neurosurgeon) shared about the importance of implementing blood drug level for children with brain injury receiving prolonged antiepileptic medicine use. The reasoning was that "blood drug level provides information that may be used by health practitioners to regulate medicines in the child's blood." "Twil" (44 years old, pediatric doctor) failed to agree citing "cultural clash with religious communities that do not promote issues related to blood." These two arguments compelled the GPG members to drop the use of blood drug level because of controversies about its "usefulness" and "cultural relevance in diverse contexts."

4. Diagnosing brain injury

In this study, participants devised a new criteria for diagnosing brain injury which include GCS, general body appearance, general body examination, sensory and motor function, brain CT and MRI scans (optional).

> The GPG members collectively agreed that "for purposes of diagnosing brain injury, every child referred for assessment should be subject to sensory and motor function test, GCS score, and description of general body appearance, including brain CT and MRI scans where applicable." As part of general body appearance, GPG members agreed to record nutritional status, self-care status, and emotional status including "happiness," "sadness," "cleanness," and "emaciation." "Twi" (59 years old, pediatric nurse) added that the child's appearance should include "weight as indicator for wasting," and "height as indicator for stunting."

5. Naming basic needs activities

Basic needs activities include child's daily life cultural choices.

> The GPG members collectively agreed that "for purposes of activity planning and implementation, caregivers and practitioners should know the child's capability and activity choices." Thus, the GPG members further agreed to include "Using Assistive Technology or Medicine, Oral-Body Hygiene, Posture and Joint Mobility Exercise, Feeding on Formulated Food, Play-Social relationships-Class" as basic needs activities that may be required by most if not all children with brain injury.

Supporting caregivers to attain psychological health

The second sub-theme for study two, ***supporting caregivers to attain psychological health,*** the second arm of CEBU symbolized red star (Figure 9). This is based on the principle of caregiver psychological health.

> The GPG members described caregiving as a "demanding job," "stigmatizing," and a "form of psychological pain that requires support." From diverse ideologies, the GPG members endorsed counselling as the main form of support for caregivers with psychological pain or health issues described as "psychological pain," "sadness," "depression," and "daily life challenges." "Fiti" (30 years old, psychiatrist) emphasized that caregivers cannot be doing caregiving role from Monday to Monday or .January to January, citing the need for "stakeholders support in daily care for a child with brain injury."

The participants reported about one of the widely held false belief which supposed that brain injury is caused by witchcraft. Because of this false belief, participants recognized that children with brain injury and their caregivers were stigmatized in communities and labelled as bewitched.

> GPG members agreed to empower caregivers through information sharing, and helping caregivers deal with both unknown and known situations summarized as "causes of brain injury," "effects of brain injury", "complications of brain injury", "prevention of brain injury", and "appropriate management of brain injury."

Involving the child in daily life activities (ICD)

The third sub-theme for study two, ***involving the child in daily life activities,*** the fourth arm of CEBU symbolized brown star (Figure 9). This is based on the principle of daily life activities.

> The GPG members gained awareness that children with brain injury were faced with activity limitations and participation restrictions in diverse contexts. Thus, ICD was one way devised by GPG members to provide appropriate help described as "dependent occupation." Notwithstanding the fact that several children with brain injury required help, there were those who experienced independent participation or who did not require help to engage in an activity of choice. In this case, those children who did not require help experienced what GPG members described as "independent occupation."

Occupation actualization was described by participants in relation to occupation scale and occupation score. Thus, the participants used both scale and score to indicate measures for basic needs activities referred to as occupation as described below:

1. Occupation scale for goal setting (OSc) detailed in (appendix six).

> The GPG members agreed to use five scale values denoted as "OSc –2 (incompetence in occupation)," "OSc -1 (minimal competence in occupation)," "OSc 0 (moderate competence in occupation)," "OSc +1 (near maximum competence in occupation)," "OSc +2 (maximum competence in occupation)." These scaled values described the child's occupation in line with applicable goal level as described by "Twori" (29 years old, occupational therapist) who said that "children with brain injury often experience body function limitations that require the use of scaled values for goal setting."

The OSc was developed based on 54 occupations under five activity domains:

I. Involving children with brain injury in the use of assistive technology product(s) (seven occupations), and use of medicine product(s) (seven occupations).
II. Involving children with brain injury in oral hygiene (four occupations), and body hygiene (ten occupations).
III. Involving children with brain injury in posture management (four occupations), and joint exercise (eight occupations).
IV. Involving children with brain injury in feeding on formulated food (six occupations).

V. Involving children with brain injury in play (three occupations), social relationships (two occupations), and class engagement (three occupations).

The OSc was developed by the GPG members to guarantee occupation fit for children with brain injury. An earlier reflection by the GPG members showed that children with brain injury were experiencing occupation misfit in the KWB-HTC; thus, the GPG member were triggered to come up with the OSc idea that was later approved by the CPG meeting as an enablement action for children with brain injury in Uganda.

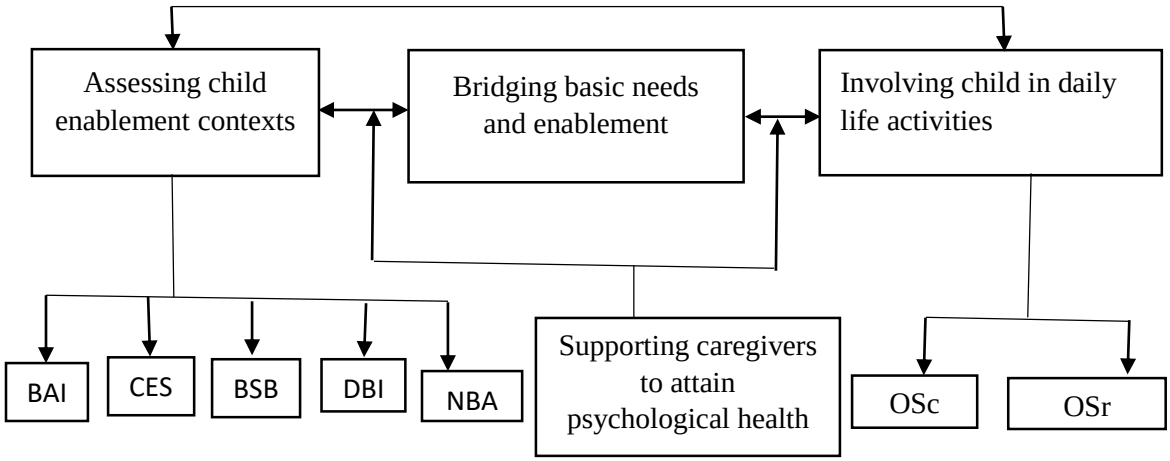
2. Occupation score for occupation engagement (OSr) (appendix seven).

The GPG members agreed to use five score values denoted as "OSr 1 (no evidence of competence in occupation)," "OSr 2 (minimal evidence of competence in occupation)," "OSr 3 (moderate evidence of competence in occupation)," "OSr 4 (near maximum evidence of competence in occupation)," "OSr 5 (maximum evidence of competence in occupation)." According to the GPG members, occupation score have to be based on diverse tasks described as "dependent occupation (DO)" or "independent occupation (IO)". "Onivo" (42 years old, physiotherapist) emphasized that "a child with brain injury is either capable or incapable." "If the child is capable, then there is no need for help." "If the child is incapable, then the child requires help." "Twori" (28 years old, occupational therapist) described the nature of help required by children with brain injury as "dependent occupation" or "independent occupation" based on the goals derived from the occupation scaled values.

Finally, this study summarized CEBU in two components:

First, ***CEBU conceptual framework,*** generated based on the shared understanding of four enablement principles: assessing child enablement contexts (ACEC), supporting caregivers to attain psychological health (SCAP-H), bridging basic needs and enablement (BBE), and involving the child in basic needs activities (ICD) as shown below (Figure 7).

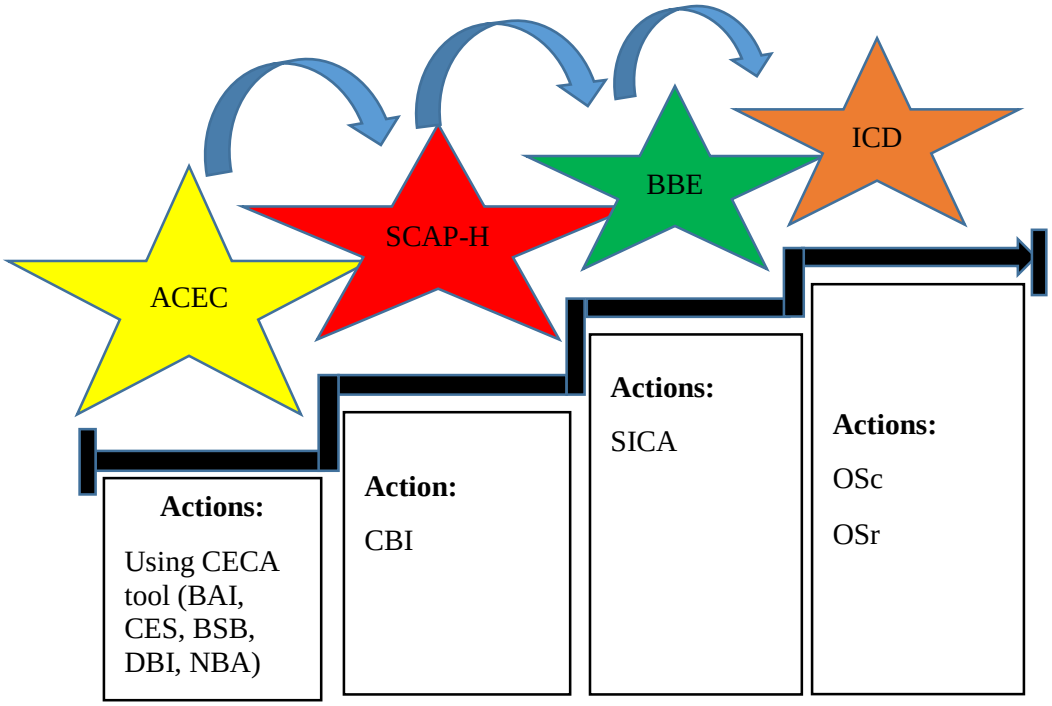
Figure 7. CEBU Conceptual Framework



Note. Figure 7 = CEBU Conceptual Framework for enabling children with brain injury in Uganda contextualized from the World Health Organization's International Classification of Functioning, Disability and Health, (2001); Rectangles on the conceptual framework denote the concepts; arrows indicate the direction of the conceptual relationship; OSc = Occupation Scale; OSr = Occupation Score; BAI = Exploring Background Information; CES = Exploring Child Environment Support System; BSB = Exploring Body Structures and Body Functions; DBI = Diagnosing Brain Injury; NBA = Naming Basic Needs Activities

Second, ***CEBU practice framework***, generated based on the shared understanding about enablement and participation of children with brain injury focused on the Four-star Model (bridging programme). The participants used star colors for describing each practice component. The use of star colors eased comprehension by children with brain injury and their caregivers. This is shown below (Figure 8).

Figure 8. The CEBU Practice Framework: Four-star Model for Enablement and Participation of Children with Brain Injury in Uganda



Note. Figure 8 = Four-star Model for Enablement and Participation of Children with Brain injury in Uganda; Black arrow indicates the direction of actions; Stars denote CEBU actions 1-4; ACEC = Assessing Child Enablement Contexts; SCAP-H = Supporting Caregivers to Attain Psychological Health; BBE = Bridging Basic Needs and Enablement; ICD = Involving the Child in Daily Life Activities; BAI = Exploring Background Information; CES = Exploring Child Environment Support System; BSB = Exploring Body Structures and Body Functions; DBI = Diagnosing Brain Injury; NBA = Naming Basic Needs Activities; CBI = Counselling Caregivers on Brain Injury; SICA = Sharing Information about Individual Child Health Condition and Activity Fit; OSc = Occupation Scale; OSr = Occupation Score.

Symbolic meaning of star color codes: Yellow = understanding the child-caregiver daily life culture & goals to deal with occupation weakness; Red = dealing with caregiver's psychological pain bringing about intensity to excitement, Green = acting to close participation gaps bringing about freshness to participation, and Brown = effective implementation of daily life culture based on child occupation groundedness.

The first star (yellow), ***assessing child enablement contexts (ACEC),*** focused on using CECA tool (Appendix 5) for exploring different contextual elements: background information, child environment support system, body structures and body functions; diagnosing brain injury, and

naming basic needs activities. The CECA tool was generated by the GPG members and researcher to change the assessment that had missing enablement contexts.

The second star (red), ***supporting caregivers to attain psychological health (SCAP-H),*** focused on counselling caregivers of children with brain injury to ease their psychological pain based on the ZCCS (Dambi, Tapera, Chiwaridzo, Tadyanemhandu, & Nhunzvic, 2017). This action was generated by the GPG members and researcher to change the caregivers' constrains.

The third star (green), ***bridging basic needs and enablement (BBE),*** focused on sharing information among health professionals and caregivers about individual child health condition: Gross Motor Function Classification (GMFCS) (Palisano, Rosenbaum, Bartlett, and Livingston, 2008); Manual Ability Function Classification (MACS) (Eliasson, Krumlinde-Sundholm, and Rosblad, et al., 2006); Communication Function Classification (CFCS) (Hidecker, Paneth, and Rosenbaum, et al., 2011); Glasgow Coma Scale (GCS) (Teasdale and Jennett, 1974); activity-fit for the chosen scale. This action was generated by the GPG members and researcher to change the intervention that did not satisfy basic needs. In addition, this action provided for the confirmation of child-activity fit using the person-environment-occupation perspective that related the child health condition (person), activity (occupation), and involvement of caregiver or health professional or any other person in the child's context (environment) to achieve activity fit for child-activity satisfaction.

The fourth star (brown), ***involving the child in daily life activities (ICD),*** focused on using occupation scale for goal setting (Appendix 6), and occupation score for occupation engagement (Appendix 7). These actions were co-created to change unwitting goal. In so doing, the researcher, GPG, and CPG retained the right to approve the use of the Four-star Model for Enablement and Participation of children with brain injury in any Uganda context. As part of the approval requirement, the context for example therapy center, school, hospital, and individual home among others had to be willing to provide opportunity for using occupation scale and occupation score for enablement and participation focused on diverse activities: Using Assistive Technology or Medicine, Oral-Body Hygiene, Posture-Joint Mobility Exercise, Feeding on Formulated Food, Play-Social relationships-Class.

The basic needs implementation action plan had to specify time slots within 24-hours that involved a child with brain injury in diverse activities that was captured with the last part of CECA tool - daily occupation planner (Appendix 5). The specified context had to involve a child with brain injury for at least five days and maximum of 20 days per month. In addition, the specified context had to be willing to involve a child with brain injury for a life span minimum duration of six months and maximum duration of four years; this was taken to be the project period for getting the child actively involved in the Four-star Model for Enablement and Participation. Upon completion, the caregiver and child had to be willing to continue on free choice and control of daily life activity within specified context.

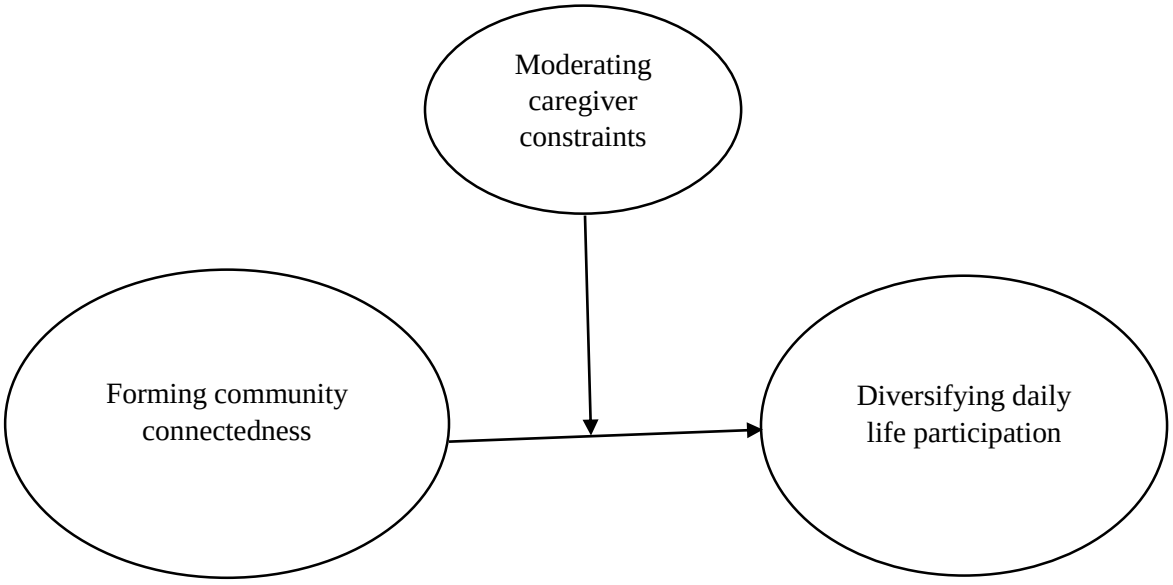
Conclusion

Theme Two suggest that the CEBU was co-created as a Four-star Model for Enablement and Participation (FMEP) of children with brain injury in Uganda.

4.3 Theme three: Diversifying daily life participation (study three)

Theme three, described the consequences and limitations of the culturally relevant programme for enabling participation of children with brain injury in Uganda as "*diversifying daily life participation."* This was linked to forming community connectedness and moderated or limited by caregiver constraints as shown below (figure 9).

Figure 9. The Ideological Linkages between the Consequences and Limitations of CEBU



Note. Figure 9 = Drawing showing the ideological linkages between the consequences and limitations of CEBU reflected in the ovals; arrows indicate the direction of the linkages

The consequences of assessing child enablement context (ACEC) using CECA tool was described as forming community connectedness. Meanwhile, involving the child in daily life activities (ICD) was linked to caregiver's constraints which moderated the influence of community connectedness on diversifying daily life participation. Thus, bridging basic needs and enablement was related to diversifying daily life participation. The summary of the thematic findings from study three is provided below (Table 9).

Table 9. Summary of Thematic Findings from Study Three

Main Theme	Sub Themes
Diversifying daily life participation	(a) Forming community connectedness
	(b) Moderating caregiver constraints

Diversifying daily life participation

The main theme for study three, ***diversifying daily life participation,*** described the outcome of CEBU as getting children with brain injury to do their activity of choice with normal children at home, school, and everywhere in the community.

> GPG members agreed that participation diversity refers to "what a child with brain injury wants and does in a defined setting within 24 hours' time space and which involves normal children."

This PAR study showed that children with brain injury benefitted from CEBU by forming community connectedness within minimal caregiver constraints. Where community connectedness was described as networking with communities from the African One Hospital.

> GPG members agreed that "through community connectedness, children with brain injury may have the opportunity to enjoy their basic needs from any hospital or diverse community settings in Uganda."

In doing all these, participants envisioned the possibility for caregiver constraints. From the participants' perspectives, caregiver constraints means the act of involving the caregiver in every activity which concerns the child's daily life participation. Thus, participants emphasized the importance of minimizing caregiver constraints to achieve caregiver psychological health.

> GPG members agreed that "the involvement of caregiver in every activity of choice for a child with brain injury may contribute caregiver constraints if not minimized.

Forming community connectedness

The first sub-theme for study three, ***forming community connectedness,*** described children with brain injury as capable of engaging in diverse cultural settings including support services with the use of the Four-star Model for Enablement and Participation.

> The GPG members agreed that "the implementation of CEBU may result in increased involvement of children with brain injury in diverse community cultural settings.

Forming community connectedness was valued by participants because it contributed increased belongingness in diverse social contexts, increased willingness to respond to the daily needs of

children with brain injury for care and support. Community connectedness, therefore, opened several opportunities for children with brain injury to access care and support from diverse settings.

> The GPG members agreed that "through community connectedness, every child with brain injury previously hidden in their homes became connected to other families/homes, churches, schools, and hospitals." In addition, "Fout" (40 years old, pediatric nurse) said: "community members became more aware about the existence, needs, and how to help children with brain injury in the society because of community connectedness." GPG members cited that "at family levels the fathers became more involved in the daily life of their children with brain injury." The benefits of community connectedness was emphasized by "Twil" (44 years old, pediatric nurse) who stated that "through community connectedness, a child who required admission because of aspiration, and other health complications did so easily because the caregiver communicated to the child's primary nurse and doctor in the hospital setting." The challenge with community connectedness was that some participants misinterpreted it as simply "community connection." Thus, the participants approved the use of these two concepts: "community awareness" and "community connectedness" as having a "common meaning" in this study contexts.

Cultural communication in community connectedness was taken as a major study limitation.

> GPG members agreed that "the non-use of Uganda's cultural languages may limit the implementation of CEBU; this is because CEBU was co-created in English." "Twic" (29 years old, caregiver) emphasized the need to translate CEBU in different Uganda cultural languages, including "Luganda," "Luo," "Iteso," "Runyakitara," and "Lugbara" to guarantee its full cultural relevance in Uganda.

Moderating caregiver constraints

The second sub-theme for study three, ***moderating caregiver constraints,*** described caregivers as having daily life priorities or demands that they should fulfil within set time other than always caring for a child with brain injury.

> GPG members agreed that "time limitations restrict caregiver's actions to set priorities which may include caring for a child with brain injury."

Looking at the constructive interaction between the child and caregiver, the participants generated two terminologies describing the caregiver constraints:

(i) Satisfying child's activity - this was taken by participants to mean the constructive interaction between the child and caregiver during daily life activity performance because of increased support for caregiver psychological health.

> GPG members agreed that "with stakeholders' involvement, there may be child activity satisfaction and caregiver psychological pain freedom."

(ii) Dissatisfying child's activity - this was taken by participants to mean lack of constructive interaction between the child and caregiver during daily life activity performance because of reduced or no support for caregiver psychological health.

> GPG members agreed that "a lack of stakeholders' involvement may lead to child's activity dissatisfaction and caregiver psychological pain."

To maintain child involvement in daily life activities, participants emphasized the importance of relevant stakeholders' involvement in ensuring caregiver's psychological pain freedom in different participation contexts.

> GPG members agreed that "stakeholders such as doctors, nurses, therapists, C2C caregivers, and teachers have roles to play in alleviating psychological pain of children with brain injury and their caregivers."

Conclusion

Theme three suggests that diversifying daily life participation is the positive outcome of forming community connectedness within minimal caregiver constraints. Where diversifying daily life participation refers to getting children with brain injury to do their activity of choice with normal children in homes, schools, hospitals, and other relevant contexts; community connectedness means creating community awareness about the existence of the Four-star Model in the African One Hospital; caregiver constraints are the limitations that a caregiver may have while caring for a child with brain injury.

Chapter five: Discussion

5.0 Discussion

This section discusses the key findings of three studies informing the co-creation of a culturally relevant programme for enabling the participation of children with brain injury in Uganda (CEBU). Study one explored the participants' thoughts, feelings, and perceptions of the usual intervention programme in KWB-HTC Uganda. The findings of study one pointed that the usual intervention did not satisfy basic needs of children with brain injury because the caregivers and health professionals' actions ignored the child's condition, conducted assessments that did not focus on functional issues, and used unwitting goals which were unfocused and led to inappropriate handling of the child. The findings showed that the practice principles which guided the usual intervention were incongruent with the being in place perspective (Rowles, 2000), person-environment-occupation practice model (P-E-O) (Law et al., 1996), and enablement conceptual framework (World Health Organization, 2001, 2007) used in this study; in addition, the findings showed that the usual intervention did not align with the Occupation Actualization (OA) philosophy generated in this thesis. **Occupation Actualization philosophy claims that there is a positive relationship between occupation scale, occupation score, and enablement within the guiding principles of the Four-star Model.** As we will discuss later in details, the Occupation Actualization (OA) philosophy was proposed by the researcher as a theoretical construct that focuses on brining into action the child with brain injury through interaction with valued occupation and relevant stake holders, assistive products, medicines, and other objects in the contexts.

To back Occupation Actualization philosophy, this study used the being in place perspective which assumes that human and contexts are inseparable, and grounded in habitual physical routines described as inextricably interrelated actions, habitual social routines described as relationships, and a sense of autobiographical insideness described as environment meaning homeostatic to the body (Rowles, 2000). According to Librettis and Puckett (2023) the term homeostatic is used to describe a state of balance among all the body systems, needed for the body to function properly. It can be argued that in a homeostatic state, the body is at one to its internal environment referred to as body systems. This further support the belief by Rowles (2018) that a person's wellbeing involves identifying with and being at one with one's environment. However, according to Bruya

(2012) the notion - “being at one with one’s environment” relates to self-consciousness. This study, therefore, agrees with the use of the concept self-consciousness based on two principles: Self-Invoking Trigger (Wulf, 2007), and Flow (Csikszentmihalyi & Nakamura, 2010). The principle, Self-Invoking Trigger describes the subjective act in physical tasks under distinct attentional conditions: attention on aspects of the task external to the person; attention on aspects of the body, for example, fingers or a particular muscle (Wulf, 2007). On the other hand, the principle, Flow describes the state in which one is so absorbed in an activity that a sense of self entirely drops away from consciousness; in this state the suspension of self-consciousness is total and yet one continues to perform at normal level of achievement (Csikszentmihalyi & Nakamura, 2010).

According to Bruya (2012) the two basic features of Flow include: engaging in an activity in which one has freely chosen to challenge oneself to excel and ability for one to meet the challenges of the activity. Because the caregivers and health professionals’ actions ignored the child’s condition, it was not possible for them to achieve what was earlier described by Bruya (2012) as Flow or what was earlier described by Wulf (2007) as Self-Invoking Trigger; this means that the caregivers and health professionals were not at one with the child’s environment. This study argues that the caregivers’ psychological support is required for children with brain injury to be at one with the caregivers. Other literature sources emphasize the need to provide a structured support system, including mental health services for caregivers experiencing psychological distress and depression (Gumikiriza-Onoria, Nakigudde, Giordani, Mayega, Sajatovic, Mukasa, Buwembo, Lwere, & Nakasujja, 2024). In addition, this study further argues that the appropriate strategy for one to be at one with one’s environment includes the use of occupation perspective of health: knowing, doing, being, and belonging (Wilcock, 1998). Occupation Actualization, therefore, has a lot to do with the health and wellbeing of children with brain injury in Uganda. This is backed by what Bruya (2012) described as self-considerations: when situations are demanding, a response is expected, and the response should be with appropriate level of efficacy. For example, this study found that when a brightly coloured moving toy with great sound and size was presented to a child with brain injury, the child’s mind shifted to the toy as part of the response. This kind of response relates to the “mirror mind,” a term used in psychology, and shaped by natural order: whatever happens to the individual that occurs outside the individual’s direct control is, at worst, normatively neutral, and at best it is normatively positive, and what happens naturally cannot be bad. This study further argues that for children with brain injury to be at one with their

environment, their “mirror mind” should include natural order based on natural happening or normatively positive, in exclusion of natural order based on occurrence outside the child’s direct control described as normatively neutral (Bruya, 2012).

The perspective of being at one with one’s environment is what Law and friends described as occupation fit; in occupation fit, the person, environment, and occupation are supposed to be congruent with each individual component to realize occupational performance (Law et al., 1996). In this case, the assurance of being at one with the child’s environment should have formed the core of the usual intervention programme, starting with assessment. Conversely, this study found that the assessments conducted did not focus on functional issues. The participants were concerned that the assessment tools specifically designed to assess enabling contexts were not being used. This contributed to using unwitting goals not aligned with meeting the needs of the child. These goals led to concerning actions such as inconsistent use of medicines and assistive products contrary to their prescriptions; feeding the child by pouring feeds in the mouth and limited use of appropriate positions to prevent chocking and aspiration.

To tackle the problem of unwitting goals, this study argues that the usual intervention programme should have used the World Health Organization’s ICF concepts and ICF-CY coded items in its design and implementation; however, there was no theoretical connection drawn to guide the usual intervention programme as a developed framework from the World Health Organization’s enablement conceptual framework (World Health Organization, 2001, 2007). This study, therefore, recognized the use of enablement conceptual framework in disability and rehabilitation programmes as a way to relate body structures - body functions - activities - participation and environment (World Health Organization, 2001, 2007). This relationship is described in other studies as enablement and valued occupations (Rowles & Watkins, 2003; Kielhofner, 2008; Townsend & Polatajko, 2007). In this case, valued occupation should inform the child’s goal for enablement and participation which have to be grounded in the occupation fit ideology (Law et al., 1996).

Occupation fit was largely absent in the usual intervention programme because there was no applicable procedure to engage children in occupation (for example, feeding, posture and joint

mobility exercise, and oral-body hygiene among others); this was further compounded by the severity of brain injury condition that required complex care.

One feasible procedure to engage children with brain injury in occupation described by participants as occupation scale and occupation score will be discussed later in study two. The failure by the usual intervention programme to provide the appropriate level of care for children with brain injury contributed to caregivers' psychological stress. Because of psychological stress, several caregivers used violent communication as a way to interact with their children during occupation engagement. For example, one caregiver was observed telling a child with brain injury that "I am tired with you, for how long will I suffer with you, and if you do not want to feed leave." This example shows how caregivers' psychological stress affected children's occupation for health and wellbeing. Caregivers, therefore, were physically and emotionally exhausted to continue with the required level of childcare. Other studies (Bergstrom, von Koch, Andersson, Tham, and Eriksson, 2015; Egan, Davis, Dubouloz, Kessler, and Kubina, 2014; Singam, Ytterberg, Tham, and von Koch, 2015) support a belief that without valued occupation and relevant support, several children with brain injury in Uganda could die; others could suffer from activity functional loss, regress in life satisfaction, and their caregivers could experience poor health outcomes as a consequence of stress from seeing and caring for their struggling children. This study, therefore, assumed that **every child with brain injury deserves a programme tuned to their cultural values that have to satisfy basic needs.** The cultural values of children with brain injury was described in this study as follows:

I. Involving children with brain injury in the use of assistive technology product(s) (seven occupations), and the use of medicine product(s) (seven occupations).
II. Involving children with brain injury in oral hygiene (four occupations), and body hygiene (ten occupations).
III. Involving children with brain injury in posture management (four occupations), and joint exercise (eight occupations).
IV. Involving children with brain injury in feeding on formulated food (six occupations).
V. Involving children with brain injury in play (three occupations), social relationships (two occupations), and class engagement (three occupations).

This assumption contributed new knowledge that participants used to generate a culturally relevant programme for enabling participation of children with brain injury in Uganda (CEBU) as discussed in the next section - study two.

In conclusion, it should be noted that the nexus of change to the usual intervention programme in KWB-HTC Uganda was enshrined in Occupation Actualization philosophy, backed by being in place perspective (Rowles, 2000), enablement conceptual framework (World Health Organization, 2001, 2007), and P-E-O practice model (Law et al., 1996). With this nexus being ingrained or rooted in occupation marked an important turning point in an intervention that did not satisfy basic needs leveraging what participants accepted in principle as CEBU based on valued occupation in context (Rowles & Watkins, 2003; Kielhofner, 2008; Townsend & Polatajko, 2007). The valued occupation in contexts is what most interventions for children with brain injury require for enabling participation. This study believes that it may be easier to attain international consensus in the three domains - disability, health, and wellbeing with the use of enablement conceptual framework (World Health Organization, 2001, 2007). Moving forward, only actions described as valued occupations and representing the cultural values and voices of children with brain injury were included in the CEBU as discussed in study two.

Study two generated a culturally relevant programme for enabling participation of children with brain injury in KWB-HTC Uganda. The findings of study two pointed that CEBU was co-created as a Four-star Model for Enablement and Participation of children with brain injury in Uganda: The yellow star, assessing child enablement contexts (ACEC) was found to be based on the child enablement contexts assessment (CECA) tool for exploring the child background information, environment support system, body structures and body functions, brain injury diagnosis, and naming basic needs activities. In its design, the CECA tool was grounded on the enablement conceptual framework (World Health Organization, 2001, 2007).

The red star, supporting caregivers to attain psychological health (SCAP-H) was found to be based on ZCCS (Dambi et al., 2017). The use of ZCCS assessment tool supported the caregivers to attain psychological health via the social model of disability that recognizes the impact of impairment, identifies constraints in social environment which often are the most significant barriers to participation of children with brain injury (Dempsey & Nakkervis, 2005).

The green star, bridging basic needs and enablement (BBE) was found to be based on the body-activity function capacity in diverse contexts. This study found that to bridge basic needs and enablement, the child's conditions have to be well defined based on the enablement conceptual framework (World Health Organization, 2001, 2007); and backed by important conceptions such as Gross Motor Function Classification (GMFCS) (Palisano, Rosenbaum, Bartlett, and Livingston, 2008); Manual Ability Function Classification (MACS) (Eliasson, Krumlinde-Sundholm, and Rosblad, et al., 2006); Communication Function Classification (CFCS) (Hidecker, Paneth, and Rosenbaum, et al., 2011); Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974). It was argued that a child with brain injury condition (person) should engage in an activity of choice referred to as occupation while taking on supporters or enablers referred to as caregivers or health professionals or any other person or assistive product in the context (environment).

The brown star, involving the child in daily life activities (ICD) was described as occupation actualization (OA). **In its conceptual framing, OA was formed by occupation scale and occupation score** and backed by the P-E-O practice model (Law et al., 1996). This study, therefore, adds to the existing knowledge about human occupation especially looking at valued occupation (Rowles and Watkins, 2003; Kielhofner, 2008; Townsend and Polatajko, 2007) linked to enablement (World Health Organization, 2001, 2007). In this context, occupation scale relates to goal setting (Ketelaar, Vermeer, Hart, van Petgem-van Beek, and Helders, 2001), and occupation score relates to occupation engagement in daily life contexts (Rowles and Watkins, 2003; Kielhofner, 2008; Townsend and Polatajko, 2007). Both occupation scale and occupation score are important conceptions for describing occupation fit (Law et al., 1996) embodied within the being in place perspective (Rowles, 2000) with the background of starting to use the Four-star Model: child enablement context assessment (CECA), supporting caregivers to attain psychological health (SCAP-H), bridging basic needs and enablement (BBE), and involving the child in daily life activities (ICD).

The child enablement contexts assessment (CECA) tool, draws philosophical connections to the World Health Organization's enablement conceptual framework which emphasizes the relationship between the body structures and function – activity – participation which are influenced by personal and environment factors; the personal factors, in this case, are background

information (World Health Organization, 2007). According to the World Health Organization, the personal factors are not classified in the ICF-CY because of large social and cultural variance (World Health Organization, 2007). The World Health Organization further the discussion to support personal factors as influential to the outcome of various interventions involving implementation of rehabilitation goals (World Health Organization, 2007).

This study, therefore, highlighted several personal factors or background information such as age, gender, language, tribe, complex health care needs among others. Previous studies highlighted similar personal factors as essential considerations when developing interventions for children with brain injury; for example, the age of a child with brain injury relates to their health status (Okumura et al., 2013), access to care (Lotstein, McPherson, Strickland, Newacheck (2005), functioning in daily activities (Donkervoort et al., 2009), and funding or insurance coverage (Kuo, Goudie, Cohen, Houtrow, Agrawal, Carle, and Wells, 2014); complex health care needs relate to the reason why some institutions that have inadequate equipment find it challenging to handle children with brain injury or those with complex health issues (Kuo et al., 2014).

The CECA tool included 28 coded items from the World Health Organization's ICF-CY; all these coded items were supported by participants as culturally relevant in the Uganda cultural contexts, and with potential for international adaptability and usability in future research and care projects involving children with brain injury in other African countries or world-wide. Examples of the World Health Organization's ICF-CY coded items in the CECA tool include: immediate family (e310), attitude of immediate family members (e410), health professionals (e355), individual attitudes of health professionals (e450), respiratory functions (b440), digestive functions (b515), structure of trunk (s760), involuntary movement functions (b765), muscle power functions (b730), muscle tone functions (b735), structure of brain (s110), and mobility of joint function (b710) among others (World Health Organization, 2007).

Supporting caregivers to attain psychological health (SCAP-H) draws philosophical connection to the social model of disability that recognizes the impact of impairment and identifies constraints in social environment (Dempsey & Nankervis, 2005). The social model of disability deepened the participants' knowledge of caregivers' stress. In addition, the social model of disability strengthened the belief that caregivers should be supported to positively deal with negative

feelings, stigma, and psychological pain associated with the demands of caregiving - seeking help when necessary. In this way, the participants guided by the P-E-O practice model (Law et al., 1996) reasoned that a positive minded caregiver is usually reliable, capable of providing safe, and quality caregiving that orchestrate the child's fit in valued occupation for enablement to be actualized. For example, participants described how a child engaged in exercise by a positive minded caregiver smiled and a child engaged in exercise by a negative minded caregiver cried.
In the process of co-creating CEBU, children's cry was taken to mean action disapproval and children's smile was taken to mean action approval. For example, some caregivers who remained negative were equivocally dissolving the required actions for occupation. For purposes of child care and support, this thesis suggested that a negative minded caregiver requires support for mind change to warrant occupation fit via occupation scale and occupation score which is backed by the P-E-O practice model (Law et al., 1996). This further validates our earlier assumption that every child with brain injury deserves valued occupation in esteemed contexts (Rowles and Watkins, 2003; Kielhofner, 2008; Townsend & Polatajko, 2007). The valued occupation in this case was found to be shaped by the caregiver, health professional, and any other person in the child's context working collaboratively to help the child attain occupation fit.

Other studies found that the collaborative working relationship among different stakeholders uses a social model where spaces are created to change a lack of inclusive attitudes and develop actions geared towards barriers to inclusion and participation of children with brain injury at both family and society level in a way that reduces caregiver's constraints (Thompson, Elliott, Willis, Ward, and Falkmer et al., 2016). The challenge with the social model is that it poses complex care demands because of its community approach (Dempsey & Nankervis, 2005). Aware about the challenge of using a social model, this study, therefore, motivated a group of volunteer health professionals and caregivers to come together and form an association referred to as Brain Health and Rehabilitation in Communities (BHRC) to ensure sustainable caregivers support via counselling and information sharing. Based on the BHRC concepts, brain health means access and use of FMEP; rehabilitation refers to enablement of valued occupation (Rowles & Watkins, 2003; Kielhofner, 2008; Townsend & Polatajko, 2007); communities refers to hospital, health center, school, home, church, mosque, and rehabilitation center.

Bridging basic needs and enablement (BBE) draws philosophical connection to enablement conceptual framework (World Health Organization, 2001, 2007), P-E-O practice model (Law et al., 1996), and being in place perspective (Rowles, 2000). Bridging basic needs and enablement, therefore, interlocks with the occupation actualization through collaboration between the child with brain injury, caregiver, health professional, and any other person in the child's context. Available literature emphasizes collaboration between stakeholders as an important requirement for enabling child's participation (Thompson, Elliott, Willis, Ward, & Falkmer et al., 2016). In a study by Pachter and Harwood (1996), collaboration between the parents/caregivers and therapists when supported by the family usually will socially construct ways to enable the cultural life of its member requiring activity help. To achieve this, the family usually require understandings, emotions, attitudes, and pattern of behaviors concerning their member who requires activity help (Pachter & Harwood, 1996).

From the occupation fit perspective, Law and friends (1996) emphasized that the occupation should match context to enable participation. Thus, the intentional focus on the occupation context match usually forms the first action step to bridge basic needs and enablement for every child with brain injury (person) involved in the activity of choice (occupation) influenced by the caregiver or involved health professional or community member (environment) (Law et al., 1996). This argumentation signifies the importance of ensuring occupation fit between the person, environment, and occupation for enablement to be actualized. Where there is reduced occupation fit between the person and environment, the child's enablement is expected to be low (Law et al., 1996). Thus, the occupation fit is the core of occupational therapy (Kielhofner, 2008; Townsend & Polatajko, 2007).

In occupational therapy, occupation refers to the everyday activities that people do as families in families and with communities to occupy time and bring meaning and purpose to life, occupation include things people need to, want to, and are expected to do (World Federation of Occupational Therapists, 2014). In this context, the child's activity refers to the child's occupation which should be the goal or focus of occupation interventions. The occupation intervention focuses on occupational performance coaching (Graham, Rodger, & Ziviani, 2009). In this study, the researcher looked at occupation intervention as occupation scale and occupation score. This is similar to goal directed therapy involving active, motor learning environment (Ketelaar et al.,

2001). Several studies demonstrated successful use of goal directed therapy that requires scaling goals to guide the implementation of goal directed programmes (Ahl, Johansson, & Granat et al., 2005; Lowing, Bexelius, & Brogren Carlberg, 2009). There are however growing concerns that most of the goal-directed programmes are from HICs with no reports about similar programmes from LMICs (Saloojee et al., 2021).

To implement goal-directed programme in LMICs, Saloojee and friends (2021) clarified that a child and caregiver supported by a health professional identifies three realistic goals and creates action plans for how to achieve them through daily training and practice in the home environment; the goal setting procedure starts shortly after assessment; during this time, the caregiver and health professional are already conversant with the child's functional limitations and participation restrictions. In this case, goals bridge enablement and basic needs. The philosophical marker for CEBU derived from this study is occupation actualization (OA). **The OA philosophy brought into action the child with brain injury through interaction with valued occupation and relevant stake holders, assistive products, medicines, and other objects in the contexts for purposes of supporting a claim that there is a positive relationship between occupation scale, occupation score, and enablement within the guiding principles of the Four-star Model.** This study, therefore, recognized valued occupation as occupation scale and occupation score, expanding on our understanding that occupational therapy focuses on human occupation that should include occupation scale and occupation score. For occupation to be inclusive of scale and score, it is important to apply the principle of dependent occupation or independent occupation. In this case, dependent occupation scale refers to OSc -2 (incompetence in occupation); OSc -1 (minimal competence in occupation); OSc 0 (moderate competence in occupation); OSc +1 (near maximum competence in occupation). On the other hand, independent occupation scale refers to OSc +2 (maximum competence in occupation).

Further to this, dependent occupation score refers to OSr 1 (no evidence of competence in occupation); OSr 2 (minimal evidence of competence in occupation); OSr 3 (moderate evidence of competence in occupation); OSr 4 (near maximum evidence of competence in occupation). On the other hand, independent occupation score refers to OSr 5 (maximum evidence of competence in occupation).

This scaling and scoring system is consistent with the capability ideology that looks at children with brain injury as either capable or incapable (Kakooza-Mwesige et al., 2018; Ekwan et al., 2022). This study, therefore, asserts that a culturally relevant way of describing occupation in the Uganda context is embedded in the occupation actualization philosophy: Occupation scale described as dependent occupation scale and independent occupation scale; occupation score described as dependent occupation score and independent occupation score.
The two terms: ICD and OA are used in this thesis interchangeably to mean the same thing. The implementation of the OA philosophy is grounded in the Four-star Model for Enablement and Participation with potential consequences and limitations.

Study three discusses the consequences and limitations of the culturally relevant programme enabling participation of children with brain injury in Uganda. The findings of study three suggests that CEBU diversifies daily life participation of children with brain injury which is a positive outcome of forming community connectedness within minimal caregiver constraints. From occupation perspective, diversifying daily life participation signifies how children with brain injury should do their activity of choice with normal children at home, school, and everywhere in the community within allowable network formed by the Four-star Model for Enablement and Participation. The understanding that **the African One Hospital delivered the Four-star Model for Enablement and Participation inspired a need for community connectedness for every Ugandan child with brain injury to receive occupation scale and occupation score**.

This assumption recognizes the importance of social model of disability for identifying constraints in social environment seen as barriers to participation of children with brain injury (Dempsey & Nankervis, 2005). The social model, in this case, relate to the usability of the Four-star Model for Enablement and Participation. This study further assumes that with the African One Hospital's community connectedness, more opportunities exist for stakeholders to start working collaboratively, strengthening brain injury treatment and rehabilitation within and beyond Uganda.

The foreseen potential barriers to the realization of the African One Hospital's community connectedness lies within the lack of inclusive attitudes by caregivers, health professionals, and other members of the community who may not understand the usefulness of the Four-star Model for Enablement and Participation. Other studies cited a lack of inclusive attitudes as a major barrier

to the inclusion of children with brain injury (Willis, Girdler, Thompson, Rosenberg, Reid, & Elliott, 2017). This study, therefore, proposes the involvement of BHRC via counselling and information sharing strategy to demystify all forms of stigma and negative attitudes concerning children with brain injury in Uganda. Similarly, Heah and friends (2007) cited public awareness campaign as a strategy to change a lack of inclusive attitudes. For example, when BHRC team acted through community connectedness, there was increased belongingness of children with brain injury and their caregivers in diverse social contexts, increased willingness of health professionals to respond to the needs and demands of children with brain injury which included basic needs support. In addition, this study found that a child who experienced aspiration pneumonia gained admission in the African One Hospital with less difficulty because of community connectedness.

On a negative note, this study found that community connectedness was limited by the use of English language. Without the use of other key cultural languages such as Luganda, Luo, Runyakitara, Iteso, and Lugbara, the Four-star Model for Enablement and Participation may contribute another level of participation restriction due to language barriers. This is a problem because the Four-star Model for Enablement and Participation was co-created in English language only and which may require translating in other key cultural languages in Uganda. The World Health Organization (2007) guided that language issues should be considered for successful use of ICF-CY. This study suggests that the Four-star Model for Enablement and Participation (FMEP) be translated in five main cultural languages of Uganda (Luganda, Luo, Runyakitara, Iteso, and Lugbara) as part of the studies meant to implement and evaluate its effectiveness in the Uganda contexts, and to support its full scale implementation as a national programme for children with brain injury in Uganda. This study further assumes that translating the FMEP would require a certain level of cross-cultural translation following appropriate guideline.

In line with community connectedness ideology, this study found that efforts are required to minimize caregiver constraints based on friendship arrangements. Other studies noted that friendship motivates a child with a disability to participate in basic needs (Barr & Shields, 2011). Friendship, therefore, moderates caregiver constraints. Conversely, a lack of friendship or difficulty making friends due to communication impairments among children with brain injury usually act as barriers to involvement of other stakeholders leading to caregiver constraints (Galvin, Froude, & McAleer, 2010). In addition, other contextual issues such as environmental

factors (e.g., physical geography and socio-economic status) are linked to barriers or enablers to participation of children with disability in general (Oates, Bebbington, Bourke, & Leonard, 2011; Imms, Reilly, Carlin, & Dodd, 2009). This study, therefore, created participants consensus for the use of occupation actualization philosophy formed by occupation scale and occupation score.

Chapter six: Contributions, Reflections, and Conclusion

6.0 Contributions, Reflections, and Conclusion

In this chapter I will present a summary of the contributions of this thesis, specific recommendations and how this study findings will be disseminated, limitations of the study, reflections on my learning, and conclusion.

6.1 Contributions of this thesis

The essential part of this thesis concerning occupation actualization (OA) relates this study to other existing theoretical perspectives (for example, Person-Environment-Occupation (Law et al., 1996); enablement and valued occupations (Rowles & Watkins, 2003; Kielhofner, 2008; Townsend & Polatajko, 2007); knowing, doing, being, and belonging (Wilcock, 1998); and being in place (Rowles, 2000)) supporting the practice of occupational therapy in Uganda and globally. Thus, this study has the potential to increase visibility of occupational therapy practice at different levels in Uganda and beyond. This thesis, therefore, adds new knowledge that will strengthen the position of occupational therapy in delivering occupation based and occupation focused interventions following the current assumption that occupation actualization (OA) relates to occupation scale and occupation score.

The Four-star Model for Enablement and Participation (FMEP) generated by this thesis has the potential to promote health and wellbeing of children with brain injury and their caregivers in Uganda. Once full implementation achieved in the Uganda health care system, the FMEP is likely to reduce mortality and disability resulting from brain injury. The required contributions will be tied to each action field represented by a symbolic star:

The first star, assessing child enablement contexts (ACEC) will contribute opportunity for increased community connectedness through shared understanding of the child-caregiver daily life culture and goals for occupation.

The second star, supporting caregivers to attain psychological health (SCAP-H) will contribute opportunity for dealing with psychological pain among caregivers through counselling on brain injury in the community.

The third star, bridging basic needs and enablement (BBE) will contribute opportunity for participation gaps closure in different contexts restoring any lost hope for occupation actualization among children with brain injury in Uganda.

The fourth star, involving the child in daily life activities will contribute opportunity for effective engagement of children with brain injury in daily life cultures based on occupation scale and occupation score.

The African One Hospital (MNRH), acting as a centre for Occupational therapy research involving children with brain injury and FMEP in Uganda has the potential to become a centre of excellence for occupation based and occupation focused research involving children with brain injury and their caregivers. In this case, the African One Hospital, will be supported through this study to implement and evaluate the effectiveness of the FMEP through a RCT, involving children with brain injury in Uganda.

6.1.1 Specific recommendations

6.1.1.1 for further research

This thesis recommended a randomized controlled trial to implement and evaluate the effectiveness of the Four-star Model for Enablement and Participation of children with brain injury in Uganda, and test the validity of the OA philosophy.

6.1.1.2 for occupational therapy and health care practice in Uganda

This thesis recommended the establishment of Brain Health and Rehabilitation in Communities (BHRC) to guide community connectedness for the implementation of FMEP. In addition, this thesis recommended for initiation of a national mentorship programme for occupational therapists, nurses, doctors, caregivers, and young researchers to strengthen the human resource capacity required in the BHRC.

6.1.2 Dissemination of study findings

This study findings will be disseminated through workshops, conferences, CEBU launching event, and classroom lectures. In addition, the findings will be published in Open Access, peer-reviewed scientific journals.

6.1.3 Limitations of the study

- This study used English language to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda (CEBU) described as FMEP. The implementation of FMEP will be limited to English language. The author may pair the FMEP's English version with any of the five key Uganda cultural languages: Luganda, Luo, Iteso, Runyakitara, and Lugbara for cross cultural acceptability.
- This study utilized doctors, nurses, therapists, children with brain injury, and their caregivers as data sources. Thus, the implementation of its findings will be limited to health professionals, children, and caregivers in diverse contexts.
- This study categorized children with brain injury as traumatic brain injury, cerebral palsy, stroke, and hydrocephalus. The implementation of its findings will be limited to similar groups.

6.2 Reflections on my learning

In study one, the reflections are captured poignantly as learning from the cry of children with brain injury concerning the usual intervention programme in KWB-HTC Uganda. In study two, the reflections are captured pleasurably as sharing happy moments when children with brain injury did smile in approval of action changes in KWB-HTC Uganda. Finally, in study three, the reflections are captured connectedly as occupation reality in the daily life of children with brain injury in Uganda.

6.2.1 Study One: Learning from the cry of children with brain injury concerning the usual intervention programme in KWB-HTC Uganda

The cry of children with brain injury indicated discomfort, pain, and inappropriate care. With assessments that did not focus on functional issues, actions that ignored the child's condition, and unwitting goals, children with brain injury were exposed to increased discomfort, pain, and inappropriate care. Because of this, children cried as they continued to receive intervention that

limited their potential to participate in diverse contexts, a practice detestable by being in place perspective (Rowles, 2000), and not being at one with the environment or context (Rowles, 2018). For example, children with wound in their mouth were subject to using toothbrush that resulted in pain due to repeated injury.

The cry of children with brain injury was partly associated with using toothbrush to clean the mouth that had wound; instead of a clean soft cloth soaked in boiled cool salty water for oral hygiene. One reason for using toothbrush despite its harmful nature was that caregivers' actions ignored the child's condition. Another example involves feeding; some caregivers fed their children by pouring feeds in the mouth with no consideration for food texture and the child's swallowing capability. This feeding style resulted in chocking and aspiration. Three involved children were diagnosed with aspiration pneumonia by doctors involved in the study. Children who were diagnosed with aspiration pneumonia received referral note to African One Hospital; caregivers were advised to change feeding style by formulating feeds in its right consistencies to match the child's feeding needs, age, severity of brain injury, and swallowing difficulties; then, the child fed slowly not by pouring feeds in the mouth.

It is not usual to see a Ugandan child cry during feeding; this was the norm with some of the brain injured children involved in the usual intervention programme. Doctors in the study believed that children cried during feeding because some food particles entered the airway and caused chocking.

6.2.2 Study Two: Sharing happy moments when children with brain injury did smile in approval of action change in KWB-HTC Uganda

Smiling was the most valued response that all children with brain injury provided in approval of action change. Smiles affirmed or communicated comfort, acceptance, and appropriate care. With action change involving the use of CECA tool for ACEC, supporting caregivers to attain psychological health, bridging basic needs and enablement, and involving the child in daily life activities (ICD), no child cried in different contexts. This time, the children and contexts were at one (Rowles, 2018) and backed by P-E-O practice model (Law et al., 1996); and enablement conceptual framework (World Health Organization, 2001, 2007). The act of being at one motivated community connectedness in the provision of culturally relevant intervention for children with

brain injury. This provision fitted within the ICD or occupation actualization (OA) formed by occupation scale and occupation score.

Children with brain injury who originally cried before action change, were seen smiling after action change. As children smiled, caregivers also smiled; as children cried, caregivers got distressed. Because none of the children cried following the action change, none of the caregiver was distressed. In addition, assessing child enablement contexts (ACEC) had great significance in the lives of children with brain injury especially concerning complexity of care. For example, during feeding, children were taken through six action steps i.e., cleaning the environment, child involvement in food selection, formulating food in its rightful consistency, feeding child on formulated food, documenting child involvement in feeding, and storing remaining food and feeding utensils. The previous feeding style was devastating in that it promoted an act of pouring feeds direct in the child's mouth, resulting in chocking and aspiration; this devastating action was replaced with six feeding action steps where none of the children chocked. This time round feeding was more enjoyable for children. The understanding that the child's body function, activity function, and other contextual requirements were part of action change resonated well with being in place perspective (Rowles, 2000). ICD, therefore, created shared happy moments; for instance, whenever a child smiled because of positive action change, the caregiver or health professional, or any other person in child's context smiled back to motivate continued experience of valued occupation described in this study as occupation actualization.

6.2.3 Study Three: Occupation reality in the daily life of children with brain injury in Uganda

Daily life was central focus for every child with brain injury. It created a sense of knowing, doing, being, and belonging earlier described by Wilcock (1998) in the book - occupational perspective of health; backed by being in place perspective (Rowles, 2000), social model of disability (Dempsey and Nankervis, 2005), and enablement conceptual framework (World Health Organization, 2001, 2007) which recognize relationship between human, activity, and participation in context. In this study, daily life was seen as the occupation reality of children with brain injury; if the children have to live, the children required food, exercises, body hygiene among others. Children with brain injury who did not participate in this study to experience occupation reality were assumed to be at risk of dying or experiencing functional loss; these children were

part of the major target for Brain Health and Rehabilitation in Communities (BHRC), formed by a group of volunteer health professionals and caregivers with a focus on brain health through access and use of FMEP, rehabilitation through enablement of valued occupation (Rowles & Watkins, 2003; Kielhofner, 2008; Townsend & Polatajko, 2007), and communities which include: hospital, health center, school, home, church, mosque, and rehabilitation center.

Central to the occupation reality, CECA tool was used to determine children's daily life priorities. The most rewarding experience was that all daily life priorities based on CECA tool fitted the occupation scale and occupation score, to inform the Occupation Actualization philosophy generated to support the implementation of FMEP.

6.3 Conclusion

This thesis concluded that every child with brain injury deserves a programme tuned to their cultural values that have to satisfy basic needs. The CEBU, therefore, was co-created as a Four-star Model for Enablement and Participation of children with brain injury in Uganda. To implement the CEBU, this thesis proposed occupation actualization philosophy which requires children with brain injury to be involved in daily life activities formed by occupation scale and occupation score.

The occupation actualization philosophy intends to bring into action every child with brain injury through interaction with valued occupation and relevant stake holders, assistive product, medicines, and required objects in contexts for purposes of supporting a claim that there is a positive relationship between occupation scale, occupation score, and enablement within the guiding principles of the Four-star Model delivered through community connectedness at the African One Hospital.

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Appendices

Appendix One, Ethics Approval Letter from University of Cape Town, HREC

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Division of Occupational Therapy
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Email: a.sonday@uct.ac.za
Student: ekwfra001@myuct.ac.za

Dear A/Prof Sonday

PROJECT TITLE: CO-CREATING A CULTURALLY RELEVANT PROGRAMME FOR ENABLING PARTICIPATION OF CHILDREN WITH BRAIN INJURY IN UGANDA (CEBU)- (PHD CANDDIATE-MR FRANCIS EKWAN)

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 July 2023.

Please submit a progress form, using the standardised Annual Report Form (FHS016) if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: - Mr Francis Ekwan will also be involved in this study.

Please quote the HREC REF 313/2022 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC/ref 313 2022

Appendix Two, Ethics Approval Letter from Mulago Hospital, REC

TELEPHONE: +256-41554008/1
FAX: +256-414-5325591
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug

IN ANY CORRESPONDENCE ON THIS
SUBJECT PLEASE QUOTES NO.....

MULAGO NATIONAL REFERRAL HOSPITAL
P. O. Box 7051
KAMPALA, UGANDA

8 August 2022.

Mr. Francis Ekwan
Principal Investigator – CEBU Study
Mulago National Referral Hospital.

Dear Ekwan,

Re: Approval of Protocol MHREC 2340: "Co-creating a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda

The Mulago Hospital Research and Ethics Committee reviewed your proposal referenced above and granted approval of this study on 8 August 2022. The conduct of this study will therefore run for a period of one (1) year from 8th August 2022 to 7th August 2023

This approval covers the protocol and the accompanying documents listed below.

- Protocol version 2CEBU/15/7/2022
- CEBU Study Participants Informed Consent Form: English Version 1C/12/5/2022
- CEBU Study Participants Informed Consent Form: Luganda Version 1CL/4/8/2022
- CEBU Study Assent Form for Children in the Study: English Version 2A/15/7/2022
- CEBU Study Assent Form for Children in the Study: Luganda Version 2AL/4/8/2022
- CEBU Study Agreement of Confidentiality_GPG/CPG Members: English Version 1CAGC/12/5/2022
- CEBU Study Agreement of Confidentiality GPG/CPG Members: Luganda Version 1CAGC/12/5/2022
- CEBU Study Agreement of Confidentiality for Data Secretary: English Version 1CADCS/12/5/2022
- Participants Interview Form about Children with Brain Injury: (English Version 1PIF/12/5/2022)
- Video Record Assessment (VRA) of Children with Brain Injury (English Version 1VRA/12/5/2022)
- Video Record Assessment (VRA) of Children with Brain Injury (Luganda Version 1VRA/4/8/2022)
- COVID-19 Risk Management Plan

APPROVED
APPROVAL DATE 0 8 AUG 2022 EXPIRY DATE 0 7 AUG 2023
MULAGO RESEARCH ETHICS COMMITTEE

This approval is subjected to the following conditions:

1. That the study site may be monitored by the Mulago Hospital Research and Ethics Committee at any time.
2. That you will be abide by the regulations governing research in the country as set by the Ugandan National Council for Science and Technology including abiding to all reporting requirements for serious adverse events, unanticipated events, and protocol violations.
3. That you will submit this approved protocol and all accompanying documents for approval to UNCST.
4. That no changes to the protocol and study documents will be implemented until they are reviewed and approved by the Mulago Hospital Research and Ethics Committee.

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IN ANY CORRESPONDENCE ON THIS SUBJECT PLEASE QUOTES NO.....

MULAGO NATIONAL REFERRAL HOSPITAL
P. O. Box 7051
KAMPALA, UGANDA

5. That you provide quarterly progressive reports and request for renewal of approval at least 60 days before expiry of the current approval.
6. That you provide an end of study report upon completion of the study including a summary of the results and any publications.
7. That you will include Mulago Hospital in your acknowledgements in all your publications.

I wish you the best in this Endeavour.

Signed by candidate

APPROVED
APPROVAL DATE 08 AUG 2022 EXPIRY DATE 07 AUG 2023
MULAGO RESEARCH ETHICS COMMITTEE
IRC

DR. NAKWAGALA FREDERICK NELSON
CHAIRMAN- MULAGO HOSPITAL RESEARCH AND ETHICS COMMITTEE

Appendix Three, Administrative Clearance Letter from Mulago National Referral Hospital

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IN ANY CORRESPONDENCE ON THIS
SUBJECT PLEASE QUOTES NO.....

MULAGO NATIONAL REFERRAL HOSPITAL
P. O. Box 7051
KAMPALA, UGANDA

26 October 2022.

Mr. Francis Ekwan
Principal Investigator
Department of Occupational Therapy
Mulago National Referral Hospital.

Dear Mr. Ekwan,

RE: ADMINISTRATIVE CLEARANCE GRANTED TO CONDUCT A STUDY AT MULAGO NATIONAL REFERRAL HOSPITAL.

The Administration and Management of Mulago National Referral Hospital is pleased to inform you that you have been offered clearance to conduct the trial titled **MHREC 2340: "Co-creating a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda".**

The above clearance is granted to you on the following conditions;

- That you will follow the research ethical processes
- Agreed to comply with all institutional policies and regulations of Mulago National Referral Hospital
- Agreed to provide end of study report and acknowledge Mulago hospital in all publications

Administrative clearance is valid for one (1) year effective from 26 October 2022 to 25 October 2023.

The Investigator should ensure to get final approval of the protocol and all accompanying documents from UNCST before starting the study. In case of studies involving drug, approval is obtained from National Drug Authority and for those studies involving medical devices, seek approval from Director General, Ministry of Health.

By copy of this letter, we reiterate our commitment to support this trial.

Signed by candidate

EXECUTIVE DIRECTOR
MULAGO NATIONAL REFERRAL HOSPITAL
P.O. BOX 7051, KAMPALA

DR. BYANYIMA ROSEMARY
AG. EXECUTIVE DIRECTOR
MULAGO NATIONAL REFERRAL HOSPITAL

Copied to;

1. **The Executive Secretary – Uganda National Council for Science & Technology.**
2. **In-Charge/Head – Occupational Therapy Unit.**

Vision: "To be the leading centre of Health Care Services"

Appendix Four, Ethics Approval from Uganda National Council for Science and Technology

Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: HS2509ES **8 November 2022**

Francis Ekwan
Mulago National Referral Hospital
Kampala

Re: Research Approval: **Co-creating a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda (CEBU)**

I am pleased to inform you that on **08/11/2022**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of **08/11/2022** to **08/11/2023**.

Your research registration number with the UNCST is **HS2509ES**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project. As the Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. Keeping all co-investigators informed of the status of the research.
2. Submitting all changes, amendments, and addenda to the research protocol or the consent form (where applicable) to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review with copies to the National Drug Authority and a notification to the UNCST.
4. Unanticipated problems involving risks to research participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST notification after review by the REC.
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project.

Please note that this approval includes all study related tools submitted as part of the application as shown below:

No.	Document Title	Language	Version Number	Version Date
1	Video Record Assessment in English	English	1VRA/12/5/2022	29 September 2022
2	Video Record Assessment in Luganda	Luganda	1VRA/4/8/2022	29 September 2022
3	Participants Interview Form in English	English	1PIF/12/5/2022	29 September 2022
4	Informed Consent Form English	English	ICE/24/10/2022	04 November 2022
5	Assent Form English	English	AE/24/10/2022	04 November 2022
6	Informed Consent Form Luganda	Luganda	ICL/24/10/2022	04 November 2022
7	Assent Form Luganda	Luganda	AL/24/10/2022	04 November 2022
8	Agreement of Confidentiality- GPG.CPG-English	English	CAGC/24/10/2022	04 November 2022
9	Agreement of Confidentiality- GPG.CPG-Luganda	Luganda	CAGCL/24/10/2022	04 November 2022
10	Agreement of Confidentiality-Secretary	English	CADCS/24/10/2022	04 November 2022
11	Risk Management Plan (COVID-19)	English	SOPC/24/10/2022	04 November 2022
12	Risk Management Plan (Ebola)	English	SOPE/24/10/2022	04 November 2022
13	Project Proposal	English	2CEBU/15/7/2022	
14	Approval Letter	English		
15	Administrative Clearance	English		

Yours sincerely,

Signed by candidate

Hellen Opolot
For: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE

Plot 6 Kimera Road, Ntinda
P.O. Box 6884
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 705500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: http://www.uncst.go.ug

Appendix Five, Child Enablement Contexts Assessment (CECA) Tool

1.0 CONTEXTS	DETAILS
[1.1] Background Information	Age: DOB: Gender: Tribe: Language: Religion: School/Hospital/Home: Date of assessment: Participation number: National Identification Number (NIN): Contact details: Place of delivery: Number of weeks of pregnancy: Duration of labor: Labor progress (prolonged/obstructed/assisted): Mode of delivery: Health of mother during pregnancy: Age of mother during pregnancy: Birth order of brain injured child: Any other person in family with brain injury: Vaccination (BCG at birth; Polio vaccine at birth/six weeks/ 10 weeks/14 weeks; DPT at six weeks/10 weeks/14 weeks; Rotavirus vaccine at six weeks/10 weeks; Measles, Mumps, and Rubella (MMR) vaccine at nine months; HPV vaccine at nine to 13 years; Pneumococcal vaccine to children at risk of pneumonia; Vitamin A at six months/one year/two years/three years/four years/five years; Deworming from one year to five years at six months interval). Therapy sources:

	Date of therapy/treatment initiation: Date of first evaluation: Date of second evaluation: Date of third evaluation: Date of fourth evaluation: Complex health care need:
[1.2] Environment Support System	Support from immediate family (ICF, e310): Attitude of immediate family members (ICF, e410): Support from health professionals (ICF, e355): Individual attitudes of health professionals (ICF, e450): Support from health services, systems, and policies (ICF, e580): Support from other professionals (ICF, e360): Individual attitude of other professionals (ICF, e455): Support from school services, systems, and policies (ICF, e565): Support from personal home care or school care providers (ICF, e340): Individual attitude of personal care providers (ICF, e440): General social support services, system and policies (ICF, e575):
[1.3] Body Structures and Body Function	Respiratory functions (ICF b440): Cervical vertebral column (ICF, s7600): Digestive functions (ICF, b515): Structure of trunk (ICF, s760): Ingestive functions (ICF, s510): Structure of larynx (ICF, s340): Structure of stomach (ICF, s530): Involuntary movement functions (ICF, b765): Muscle power functions (ICF, b730): Muscle tone functions (ICF, b735): Sensation related to muscles and movement (ICF, b780):

1.4 [Diagnosing Brain Injury]	Structure of brain (ICF, s110): Mobility of joint function (ICF, b710): 4. Diagnosis criteria (i*) Functional issues (indicate score or describe)* *GMFCS:* *MACS:* *CFCS:* *GCS:* *Weight:* *Height:* *Others (specify):* *(ii) Sensory issues (describe)* *Tactile:* *Visual:* Others (specify): *(iii) Child's body appearance (describe nature); how does the child looks?* *- small for age:* *- wasted:* *-malnourished:* *- physical abnormality noted:* *- head circumference bigger:* *- chest deformities:* *- deformities in the extremities:* *(iv) Body examination (describe); how is the child's reflexes?* *-Palmer grasp:* *- Rooting reflex:*

	- Tonic neck reflex: *-Moro reflex:* *-Stepping reflex:* *How is the child's muscle tone?* *- extensor pattern:* *-flexion pattern:* *(v) CT scan and MRI scan (optional):*
[1.5] Naming Basic Needs Activity	Participation issues (0 = Dependent Occupation; 1 = Independent Occupation) Prevention of secondary disabilities and enhance bod-activity function (ICF, b5702) *Using AT or Medicine (UATM):* • *Using assistive technology* Obtaining prescription for assistive product(s) for personal use in space: Obtaining assistive product(s) for personal use in space: Cleaning assistive product(s) for personal use in space: Setting up assistive product(s) for personal use in space: Using assistive product(s) in space: Documenting use of assistive product(s) in space: Storing assistive product(s) after use: • *Using medicine* Obtaining prescription for medicine product(s) for personal use in daily life: Obtaining medicine product(s) for personal use in daily life: Cleaning spaces meant for personal use of medicine product(s) in daily life: Setting medicine product(s) for personal use in daily life: Using medicine product(s) in daily life: Documenting use of medicine product(s) in daily life:

	Storing medicine product(s) after use: *Oral-Body Hygiene (OBH):* • *Oral Hygiene* Getting lukewarm water and other items for oral cleaning: Performing oral cleaning: Documenting about oral cleaning: Storing oral cleaning items after use: • *Body Hygiene* Emptying bladder: Emptying bowel: Washing hands after emptying bladder/bowel: Getting lukewarm water and other items for body cleaning: Performing body cleaning (head-to-toe) using lukewarm water and other items: Drying skin after cleaning: Smearing skin after drying: Dressing body after smearing skin: Documenting about body cleaning: Storing body cleaning items after use: *Posture-Joint Mobility Exercise (PJE):* • *Posture Management* Lying supine or prone on exercise mat equipped with pillows: Sitting upright on special seat: Standing upright supported by special stand: Documenting about lying, sitting, and standing posture: • *Joint Mobility Exercise* Exercising lower body and upper body - slow, progressive, prolonged muscle stretch using Shea nut

	oil or other natural oil, five minutes: Getting warm towel (four layers and eight layers): Using warm towel (four layers and eight layers) for body warming: Stepping with both feet weight bearing on the mat; 10 times when lying supine: Stepping with both hands weight bearing on the mat; 10 times when lying prone: Guided movement for balance and gait training, based on 11 elements (Guideline for Scoring Occupation): Documenting about joint mobility exercise: Storing joint mobility exercise items after use: *Feeding on formulated food (FFF):* Washing hands: Selecting food items to feed on (use appropriate communication: Formulating food items in its rightful consistency to feed on: Feeding on formulated food: Documenting about feeding on formulated food: Storing feeding items after use: *Play-Social relationships-Class (PSC):* Attending play based on six elements (Guideline for Scoring Occupation): Documenting about play involvement: Storing play items after use: Attending social relationships based on three elements (Guideline for Scoring Occupation):

	Documenting about social relationships: Attending class based on eight elements (Guideline for Scoring Occupation): Documenting about class involvement: Storing class items after use:
	Daily Occupation Planner Month: …….

	12 pm	1 pm	2 pm	3 pm	4 pm	5 pm
	6 pm	7 pm	8 pm	9 pm	10 pm	11 pm

Appendix Six, Occupation Scale for Goal Setting (OSc)

Participation Number:	Date:	……. Months Occupation Plan

1.0 Occupation Scale for Goal Setting (OSc)

……..assessed on …….for occupation issues:

i. using assistive technology,
ii. using medicine,
iii. oral hygiene,
iv. body hygiene,
v. posture management,
vi. joint mobility exercises,
vii. feeding on formulated food
viii. play,
ix. social relationships and
x. class engagement

Occupation Scale - important considerations:

1.1 Instructions

The identified occupation issues should be recorded as start scale value and goal scale value for an intervention period ≥ six months ≤ one year, and goal modified monthly.

1.2 Scale Description

-2: No evidence of competence in occupation - does not display any form or level of occupation competence for the skills listed.

-1: Minimal evidence of competence in occupation - displays minimal level of occupation competence for the skills listed.

0: Moderate evidence of competence in occupation - displays moderate level of occupation competence for the skills listed.

+1: Near maximum evidence of competence in occupation - displays near maximum level of occupation competence for the skills listed.

+2: Maximum evidence of competence in occupation - displays maximum level of occupation competence for skills listed.

1.3 Using Assistive Technology or Medicine (AT7M7)

Contexts	Description	Start DO/IO	Goal Scale DO/IO
Using Assistive technology	Obtaining prescription for assistive product(s) for use in space		
	Obtaining assistive product(s) for personal use in space		
	Cleaning assistive product(s) for personal use in space		
	Setting up assistive product(s) for personal use in space		
	Using assistive product(s) in space		
	Documenting use of assistive product(s) in space		
	Storing assistive product(s) after use		
Using Medicine	Obtaining prescription for medicine product(s) for personal use in daily life		
	Obtaining medicine product(s) for personal use in daily life		
	Cleaning spaces meant for personal use of medicine product(s) in daily life		
	Setting medicine product(s) for personal use in daily life		
	Using medicine product(s) in daily life		
	Documenting use of medicine product(s) in daily life		
	Storing medicine product(s) after use		

1.4 Oral-Body Hygiene (OH4BH10)

Contexts	Description	Start Scale DO/IO	Goal Scale DO/IO
Oral Hygiene	Getting lukewarm water and other items for oral cleaning		
	Performing oral cleaning		
	Documenting about oral cleaning		
	Storing oral cleaning items after use		
Body Hygiene	Emptying bladder		
	Emptying bowel		
	Washing hands after emptying bladder/bowel		
	Getting lukewarm water and other items for body cleaning		
	Performing body cleaning (head-to-toe) using lukewarm water and other items		
	Drying skin after cleaning		
	Smearing skin after drying		
	Dressing body after smearing skin		
	Documenting about body cleaning		
	Storing body cleaning items after use		

1.5 Posture-Joint Mobility Exercise (P4JE8)

Contexts	Description	Start Scale DO/IO	Goal Scale DO/IO
Posture Management	Lying supine or prone on exercise mat equipped with pillows		
	Sitting upright on special seat		
	Standing upright supported by special stand		
	Documenting about lying, sitting, and standing posture		
Joint Mobility Exercise	Exercising lower body and upper body - slow, progressive, prolonged muscle stretch using Shea nut oil or other natural oil, five minutes		
	Getting warm towel (four layers and eight layers)		
	Using warm towel (four layers and eight layers) for body warming after or during muscle stretch		
	Stepping with both feet weight bearing on the mat; 10 times when lying supine		
	Stepping with both hands weight bearing on the mat; 10 times when lying prone		
	Guided movement for balance and gait training, based on 11 elements (Guideline for Scoring Occupation).		
	Documenting about joint mobility exercise		
	Storing joint mobility exercise items after use		

1.6 Feeding on formulated food (FFF6)

Context	Description	Start Scale DO/IO	Goal Scale DO/IO
Feeding on formulated food	Washing hands		
	Selecting food items to feed on (use appropriate communication such as AAC)		
	Formulating food items in its rightful consistency to feed on		
	Feeding on formulated food		
	Documenting about feeding on formulated food		
	Storing feeding items after use		

1.7 Play-Social Relationships-Class (P3S2C3)

Contexts	Description	Start Scale DO/IO	Goal Scale DO/IO
Play	Attending play based on six elements (Guideline for Scoring Occupation)		
	Documenting about play involvement		
	Storing play items after use		
Social relationships	Attending social relationships based on three elements (Guideline for Scoring Occupation)		
	Documenting about social relationships		
Class Engagement	Attending class based on eight elements (Guideline for Scoring Occupation)		
	Documenting about class involvement		
	Storing class items after use		

Appendix Seven, Occupation Score for Occupation Engagement (OSr)

Participation Number:	Date:	……. Months Occupation Plan

2.0 Occupation Score for Occupation Engagement (OSr)

……..assessed on ……for occupation issues:

i. using assistive technology,
ii. using medicine,
iii. oral hygiene,
iv. body hygiene,
v. posture management,
vi. joint mobility exercises,
vii. feeding on formulated food
viii. play,
ix. social relationships and
x. class engagement

OA Score - important considerations:

2.1 Instructions

The specified occupation issues should be scored based on five values determined from the analysis of five minutes video recording of each activity domain; guideline for the scoring system is attached.

2.2 Score Description

1 - No evidence of competence in occupation - does not display any form or level of competence in occupation for the skills listed.

2 - Minimal evidence of competence in occupation - displays minimal competence in occupation for the skills listed.

3 - Moderate evidence of competence in occupation - displays moderate competence in occupation for the skills listed.

4 - Near maximum evidence of competence in occupation - displays near maximum competence in occupation for the skills listed.

5 - Maximum evidence of competence in occupation - displays maximum competence in occupation for skills listed.

2.3 Using Assistive Technology or Medicine (AT7M7)

Contexts	Description	Score DO/IO
Using Assistive technology	Obtaining prescription for assistive product(s) for personal use in space	
	Obtaining assistive product(s) for personal use in space	
	Cleaning assistive product(s) for personal use in space	
	Setting up assistive product(s) for personal use in space	
	Using assistive product(s) in space	
	Documenting use of assistive product(s) in space	
	Storing assistive product(s) after use	
Using Medicine	Obtaining prescription for medicine product(s) for personal use in daily life	
	Obtaining medicine product(s) for personal use in daily life	
	Cleaning spaces meant for personal use of medicine product(s) in daily life	
	Setting up medicine product(s) for personal use in daily life	
	Using medicine product(s) in daily life	
	Documenting use of medicine product(s) in daily life	
	Storing medicine product(s) after use	

Total Score, assistive technology use	**/35**

Total Score, medicine use	**/35**

2.4 Oral-Body Hygiene (OH4BH10)

Contexts	Description	Score DO/IO
Oral Hygiene	Getting lukewarm water and other items for oral cleaning	
	Performing oral cleaning	
	Documenting about oral cleaning	
	Storing oral cleaning items after use	
Body Hygiene	Emptying bladder	
	Emptying bowel	
	Washing hands after emptying bladder/bowel	
	Getting lukewarm water and other items for body cleaning	
	Performing body cleaning (head-to-toe) using lukewarm water and other items	
	Drying skin after cleaning	
	Smearing skin after drying	
	Dressing body after smearing skin	
	Documenting about body cleaning	
	Storing body cleaning items after use	

Total Score, Oral Hygiene	**/20**

Total Score, Body Hygiene	**/50**

2.5 Posture-Joint Mobility Exercise (P4JE8)

Contexts	Description	Score DO/IO
Posture Management	Lying supine or prone on exercise mat equipped with pillows	
	Sitting upright on special seat	
	Standing upright supported by special stand	
	Documenting about lying, sitting, and standing posture	
Joint Mobility Exercise	Exercising lower body and upper body - slow, progressive, prolonged muscle stretch using Shea nut oil or other natural oil, five minutes	
	Getting warm towel (four layers and eight layers)	
	Using warm towel (four layers and eight layers) for body warming after or during muscle stretch	
	Stepping with both feet weight bearing on the mat; 10 times when lying supine	
	Stepping with both hands weight bearing on the mat; 10 times when lying prone	
	Guided movement for balance and gait training, based on 11 elements (Guideline for Scoring Occupation)	
	Documenting about joint mobility exercise	
	Storing joint mobility exercise items after use	

Total Score, Posture	**/20**

Total Score, Joint Mobility Exercise	**/90**

2.6 Feeding on formulated food (FFF6)

Context	Description	Score DO/IO
Feeding on formulated food	Washing hands	
	Selecting food items to feed on (use appropriate communication such as AAC)	
	Formulating food items in its rightful consistency to feed on	
	Feeding on formulated food	
	Documenting about feeding on formulated food	
	Storing feeding items after use	

Total Score	**/30**

2.7 Play-Social Relationships-Class (P3S2C3)

Contexts	Description	Score DO/IO
Play	Attending play based on six elements (Guideline for Scoring Occupation)	
	Documenting about play involvement	
	Storing play items after use	
Social relationships	Attending social relationships based on three elements (Guideline for Scoring Occupation)	
	Documenting about social relationships	
Class Engagement	Attending class based on eight elements (Guideline for Scoring Occupation)	
	Documenting about class involvement	
	Storing class items after use	

Total Score, attending play	**/40**

Total Score, attending social relationships	**/20**

Total Score, attending class	**/50**

Overall Total Score	/ 390	%

Observations

……

……

……

……

……

……

……

Appendix Eight, Guideline for Scoring Occupation

1.0 Using Assistive Technology or Medicine

The use of assistive technology or medicine is the first ICD domain for enabling participation of children with brain injury in Uganda. This is abbreviated as AT-M. The implementation of AT-M has 14 processes; structured as **AT1-7 and M1-7**.

1.1 AT1: Obtaining prescription for assistive product(s) for personal use in space.

GPG-CPG agreed:

- *Everyone using assistive product should obtain and follow its prescription.*

1.2 AT2: Obtaining assistive product(s) for personal use in space.

GPG-CPG agreed:

- *Everyone requiring assistive product(s) should be supported to obtain the right assistive product(s) for use in space.*

1.3 AT3: Cleaning assistive product(s) for personal use in space.

GPG-CPG agreed:

- *For safely purposes, assistive product(s) should be kept clean and used in clean spaces.*
- *Hand washing should be performed as part of space cleanliness.*

1.4 AT4: Setting assistive product(s) for personal use in space.

GPG-CPG agreed:

- *Depending on the purpose….assistive product(s) should be used indoor or outdoor.*
- *The assistive product(s) should be modified to match body function level.*

1.5 AT5: Using assistive product(s) in space.

GPG-CPG agreed:

- *Assistive product(s) should when the user is happy to use it, its use should be stopped if the user starts crying.*

1.6 AT6: Documenting use of assistive product(s) in space.

GPG-CPG agreed:

- *Use AT record chart to document the date, time, assistive product(s) name, purpose of use, duration of use, body parts involved, positive response, and negative response to the use of assistive product(s).*

Table S1.

ICD - Form for Documenting Assistive Technology Use (AT Record Chart)

Date	*Time*	*Assistive technology name*	*Purpose of use*	*Duration of use*	*Body parts involved*	*Positive response*	*Negative response*

1.7 AT7: Storing assistive product(s) after use.

GPG-CPG agreed:

- *The assistive product(s) should be cleaned, dried, packed, and stored in a safe location after use.*

1.8 M1: Obtaining prescription of medicine product(s) for personal use in daily life.

GPG-CPG agreed:

- *Everyone using medicine product(s) should obtain and follow its prescription.*

1.9 M2: Obtaining medicine product(s) for personal use in daily life.

GPG-CPG agreed:

- *Everyone requiring medicine product(s) should be supported to obtain and use the right medicine product(s) in daily life.*

1.10 M3: Cleaning spaces meant for personal use of medicine product(s) in daily life.

GPG-CPG agreed:

- *For safely purposes, spaces meant for medicine use should be kept clean, free from dirt.*
- *Hand washing should be performed as part of space cleanliness.*

1.11 M4: Setting medicine product(s) for personal use in daily life.

GPG-CPG agreed:

- *Depending on the purpose, medicine product(s) should be used indoor or outdoor.*
- *The medicine product(s) should be modified to match the body function level.*

1.12 M5: Using medicine product(s) in daily life.

GPG-CPG agreed:

- *Stop use of medicine if the user starts crying, wait for the user to calm down.*
- *Observe any sign of coughing, do not give medicine until coughing stops.*
- *Observe, if the user swallowed medicine or if vomited; observe if vomiting occurred immediately or within 30minutes. This means the medicine has not worked, the user should be rested for 10 minutes and the medicine product(s) dose repeated.*
- *Observe any side effects of medicine use after successful administration.*

1.13 M6: Documenting use of medicine product(s) in daily life.

GPG-CPG agreed:

- *Use M record chart to document the date, time, and medicine name, purpose of use, duration of use, body parts involved, positive response, and negative response to the use of medicine product.*

Table S1.

ICD - Form for Documenting Medicine Use (M Record Chart)

Date	*Time*	*Medicine name*	*Purpose of use*	*Duration of use*	*Body parts involved*	*Positive response*	*Negative response*

1.14 M7: Storing medicine product(s) after use.

GPG-CPG agreed:

- *The medicine product(s) should be packed, and stored in a safe location after use.*

2.0 Oral-Body Hygiene

Oral-Body Hygiene is the second ICD domain for enabling participation of children with brain injury in Uganda. This is abbreviated as OBH. The implementation of OBH has 14 processes; structured as **OH1-4 and BH1-10**.

2.1 OH1: Getting lukewarm water and other items for oral cleaning.

GPG-CPG agreed:

- *Always get lukewarm water and required items for doing oral cleaning.*

2.2 OH2: Performing oral cleaning.

GPG-CPG agreed:

- *Always use Luke warm water, pediatric tooth paste, and pediatric tooth brush during oral cleaning, cold water usually make users stiffen and cry.*
- *If there is mouth wound or inflammation, use a clean soft cloth soaked in boiled-cooled salty water for cleaning the mouth, teeth, and tongue. The salt should be one tea spoon full in 500ml of water to avoid salt burn.*
- *The tooth brushing activity should be in accordance with best dental practices; then use down-up and side-to-side tooth brushing technique.*
- *Those less than three years should use a clean cloth for cleaning the teeth; those three years and above should use a tooth brush for cleaning the teeth i.e., if there is no wound in the mouth.*

2.3 OH3: Documenting about oral cleaning.

GPG-CPG agreed:

- *Use OH record chart to document the date, time, oral hygiene name, purpose of hygiene, duration of hygiene, body parts involved, positive response, and negative response to oral cleaning.*

Table S2.

ICD - Form for Documenting Oral Hygiene Involvement (OH Record Chart)

Date	*Time*	*Oral hygiene name*	*Purpose of hygiene*	*Duration of hygiene*	*Body parts involved*	*Positive response*	*Negative response*

2.4 OH4: Storing oral cleaning items after use.

GPG-CPG agreed:

- *The oral cleaning items should be packed and kept in a safe location after use.*

2.5 BH1: Emptying bladder.

GPG-CPG agreed:

- *Everyone four months and above should use a toilet seat or potty during bladder emptying, younger children three months or less should use pampers.*
- *Everyone with incontinency problem should be assisted to do clean intermittent catheterization using appropriate catheter or trained to manage bladder with or without catheter.*

2.6 BH2: Emptying bowel.

GPG-CPG agreed:

- *Everyone four months and above should use a toilet seat or potty during bowel emptying, younger children three months or less should use pampers.*

2.7 BH3: Washing hands after emptying bladder/bowel.

GPG-CPG agreed:

- *Routine hand washing with soap and clean water should be performed after emptying bladder/bowel.*

2.8 BH4: Getting lukewarm water and other items for body cleaning.

GPG-CPG agreed:

- *Always get lukewarm water and required items for body cleaning when preparing to perform body cleaning.*

2.9 BH5: Performing body cleaning (head-to-toe) using lukewarm water and other items.

GPG-CPG agreed:

- *Always use lukewarm water, bathing soap, and clean cotton made bathing mesh for body cleaning (head-to-toe).*
- *For head cleaning start with the hairs and proceed to the eye-nose-ear; use soap and clean warm in the basin; observe hair texture, color, distribution, and any fungal infection.*
- *For cleaning the entire body, start with the neck; use soap and clean warm water in the basin; observe skin texture, color, any fungal infection, hair distribution, skin temperature, distribution of the nail, and anemia.*

2.10 BH6: Drying skin after cleaning.

GPG-CPG agreed:

- *Always use clean cotton towel for drying skin after cleaning.*
- *To dry the skin, start with the head, proceed to the upper body, and end with lower body.*

2.11 BH7: Smearing skin after drying.

GPG-CPG agreed:

- *Always use Shea nut oil which is rich in vitamin E, an antioxidant, helps to protect cells, minimize skin dryness, and preserves the skin texture, color, health, hair distribution, and temperature.*

2.12 BH8: Dressing body after smearing skin.

GPG-CPG agreed:

- *Dressing should be done after smearing the skin with Shea nut oil; if the weather is cold, use warm clothes; if the weather is warm, use light cotton clothes or T-shirt.*

2.13 BH9: Documenting about body cleaning.

GPG-CPG agreed:

- *Use BH record chart to document the date, time, body hygiene name, purpose of hygiene, duration of hygiene, body parts involved, positive response, and negative response.*

Table S3.

ICD - Form for Documenting Body Hygiene Involvement (BH Record Chart)

Date	*Time*	*Body hygiene name*	*Purpose of hygiene*	*Duration of hygiene*	*Body parts involved*	*Positive response*	*Negative response*

2.14 BH10: Storing body cleaning items after use.
GPG-CPG agreed:

- *The body hygiene items should be packed, and kept in a safe location after use.*

3.0 Posture-Joint Mobility Exercise

Posture-Joint Mobility Exercise is the third ICD domain for enabling participation of children with brain injury in Uganda. This is abbreviated as PJE. The implementation of PJE has 12 processes; structured as **P1-4 and JE1-8**.

3.1 P1: Lying supine or prone on exercise mat equipped with pillows
GPG-CPG agreed:

- *Lie comfortably in supine or prone position, well supported with two pillows*
- *When lying supine, one pillow should be on the head and neck area; the other pillow should be on the knee area.*
- *When lying prone, one pillow should be on the head and neck area; the other pillow should be below the knee area*

3.2 P2: Sitting upright on special seat
GPG-CPG agreed:

- *Get the weight from the head through the spine to the hip and feet in a one to one to one (1-1-1) body posture in space.*
- *The first one is the head-neck-trunk.*
- *The second one is hip-knee.*
- *The third one is knee-foot.*

3.3 P3: Standing upright supported by special stand

GPG-CPG agreed:

- *Get weight from the head through the spine, hip, and to the feet in a standing position; the frontal head, chest, hip, knee, and feet should all point one direction.*

3.4 P4: Documenting about lying, sitting, and standing posture

GPG-CPG agreed:

- *Use P record chart to document the date, time, posture name, purpose of posture, duration of posture, body parts involved, positive response, and negative response to the state of body posture.*

Table S4.

ICD - Form for Documenting Posture Involvement (P Record Chart)

Date	*Time*	*Posture name*	*Purpose of posture*	*Duration of posture*	*Body parts involved*	*Positive response*	*Negative response*

3.5 JE1: Exercising lower body and upper body - slow, progressive, prolonged muscle stretch using Shea nut oil or other natural oil, five minutes

GPG-CPG agreed:

- *Lie comfortably in supine or prone position…..well supported with pillows and then perform slow passive muscle stretches for increased ROM on the fingers, wrist, elbow, shoulder, toes, ankle, knee, and hip joints.*

3.6 JE2: Getting warm towel (four layers and eight layers)

GPG-CPG agreed:

- *The temperature of the warm towel set for body warming should meet safety and body needs.*

3.7 JE3: Using warm towel (four layers and eight layers) for body warming after or during muscle stretch

GPG-CPG agreed:

- *To test safety in using warm towel (four and eight layers), the provider should apply it on his or her own hand dorsal area for five seconds and confirm that it does not hurt.*

3.8 JE4: Stepping with both feet weight bearing on the mat; 10 times when lying supine

GPG-CPG agreed:

- *At four months and above, weight bearing may be initiated in supine position….reciprocal foot stepping exercise can be maintained within comfortable hip-knee-ankle ROM taking two minutes…repeated three times per session twice a day*
- *At 10 months and above, weight bearing may be initiated in standing position with the help of a table framed at the level of child's umbilicus and knee to help in getting the weight from the head through the spine to the hip, knee, and ankle joints while maintaining the feet flat on the floor for 15-20minutes…repeat two times per session….twice a day.*

3.9 JE5: Stepping with both hands weight bearing on the mat; 10 times when lying prone

GPG-CPG agreed:

- *When lying prone, weight bearing should be through the shoulder-elbow-wrist with the extended hands; this should be done reciprocally with comfort, two minutes, and repeated three times per session, twice a day.*

3.10 JE6: Guided movement for balance and gait training, based on 11 elements (S4O Guideline)
GPG-CPG agreed:

i. *Front stepping on the tip of the opposite toe, 10 times.*
ii. *Heal rise, 10 times.*
iii. *Knee flexion to direction of buttocks, 10 times.*
iv. *Side stepping, 10 times.*
v. *Sitting and standing from the chair, 10 times.*
vi. *Walking along a straight line tape, five meters, 10 times.*
vii. *Walking 10 steps forward and 10 steps backward, 10 times.*
viii. *Tapping each foot on step platform, 10 times.*
ix. *Stepping forward and backward over an object, 10 times.*
x. *Stepping down and up on a step platform, 10 times.*
xi. *Pounding sand in container using hand held dowel rod while standing, 2-5minutes*

3.11 JE7: Documenting about joint mobility exercise
GPG-CPG agreed:

- *Use JE record chart to document the date, time, joint mobility exercise name, purpose of exercise, duration of exercise, body parts involved, positive response, and negative response.*

Table S5.

ICD - Form for Documenting Joint Mobility Exercise Involvement (JE Record Chart)

Date	*Time*	*Joint mobility exercise name*	*Purpose of exercise*	*Duration of exercise*	*Body parts involved*	*Positive response*	*Negative response*

3.12 JE8: Storing joint mobility exercise items after use

GPG-CPG agreed:

- *The joint mobility exercise items should be packed and kept in a safe location after use.*

4.0 Feeding on Formulated Food

Feeding on Formulated Food is the fourth ICD domain for enabling participation of children with brain injury in Uganda. This is abbreviated as FFF. The implementation of FFF has six processes; structured as **FFF1-6.**

4.1 FFF1: Washing hands.

GPG-CPG agreed:

- *The process of feeding should start with hand washing, free from dirt.*

4.2 FFF2: Selecting food items to feed on (use appropriate communication such as AAC)

GPG-CPG agreed:

- *Present the ready foot items in its original form to enable comprehension and selection; engaging different sensory organs.*

4.3 FFF3: Formulating food items in its rightful consistency to feed on.

- *Formulate the food in its right consistency to make it easy to feed on.*
- *The content of formulated food should be stated: your food was formulated from different food items that you saw earlier.*

4.4 FFF4: Feeding on formulated food.

- *Use upright position (1-1-1) to feed on formulated food.*
- *Crying or any sign of coughing during feeding requires one to first discontinue feeding until the event that led to crying or coughing is resolved.*
- *Monitor and prevent vomiting after feeding; do this using a relaxing position for about five minutes.*

4.5 FFF5: Documenting about feeding on formulated food

GPG-CPG agreed:

- *Use FFF record chart to document the date, time, feeding on formulated food name, purpose of feeding, duration of feeding, body parts involved, positive response, and negative response to feeding on formulated food.*

Table S6.

ICD - Form for Documenting Feeding on Formulated Food Involvement (FFF Record Chart)

Date	*Time*	*Feeding on formulated food name*	*Purpose of feeding*	*Duration of feeding*	*Body parts involved*	*Positive response*	*Negative response*

4.6 FFF6: Storing feeding items after use.

GPG-CPG agreed:

- *The feeding items should be packed and kept in a safe location after use.*

5.0 Play-Social relationships-Class

Play-Social relationships-Class is the fifth ICD domain for enabling participation of children with brain injury in Uganda. This is abbreviated as PSC. The implementation of PSC has eight processes; structured as **P1-3, S1-2, and C1-3**.

5.1 P1: Attending play based on six elements (S4O Guideline)

GPG-CPG agreed to apply six principles to enable play:

i. *Preparing the environment for play*
ii. *Seeing play object*
iii. *Hearing play object*
iv. *Feeling play object*
v. *Understanding play object*

vi. *Using appropriate communication in play*

5.2 P2: Documenting about play involvement

GPG-CPG agreed:

- *Use P record chart to document the date, time, play name, purpose of play, duration of play, body parts involved, positive response, and negative response to play.*

Table S7.

ICD - Form for Documenting Play Involvement (P Record Chart)

Date	*Time*	*Play name*	*Purpose of play*	*Duration of play*	*Body parts involved*	*Positive response*	*Negative response*

5.3 P3: Storing play items after use

GPG-CPG agreed:

- *The play items should be packed and kept in a safe location after use.*

5.4 S1: Attending social relationships based on three elements (S4O Guideline)

GPG-CPG agreed to apply three principles to enable social relationships

i. *Enjoying informal relationship*
ii. *Enjoying formal relationship*
iii. *Enjoying relationship with strangers*

5.5 S2: Documenting about social relationships

GPG-CPG agreed:

- *Use S record chart to document the date, time, social relationship name, purpose of social relationship, duration of social relationship, body parts involved, positive response, and negative response to social relationships.*

Table S8.

ICD - Form for Documenting Social Relationships Involvement (S Record Chart)

Date	*Time*	*Social relationships name*	*Purpose of social relationships*	*Duration of social relationships*	*Body parts involved*	*Positive response*	*Negative response*

5.6 C1: Attending class based on eight elements (S4O Guideline)

GPG-CPG agreed to apply eight principles to enable class involvement:

i. Preparing the environment for class work
ii. Watching objects in the learning space
iii. Listening to objects in the learning space
iv. Reading figures, words, and numbers
v. Writing figures, words, and numbers
vi. Calculating numbers
vii. Solving problem in assignment
viii. Using appropriate communication in class

5.7 C2: Documenting about class involvement

GPG-CPG agreed:

- *Use C record chart to document the date, time, class name, purpose of class, duration of class, body parts involved, positive response, and negative response to class involvement.*

Table S9.

ICD - Form for Documenting Class Involvement (C Record Chart)

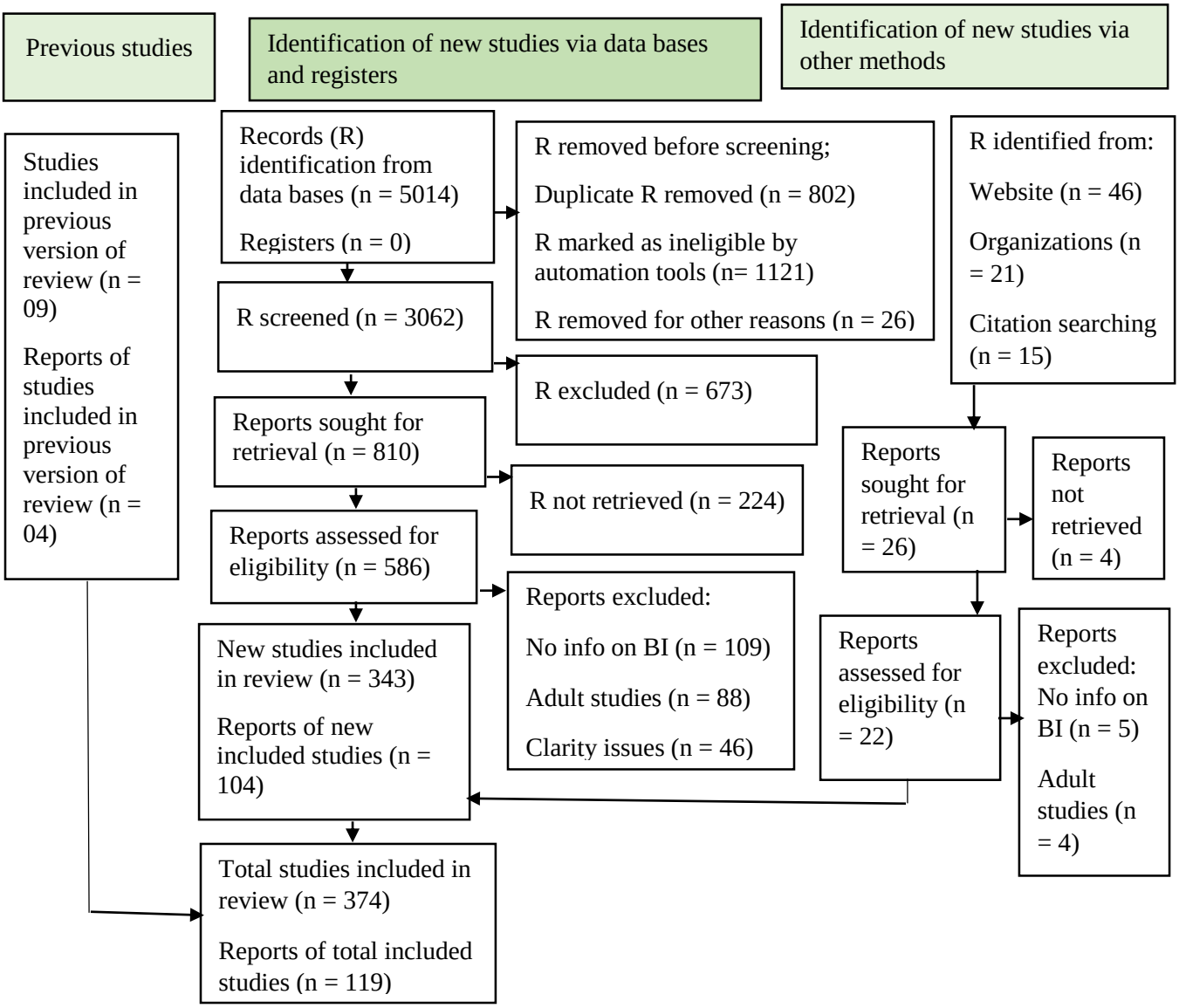
Date	*Time*	*Class name*	*Purpose of class*	*Duration of class*	*Body parts involved*	*Positive response*	*Negative response*

5.8 C3: Storing class items after use

GPG-CPG agreed:

- *The class items should be packed and kept in a safe location after use.*

Appendix Nine, PRISMA Flow Diagram Showing How Literature Review was conducted



Appendix Ten, Example of Data Gathered Through Interview with a Participant

Ok… I want to start by thanking you dear participant for accepting to take part in study to co-create a culturally relevant programme for enabling participation of children with brain injury in Uganda…when used in this study the term brain injury refers to traumatic brain injury… stroke….cerebral palsy….hydrocephalus…..and other forms of brain damage…through this interview I want to hear your reflection concerning the participation of children with brain injury in the Kampala-Wakiso Brain Injury Home Therapy Center (KWB-HTC)….your reflection should include general description about what you observed when you interacted with children with brain injury in the KWB-HTC.…specific observation….about some of the questions that were discussed at the KWB-HTC and any findings that you can be able to share concerning what you observed from the center concerning your experience about caring for children with brain injury…I would be asking you questions under each specific objective of the study…the first objective is to explore the participants thoughts, feelings and perceptions of the current intervention at the KWB-HTC…now I ask you the first question:

Question one: As a participant, what do you say are the activities being implemented at the KWB-HTC where you interacted with children with brain injury?

T1: some of the activities we looked at 1. training children with brain injury in activities of daily living that is dressing….upper body…lower body…second was exercises such as stretches….the third was tooth brushing…fourth was play…fifth was feeding

Researcher: thoughts about the activities

T1: actually that programme I should say it is a comprehensive programme that look at empowering cwbi and their caregivers…independence in all the activities of daily living they are doing…where I saw children having challenges was exercise…I should say it is a programme that requires changes to match the needs of children with brain injury….we need a programme that is responsive to the functional needs of children with brain injury and aims to enable cwbi attain a level of functional independence.

Researcher: how do you feel being part of the KWB-HTC

T1: the programme gives me the opportunity to interact and network with other therapists like SLT…PT…OT on the same child….so as a MDT we can come with a very good treatment plan for this child so we cannot leave any stone unturned….as an OT I may come up with some goals which are OT related leaving the goal that are PT and SLT related which further limit the child participation in all the activities of daily life….this programme if fully developed will offers opportunity for collaboration where all the professionals are involved doing their unique function that would create opportunity for collaboration, networking and to the end enable participation of children with brain injury

Researcher: Aspects that require changes

T1: in the discussion I had with some children…most children were struggling to participate in different activities such as feeding….play…dressing we need assistive devices to enable children participate in such activities….we want to see a programme that is capable of responding to the functional needs of children with brain injury…for that to happen the programme should indicate the assistive technology…how we use the assistive technology…and the programme should offer opportunity for children with brain injury to use the assistive technology…one example of assistive technology is cp chair….how we are using it we are using during feeding….we also need a more involved caregiver…its looks like most caregivers are unhappy which makes it hard to involve them…a clear strategy of providing psychological support for caregivers should be put in place among other things.

T1: The entire exercise practices at the center should be changed to match the participation needs of children with brain injury….i think should focus on posture and strength….spine mobility and strength….upper body and lower body function….for posture and strength…I think children with brain injury need more of chin tuck exercise….for spine mobility and strength….i think children with brain injury need more of spine-trunk rotation exercise…for upper body and lower body function…I think children with brain injury need to participate in a wide range of shoulder protraction and retraction exercises paired with activities in lying…sitting…and standing.

Researcher: Tell us a little more information about postural management that you mentioned about required changes.

T1: Some people refer to the chin tuck exercise as neck retraction chin tuck exercise….this is one of the key exercises recommended for keeping the head aligned above the spine, rather than drifting forward into poor posture….to perform the chin tuck exercise the following steps may apply:

i. Sit the child on a chair with feet flat on the floor or make the child stand up straight…or lie straight supine with a small pillow across the neck curve.
ii. Tell or motivate the child to relax the shoulders
iii. Tell or motivate the child to look straight in front.
iv. Tell or motivate or help a child to gently glide his or her chin straight back….this is not a big movement.
v. Tell or motivate or help a child to maintain this posture for 6-10 seconds…then relax.
vi. Repeat this exercise four to six times.

Researcher: Tell us a little bit more about other exercise for spine mobility and strength that you just mentioned among required changes in the KWB-HTC.

T1: Spine rotation exercise also referred to as spine-trunk rotation exercise targets the obliques, rectus abdominis, and lumber multifidus (muscles for low back stabilization)….

Spine-trunk rotation movement that involves the thoracic and lumber vertebrae and its surrounding muscles.

Because spine muscles play a vital part in any motion that the body performs…improves balance and gait in walking……increase low back and hip stability….improves postures within a 24 hour space…improves performance of daily activities…improves muscle strength required for sitting, standing and walking…increase trunk rotation, flexibility and ROM…through a spine-trunk rotation exercise can enable a child achieve such all such function…and may reduce the risk of injury from a fall or positional error.

In addition, by doing spine rotation exercise….the likelihood of spine deformity or tensional back pain can be minimized…spine deformity is a common problem among children with brain injury and such deformities could have been prevented by teaching children with brain injury and their

caregivers how to do regular spine rotational exercises…even those children already experiencing spine deformities or pain can have their deformities or pain addressed through spine rotation exercises.

To perform the spine rotation exercises for children with brain injury….the center should encourage the following steps:

In a lying position:

i. Get the child lie supine (back) on an exercise mat
ii. Keep the child's knee bent and feet flat on top of a flat floor
iii. Maintain the child's shoulder and upper body firmly against the floor
iv. Outstretch the child's arms and rest them on flat pillows placed on both sides of the body to help with balancing during movement.
v. Maintain the activity of the abdominal muscles
vi. Rotate the knees slowly to one side with the child's control…working within acceptable ROM…the feet will shift but should remain on the flat floor.
vii. Hold the child in this new position for 6-10 seconds.
viii. Maintain the activity of the abdominal muscles to move the child's legs to the opposite side.
ix. Hold the child in this new position for 6-10 seconds.
x. Encourage the child to be more involved through the exercise.
xi. Repeat this exercise 4-6 times.

I am sure that the variations of spine-trunk exercises will help accommodate the functional needs of a child with brain injury…being able to throw or kick or turn to pick a play object….such variations should also include:

i. Pelvic tilt- to help relax tight back muscles and increase flexibility…often done in supine position with knees up and feet flat on the flat on the floor…tell or motivate the child to tighten the core muscles (abdominal to spine) and tell or motivate or help the child to tilt the pelvis up toward the ceiling and back again.

ii. Feet raise- tell or motivate or help a child perform a trunk rotation in the spine position but with feet raised off the floor and knees bent at 90 degree angle. When doing…increase the intensity of the exercise by activating greater abdominal contraction during the movement.
iii. Leg extended- tell or motivate or help a child perform trunk rotation in supine position but with legs extended at the knee….this engages the core muscles more during the movement….do this slowly while focusing at the child being in control of the movement.
iv. Leg extended- tell or motivate or help a child perform trunk rotation in supine position but with knees up and feet flat on the floor…as the child moves the outer knee towards the opposite side…extend the other leg flat along the floor…then bring both legs back to the standing position.
v. Seated rotation- while the child is sitting on the exercise mat with legs extended in front, tell or motivate or help the child twist the upper body, touching the floor on one side and moving with the child's control to the opposite side….encourage the child to engage the core muscles during this exercise.
vi. Standing rotation- while standing upright…tell or motivate or help a child move the upper body to one side while keeping the hips still…the child bends the arms at the elbow with hands clasped together at the chest or the child holds arms extended out in front….in either arm position move the arms with the upper body as it twists
vii. During standing rotation- challenge the child…with either of the mentioned arm positions…the child holds a weighted medicine ball in the hands either right in front of the chest or extended out from the chest.

Researcher: thoughts about safety issues during exercises

T1: I think the safety should be emphasized during exercise, this should include:

i. Child does exercises within muscle activity level.
ii. Child maintain body awareness during exercises
iii. Child engages core during the exercises to effectively execute the movement without potential risk of discomfort or injury.
iv. Child completes the required dose of each form of exercise as being prescribed.
v. Child encouraged to control movement during exercise.
vi. Child repeats exercises at his/her body function level and/or different joint range of motion.

vii. The person helping the child should think of smaller range of motion that the child can control and keeps increasing ROM as the child improves.

viii. The person helping the child adds challenges when the child has mastered the basic movement.

ix. The person helping the child stops exercise if the child experiences pain…discomfort that does not feel right during the movement and immediately consult the child's therapy specialist or any other person acting in that capacity.

Researcher: You just mentioned changes about exercises that relate to trunk, tell us a little bit about shoulder exercises.

T1: protraction of the scapula is sometimes called abduction of scapula…the scapula is moved laterally and anteriorly along the chest wall

Position for movement: lying supine….sitting …and standing

Sitting/standing instructions:

The child sits or stand and elevate the target arm in front 90 degree

The child maintains a straight elbow…moves the arm forward by allowing the shoulder blade to move outwardly.

The child returns to the start position by drawing the shoulder blades towards the spine.

The child repeats this movement 4-6 times.

Lying supine instruction:

The child lies on the back and raises the arm towards the ceiling.

The child keeps the back and head on the bed ….reach with the hands towards the ceiling.

The child returns to the start position by drawing the shoulders back towards the spine.

The child repeats this movement 4-6 times.

Scapular protraction exercises to strengthen shoulder improves scapula stability…..this involves the following process:

Standing position; The child stands straight with flexed elbow 90 degree and fore arm with outstretched hand resting on the wall…..assistive device…standing frame may be required to attain upright posture during standing.

Avoid sagging of the shoulder or spine

Spine in straight position

Shoulder blade flashed on rib cage…apply pressure on the wall applies a negative force the introduces shoulder protraction

Kneeling position:

i. On fours with extended elbow and wrist extended to give a flattened hand on a flat surface
ii. Shoulder blade glides on the rib cage…apply pressure on the flat surface.
iii. Lying on an inclined prone board…
iv. Maintain the following during shoulder and upper body exercise in general:
v. Scapular anterior tilt when the sharp edge of scapula tips out….poor posture to be avoided
vi. Scapular internal rotation…when the inner part of scapula comes off…poor posture be avoided.
vii. The child's scapula should flash on the rib cage for building stability
viii. The lump often observed around the thoracic region where the scapula glides indicates poor posture…poor gliding surface for scapula…unstable scapula…and unstable shoulder….which has to be corrected.
ix. Note; scapula anterior tilt and scapula internal rotation increases scapula instability.
x. Scapula retraction stabilizes the thoracic spine but not the scapula which works independent of the spine….after you have stabilized the spine the next thing is to stabilize the scapula through scapula protraction exercise

xi. Researcher: What are some of the assistive technologies you suggest as changes in the KWB-HTC.

T1: we may have cp chair to position child for feeding….standing frame to position child for play…AFO to position foot for mobility training….nosed cup for enabling fluid feeding without having to tilt the head backward….swiveled spoon to enable grip to get the feeds in the mouth…the spoon should be plastic nonmetallic because some of these children have bite reflexes…the plates can be ordinary plates but the plate should be placed on non-slide mat…some of the children with CP athetosis with uncontrolled or exaggerated movement of the hand may not hit the plate and the plate slides away…for seating, in addition to CP chair…we may need corner seat for younger children less than four years…we can also have wheel chair on wheels…this is mainly prescribed if we are not working for independent mobility goal….the technology for activities in a lying position is mainly prone board…wedge…rolls….talk not most activities require children to be in a sitting or lying position…other than standing frame…other technologies for standing include parallel bar…wall bars…mobile bars…rails to enable a child stand….if modifying the child's environment…we can create a sand pit where you create a pit where a child can stand and fit there ….to create a sand pit you get sand and put it in a place…what you add on is that you put a tent so that even if it is a sunny day the child can still use it …the sand should be about three meter high…the therapist create a ditch in the sand using a hoe or hand the child is placed in that ditch and the sand pushed back to cover the child up to breast….such that the rest of the body the lower limb is sunken in to the sand…the head and upper limb are outside and free for playing with the sand and toys…sometimes it's used for sensory integration…children playing with the sand and feel the texture….you can even place toys for the child to play….actually a sand pit is more comfortable than standing frame where we see straps tied around the child….but this sand the child does not feel the pressure that sand is pressing me….so the child stand there plays around…actually no child cries when placed in a stand pit but children often over cry when placed in a standing frame…where you need to adjust the strapping.….we need cushion around the standing frame….but for sand we do not need the cushion…so you find that it is cost effective for some of our caregivers who can easily access sand in their communities….than a standing frame that is a bit expensive….you need to do some repair…you need some cushions…and adjustment…need some technical person to guide you on how to use it here and there…but the sand is more appropriate you find the children are using it with no complaint.

Technologies for walking: …the technology we often recommend for walking…. Posterior walker….this walker the child has where to grip and push……there are different forms of posterior walkers….prescribed depending on the need after you have assessed the child…..each with its limitation….on four wheels without break…and the child walks from behind the walker…here the child should have at least some strength to move a bit faster and control it independently…capable of walking fast with some degree of good motor strength and control to control the speed of the walker without the use of a break…..on four wheels with break…..comes when the child has good cognitive skill to know that the walker is propelling very fast and apply the break to minimize the speed…..on two wheels that is the front wheel…. the behind part there is no wheel…but rather the rubbers to control the speed…..mainly we look at those ones…we also have parallel bars but these ones are stationary the child does not move with them…the child grabs one on the left and another on the right hand…so the child moves while taking steps forward as he/she is walking……we also take this to be a mobility device but it is stationary but the walker can be moved indoor and or even outdoor….we can also use wheel chair for mobility but this is dependent mobility but if we are looking at independent mobility we look at walker and parallel bar….the concept posterior walker means the child walks from behind the walker…..crutches either axilla or elbow…why it is not so common in our children is because it need a child who is able to stand with no support…but this one come at a later stage…we often start with walker or parallel bar to minimize incidences of fall among children with brain injury…these on can come later as the child develop the skill of independent standing….

Researcher: Cultural issues with the use of walker…parallel bar…wheel chair

T1: all these appliances…walker…parallel bar…wheel chair…axilla crutch…elbow crutch none of these have registered any cultural conflict….may be people do not like them…people do not think they are applicable in their environment…all of them are totally accepted because we have been using it for some time.

Researcher: By culture we also mean the make…metallic...wooden…paper…..because culture takes more the dimension of the product…what make are more applicable in our setting?...

T1: the most culturally relevant and applicable technology products are the metallic one because metal are more durable…we mainly use steel metal because steel is readily available and is

cheaper…for the posterior walker we use wooden tire with small pieces of bicycle tire as lining for the wooden tire.

Researcher: which any other technology you want in the KWB-HTC…

T1: the most commonly used technology for visual stimulation is a torch…because some children have low vision…we need torches in the center….because a torch is readily available in our setting and it is cheap…sometimes we use colored light but it may not be so common in our setting…when doing the visual stimulation we always encourage moving away from the eye…when starting we start from mid line of the child's eye…but not directly on the eye…when starting the light should be dim and you go on intensifying the brightness of the light…as you start you move on the side of the child as you are checking laterally….. it can be from left…then midline…then to the right…then down the chin and up on to the face…of course the light should be dim… the response…the child opening the eye widely or closing the eye meaning the beam of the light is too much…..most of the time we advise caregiver if doing the visual stimulation it should be in a dark room…sometimes it can be during night time…but do not interrupt the child's sleep…the child should be awake….the requirement for visual stimulation is a dark room and a touch…to create a dark room a dark curtain is necessary.

Upper limb/hand technologies…we mainly use splints like wrist extension splint…elbow extension splint…shoulder abduction splint…for activity of daily living training we need ADL training board we need a multi-sensory board for stimulating hand function.

Hearing technologies….for hearing we mainly use hearing aid…there are two types…the best type we use in our setting is the digital one….where for it the moment you put the battery…and you move to a room that has a loud sound it make a lot of noise so you adjust to the kind of sound the ear drum is ready to handle….this technology has not been tried on children with brain injury…and it require children who are cognitively okay otherwise the child can easily pluck it out or dump it during play….the technology is also quite expensive i.e., aroung ugx 350,000.

Any technologies for children with bigger head…poor neck on trunk control…what we always use for children with hydrocephalus with big head…or poor head/neck/trunk control we always use a CP chair…with head support…even if it is a wheel chair we always modify to include head control.

Researcher: Special training required for the involved team

T1: training number on we should have therapists trained in disability and management of various conditions….training in assistive tec….which tec do we have and how can we use those technologies….if a technology is to be used by an OT you find a speech therapist very green about that technology….if the tec is to be used by a PT you find the OT green about the tec…so the therapists should know about the available tec…and how to operate them.

Researcher: What opportunities for training

T1: The center have rooms that are wide enough…so we can create rooms that can enable training on the use of technologies and the child can participate in mobility training session and use technologies….its a well-established center but require advise on the tec aspect.

Researcher: Funding for the center.

T1: When I got the chance to interact with one of the caregiver who takes her child to the center…the funding basically come from caregivers who take their children there…not every caregiver may not afford to privately pay for the services offered at the center.

Researcher: equipment for enablement of participation sufficient.

T1: equipment for mobility…positioning…sitting….standing….walking are not available in the center…the play equipment are sufficient.

Researcher: the response addresses the available and required equipment.

Researcher: Current equipment maintenance practice in the center?

T1: equipment we saw were in good functional condition…but we did not see the equipment maintenance plan in place….several equipment relevant for children with brain injury were not in the centre.

Researcher: What do you recommend as ways equipment be maintained in the center.

T1: we should have at least a store where we keep all equipment that is not being used and after use take them back to the store…..the current practice where drawers and wardrobes are used for keeping play items…appliances like wheel chairs can not be kept in the wardrobers or drowers.

Researcher: Current data management system

T1: currently data management is paper based where most data entered in children's files.

Researcher: Recommendation for data mgt.

T1: we will need computers…i-pads…lap tops and e-mails…google drive to keep our data safe

Researcher: CRP Activities

T1: Activity number on is feeding…the children should be trained on the feeds and how to feed…the second is hygiene liking at oral care….play and dressing…these activities should be structured to match the daily needs of children with brain injury….caregivers should accommodate the occupation needs of their children in making activity choices and engagement of the child.

Researcher: Enablers/Requirement

T1: Feeding> feeds is enabler number one…the therapist training feeding…the caregiver to be trained in feeding….the child to be fed following the recommended feeding steps….then funding for feeds and facilitation of therapists…..feeding materials such as plates/cups/spoon….space where feeding takes place.

Hygiene/oral care/tooth brushing> enabler number one…the therapist training tooth brushing…the caregiver to be trained in tooth brushing….the child to be engaged in body hygiene following the recommended body hygiene steps….funding to buy the tooth brushing materials…tooth brushing materials….. we require tooth brush…tooth paste…basin…bucket…water…cup….space…some settings we may require sink… where to do tooth brushing from…

Play> therapist…caregiver…child….we should have play materials…shakers or rattle...play ball…toy that produce sound…toy car…space….child to be engaged in play following the recommended play engagement steps…

Exercise> therapist…caregiver…child…therapy mat or a bed comfortable for both therapist/caregiver and child during exercise…some of the assistive devices for postural management and activity engagement of the child after exercise…space…..all in all the child should be involved in exercise following the recommended exercise steps…

Dressing> therapist…caregiver trained as with other activities and the child engaged following the recommended dressing activity steps in appropriate space.

Researcher: Activity Performance process

T1: Feeding> process number one is preparation of meal…space for feeding clean enough.….child in space for feeding….position of the child….modification of child to enable feeding…washing hands….feeding takes place….cleaning up….reposition the child for other activity.

Tooth brushing> first ensure place is clean and comfortable…water…tooth brush…tooth paste…therapist….caregiver….child….position child ready for tooth brushing…..hand washing….tooth brushing…rinse or clean the mouth…cleaning up….assemble the materials and take them back.

Play> first have enough space where players can move from one corner to another….remove obstacles that might limit movement….have play toys in place…have therapist…have caregiver…have child…have assistive technology for positioning the child if required to participate in play without limitation.

Exercise> first look at the space do we need the mat or bed….have the therapist in place if the right person to perform this exercise…have the caregiver…have child…create rapport for the child to allow touch or move his/her body parts like the arm…leg.

Dressing> first look at the space…materials for upper and lower body dressing…shock…shoe… positioning when doing dressing is it while seating…standing…technologies required for positioning when performing dressing…therapist…caregiver….child….dressing takes place.

Researcher: Setting for performing activities

T1: Feeding> first the environment should be free from contamination ie very clean….do we have the materials to help us in training feeding…do we need body supportive devices to position the child for feeding….is the feeds available in various preparations…do we have support team to help when required….then feeding can take place..

Tooth brushing> first the setting that have clean safe water for brushing….draining system for waste water.

Play> environment that does not have sharps…obstacles…if using floor for toy car play…clear every other thing including other play toys for the child to focus on a toy car.

Exercise> environment with a therapy mat or therapy bed…very clean…well lit…play toys to motivate the child…chart to guide exercises…

Dressing> set cloth the child to put on…remove other types of clothes that can obstruct the child.

Researcher: Appropriate time space for participation in different activities at the KWB-HTC

T1: for most of these activities we can recommend at least 30 to 45 minutes per activity…the feeding activity can take more time than any other activity…..so we can look at a time frame of four hours of engagement in the center…..as the child transitions from one activity to another activity there can be some sort of play…..start time: 8:30pm end time: 1:00pm

Frequency of coming to the center…at least each child comes to the center at least three times a week for a period of three months and a break of 3-4 weeks.

Feeding….10am and 1pm

Tooth brushing….8:30am

Play….12:00noon

Exercises….11am

Dressing…..9am

Researcher: Consequences and Limitation of implementing the programme.

T1: one of the consequence would be…we are going to empower our caregiver to be involved in enabling participation of their children with brain injury…because currently the caregivers believe it is the tjerapist or doctor to handle their children….the programme will also open the eyes of caregivers that in our communities we have low cost materials for enabling participation such as sand….the programme will impact in funding to facilitate involved health team…the programme will open the eyes of involved team members to understand the relevance of handling children with brain injury in a MDT…..The main limitation will be funding limitation to facilitate involved team members….another limitation is that it is un predictable whether the child lives or dies….some children may die….some caregivers may think they are empowered enough and can continue with the therapy at home without having to get to the center.

Researcher: Looking at the child's context what would you take as the activity that can enable the child to participate

T1: one would be health of the child at the time of activity training or programme…. may be the child has underlying condition like malaria that might have an impact on the participation of the child….another one is handling of the child…what referred as rapport with the child during activity performance…may be you are doing tooth brushing…no smiling…no laughing…no use of play toy….instructing the child not to touch here and there….Looking at the child's current mood is the child interested in the activity…nonverbal responses

Researcher: Looking at the child's context which activity performance process can enable participation of the child in the KWB-HTC

T1: so for these activities…we start with tooth brushing…then we have a snack…so that the child learns to connects tooth brushing and something nice that follows….actually having a snack after each activity performance will act as motivator for performance because the child will learn to pair something pleasant with activity performance and may work harder to complete the activity.

Researcher: Looking at the child's context any setting that enables child's participation

T1: available therapists that are welcoming to the child…availability of therapy equipment and play toys

Researcher: Time space for each of the activity.

T1: Tooth brushing 8:30am to 9:00am….dressing 9:00am to 9:50am…..feeding 10am to 11am….exercise 11am to 11:45am….rest 11:45am to 12:00 noon…..play 12:00noon to 1:00pm….feeding 1:00pm to 2:00pm….departure back home 2:00pm

END (Interview lasted three hours and 32 minutes)

Appendix Eleven, Video Record Assessment (VRA) of Children with Brain Injury (English Version 1VRA/12/5/2022)

Instruction

A five minutes video recording is taken from the KWB-HTC when a specified participant (caregiver/therapist/ nurse/doctor) interacts with a child with brain injury engaging in any of the following six activities: (i) exercises (ii) feeding (iii) oral & body hygiene (iv) dressing (v) play and (vi) use of assistive technology or medicine.

The video must be in landscape, and the child and involved stakeholder must be clearly visible.

Caregiver/Therapist/Nurse/Doctor interacts with child during exercise

Context to be observed	**Description**
Child	Ensure the child's body is well positioned in a comfortable location suitable for the nature of exercise to be undertaken
Caregiver/Therapist/Nurse/Doctor	Ensure the caregiver/therapist/nurse/doctor positions self comfortably at the child's level, ready to support the child during exercise.
Exercise	Child is viewed engaging in exercise that promotes body functioning.
Interaction focusing caregiver/therapist/nurse/doctor	Caregiver/therapist/nurse/doctor is viewed talking and supporting the child during exercise happening in KWB-HTC.
Interaction focusing child	Child is viewed making relevant communication during exercise happening in KWB-HTC.

Caregiver/Therapist/Nurse/Doctor interacts with child during feeding

Context to be observed	**Description**
Child	Ensure the child's body is well positioned in a comfortable location for feeding to take place.
Caregiver/Therapist/Nurse/Doctor	Ensure the caregiver/therapist/nurse/doctor positions self comfortably at the child's level, ready to support the child during feeding.
Feeding	Child is viewed engaging in feeding activity.
Interaction focusing caregiver/therapist/nurse/doctor	Caregiver/therapist/nurse/doctor is viewed talking and supporting the child during feeding activity happening in KWB-HTC.

Interaction focusing child	Child is viewed making relevant communication during feeding activity happening in KWB-HTC.

Caregiver/Therapist/Nurse/Doctor interacts with the child during oral and body hygiene

Context to be observed	**Description**
Child	Ensure the child's body is well positioned in a comfortable location for oral and body hygiene to take place.
Caregiver/Therapist/Nurse/Doctor	Ensure the caregiver/therapist/nurse/doctor positions self comfortably at the child's level, ready to support the child during oral and body hygiene.
Oral and/or body hygiene	Child is viewed engaging in oral and body hygiene activity.
Interaction focusing caregiver/therapist/nurse/doctor	Caregiver/therapist/nurse/doctor is viewed talking and supporting the child during the oral and body hygiene activity happening in KWB-HTC.
Interaction focusing child	Child is viewed making relevant communication during the oral and body hygiene activity happening in KWB-HTC.

Caregiver/Therapist/Nurse/Doctor interacts with child during dressing

Context to be observed	**Description**
Child	Ensure the child's body is well positioned in a comfortable location for dressing to take place.
Caregiver/Therapist/Nurse/Doctor	Ensure the caregiver/therapist/nurse/doctor positions self comfortably at the child's level, ready to support the child during dressing.
Dressing	Child is viewed engaging in dressing activity.
Interaction focusing caregiver/therapist/nurse/doctor	Caregiver/therapist/nurse/doctor is viewed talking and supporting the child during dressing activity happening in KWB-HTC.
Interaction focusing child	Child is viewed making relevant communication during dressing activity happening in KWB-HTC.

Caregiver/Therapist/Nurse/Doctor interacts with child during play

Context to be observed	Description
Child	Ensure the child's body is well positioned in a comfortable location for play to take place.
Caregiver/Therapist/Nurse/Doctor	Ensure the caregiver/therapist/nurse/doctor positions self comfortably at the child's level, ready to support the child during play.
Play	Child is viewed engaging in play activity.
Interaction focusing caregiver/therapist/nurse/doctor	Caregiver/therapist/nurse/doctor is viewed talking and supporting the child during play activity happening in KWB-HTC.
Interaction focusing child	Child is viewed making relevant communication during play activity happening in KWB-HTC.

Caregiver/Therapist/Nurse/Doctor interacts with child during use of assistive technology or medicines

Context to be observed	Description
Child	Ensure the child's body is well positioned in a comfortable location for the use of assistive technology or medicine prescribed as part of a previous care.
Caregiver/Therapist/Nurse/Doctor	Ensure the caregiver/therapist/nurse/doctor positions self comfortably at the child's level, ready to support the child during the use of assistive technology or medicine prescribed as part of a previous care.
Use of assistive technology and/or medicines	Child is viewed using assistive technology or medicine prescribed as part of a previous care.
Interaction focusing caregiver/therapist/nurse/doctor	Caregiver/therapist/nurse/doctor is viewed talking and supporting the child during the use of assistive technology or medicine prescribed as part of a previous care.
Interaction focusing child	Child is viewed making relevant communication during the use of assistive technology or medicines prescribed as part of a previous care.

Appendix Twelve, Participants' Interview Form about Children with Brain Injury (English Version 1PIF/12/5/2022)

Introduction

Thank you for accepting to take part in this PAR focusing on children with brain injury. The goal for this study is to co-create a culturally relevant programme enabling participation of children with brain injury in Uganda.

In this study, the researcher is interested in knowing the participants' thoughts, feelings, and perceptions of the current intervention programme in KWB-HTC Uganda; Culturally relevant programme Enabling participation of children with Brain injury in Uganda (CEBU) and the consequences and limitations of CEBU.

When used in this study, the term brain injury refers to children with traumatic brain injury, stroke, cerebral palsy, hydrocephalus, and varying forms of brain damage.

Through this interview, the researcher requires you to provide your reflections concerning participation of children with brain injury in KWB-HTC. The reflections will be based on:

General descriptive observation (i.e., observed setting/context).

Focused observation (i.e., specific aspects of the research questions(s).

Selective observation (i.e., finding evidence and examples of specific processes and aspects of the observed setting that answer the research question(s).

Should you have any questions about the study, feel free to ask the researcher now or during the interview.

Questions:

Objective one: *To explore the participants' thoughts, feelings, and perceptions of the current intervention programme in KWB-HTC Uganda.*

As a participant, what do you see being implemented as the usual intervention programme for children with brain injury in KWB-HTC Uganda? Please explain.

As a participant, what are your thoughts about the usual intervention programme for children with brain injury being implemented in KWB-HTC Uganda? Please explain.

As a participant, how do you feel being part of the usual intervention programme for children with brain injury in KWB-HTC Uganda? Please explain

As a participant, what aspects of the usual intervention programme for children with brain injury in KWB-HTC Uganda should be changed? Please explain.

As a participant, what formal or special training do you think is necessary for the team implementing the usual intervention programme for children with brain injury in KWB-HTC Uganda? Please explain.

What additional knowledge and skilling opportunities are currently available in KWB-HTC Uganda?

How is funding for KWB-HTC Uganda provided and allocated? How are the involved team being paid? Please explain.

Does the KWB-HTC Uganda currently have sufficient equipment to provide high quality therapy services for children with brain injury? Please explain.

What are some of those equipment currently available in KWB-HTC Uganda? Please explain.

What other equipment currently not available and are necessary in KWB-HTC Uganda? Please explain.

How are the equipment being maintained in KWB-HTC Uganda? Please explain.

As a participant, how do you think equipment should be maintained in KWB-HTC Uganda? Please explain.

What kind of data management systems are currently available in KWB-HTC Uganda? Please explain.

As a participant, how do you think data should be managed in KWB-HTC Uganda? Please explain.

Objective two: *To generate a culturally relevant programme enabling participation of children with brain injury in the KWB-HTC, Uganda (CEBU)*

As a participant, what do you say is expected to be the culturally relevant programme enabling participation of children with brain injury in KWB-HTC Uganda (CEBU)? Please explain

What kind of child's activity should be taken as CEBU? Please explain.

Looking at the child's activity, what activity performance processes should be part the CEBU? Please explain.

Looking at the child's activity, what settings should be part of CEBU? Please explain.

Looking at the child's activity, what time space should be part of CEBU? Please explain.

Objective three: *To describe the consequences and limitations of CEBU*

As a participant, what do you say are the consequences and limitations of CEBU?

Looking at the child's context, which activity enables children with brain injury to attend or be involved in KWB-HTC Uganda? Please explain.

Looking at the child's context, which activity performance processes enable children with brain injury to attend or be involved in KWB-HTC Uganda? Please explain.

Looking at the child's context, what settings enable children with brain injury to attend or be involved in KWB-HTC Uganda? Please explain.

Looking at the child's context, what time space should be part of CEBU? Please explain.

Appendix Thirteen, CEBU Study Participants' Informed Consent Form- English Version: ICE/24/10/2022

Protocol Title: Co-creating a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda (CEBU)

Protocol Number: 1865664

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Introduction

Dear Participant,

I, Francis Ekwan am a PhD student who is aiming to develop a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda (CEBU).

I invite you to participate in a Participatory Action Research (PAR) with a goal to collect diverse viewpoints concerning your experiences of working with the brain injured children and to use this information to develop the CEBU. You will also contribute ideas about the consequences and limitations of CEBU.

In this study, the researcher believes that the concept culturally relevant programme (CRP) is tied to the child's age, needs, and severity of the child's condition, and that the CRP will be formed when participants collectively decide on the relevant changes to the usual intervention programme in KWB-HTC, Uganda focusing: child's activity, time, and setting.

Within the child's contexts two broad concepts are emphasized, namely:

Culture – refers to recurrent pattern of behavior that influence health through its established environmental parameters to which individuals must respond (Gannotti and Handwerker, 2002).

Relevance – refers to cultures that are shaped by the dimensions and severity of particular conditions or diseases through the socially constructed meaning of the condition or impairment to the individual, to other social actors in the individual's life, and the presence of barriers to independence within the physical and cultural environment (Gannotti and Handwerker, 2002).

This form will explain the details of the study and what is involved if you choose to participate in this study. I am available to answer any questions that you may have about this study.

The study purpose and procedures

The purpose of this study is to co-create the CEBU with the participants. As a selected participant, you will participate in five activities:

GPG/CPG monthly meetings (five months).

KWB-HTC monthly visits to engage children with brain injury (four months).

Semi-structured interview for about two hours after each of the above-mentioned meetings.

Follow-up interviews to clarify information if necessary

Video recording of children with brain injury.

Research Ethics Committees

This protocol has been reviewed and approved by the UCT, Faculty of Health Sciences Human Research Ethics Committee (HREC). After the UCT approval, the protocol was again reviewed by the Mulago Research Ethics Committee (MREC) for purposes of providing ethics recommendation. The Uganda National Council for Science and Technology (UNCST) gave the ethics approval of this study.

Risks of participating in the study

There is a possible risk of participants misinterpreting this PAR study to be a form of intervention. There is also another risk of COVID-19 and Ebola infection, and compromise on privacy/confidentiality of participants. To manage the risk of participants misinterpreting the study, the researcher/principal investigator will share information about PAR, causes, development and effects of brain injury in the general participants' and core participants' group meetings to improve each other's ability to adequately plan, act, observe, and reflect throughout the PAR process. In addition, the researcher will include the voices of children with brain injury in all PAR stages. For example, video clips taken during participants' interactions with brain injured children will be used to communicate the feelings and non-verbal responses of children with brain injury involved in the study. To manage the risk of COVID-19 and Ebola infection the researcher has developed the risk management plan/standard operating procedures (SOPs) on COVID-19 and Ebola prevention and control for research staff and participants' safety. The PI will ensure compliance to the SOPs.

To ensure confidentiality and privacy, all research activities will take place in a private room excluded from others who are not part of the study, the researcher has also put in place measures such as the use of code names for participants across all settings of CEBU research undertakings. The researcher has taken care to design the interview questions for this study such that the questions are unlikely to elicit the disclosure of information that could compromise confidentiality or privacy.

As a participant, you should decline to answer any question that you feel would elicit information that can have a negative impact on your confidentiality or privacy.

In case you disclose sensitive information during this study, that information will not be reflected against your name. This additional measure is specifically designed to prevent the risk that you could, on the basis of your statements, be later identified by others – potentially resulting in a risk to your confidentiality or privacy. Similarly, all publications, and other disclosures of information outside of the research will be well coded to ensure that you cannot be identified using a combination of specific titles and locations, etc. In addition, you will be reminded that while participating in this research you are doing so on your own behalf, representing yourself as an individual and not others or your organization. As a researcher/PI, I am obliged to report certain incidents or observations like abuse.

There is a probability of some minor risk of discomfort in participating in the monthly participants' research meetings, monthly KWB-HTC research visits, and semi-structured interviews. The design of the monthly participants' research meetings, monthly KWB-HTC research visits, and semi-structured interviews are not intended to be harmful or distressing. If at any time you feel uncomfortable with any planned research activity, you may choose not to participate.

There are minimal risks posed to a child with brain injury involved in this study. It is possible that the child may experience a little discomfort during the KWB-HTC engagement. The discomfort is part of therapy undertaking and has no adverse effects.

E. Benefits of participating in the study

This study will empower each participant with appropriate knowledge concerning brain injury, PAR, and use of CRP to further care of children with brain injury in home context.

The CRP will contribute in the development of the practice guidelines and RCT for the home-based rehabilitation or management of children with brain injury in Uganda.

The use of the CRP will increase activity participation of children with brain injury.

The Researcher/PI will devise ways to integrate the CRP with existing health services, needs assessment, and helping a wider community including children with brain injury and their caregivers access the right information and services.

F. Privacy and confidentiality

All the data collected in form of video clips, photos, medical forms, assessment forms, audio recording among others will be managed in a safe and secure lockable room in OTD-M. Any picture/video data will only be made public through informed consent of affected participant. Individuals who are not part of the study team or participants will not be allowed in the study setting for confidentiality reasons.

The PI will remove from the data all personal identifiers at the end of the study and the link connecting you to the information you provide to the researchers will be destroyed. However, as identifiable information will be maintained for some period of time, absolute privacy and confidentiality will be limited. Thus, unless otherwise required by law, only the Principal Investigator (PI) have full access to confidential information which will be kept in a lockable room or computer with password in OTD-M. The members of the research team and accredited IRB

may have access to limited confidential information if identifiable information are shielded. During your interview, we will remind you to refrain from identifying yourself to the extent possible. Any identifiable information accidentally disclosed by you during the study will be removed from the text and transcripts of your responses to the study interview or meeting question. After identifiers are removed from the information you provide as part of this study, the information could be used for future research studies or distributed to another investigator for future research studies without your additional informed consent.

The research findings may be presented at professional meetings or publish the results of this research study in relevant journals. However, these presentations and publications will never include your name, address, or other identifying information about you.

G. Disclosure of appropriate alternatives

As there is no full compensation to your participation in this study, your alternative is not to participate. The Principal Investigator may also withdraw you from the study if it is in your best interest. You may also be withdrawn from this study without your consent if you do not follow the instructions given to you by the PI, or if you fail to keep your scheduled research appointment time.

H. Re-imbursement and compensations for participation

You will receive between UGX. 50,000-100,000 (R 165-330) to cover transport, time compensation, and lunch for taking part in the monthly meeting. The stakeholders taking part in the monthly KWB-HTC visits will receive UGX 50,000 (R 165) to cover transport and lunch. Drinks and snacks will be provided during group discussions.

You will not be paid for taking part in the research interview. Being a qualitative research study, there is no risk of you getting hurt in this study. Thus, no need for the UCT No-fault insurance cover for you.

I. Contact information

If you have any questions about the research, research participants' rights, or in case of research related injury, please contact the principal investigator or research supervisor at the contact information located on the first page of this consent form.

You are free to refuse to participate in this research project or to withdraw your consent and discontinue participation in the project at any time without penalty or loss of benefits to which you are otherwise entitled

J. Participants rights.

If you have any questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you are encouraged to (anonymously if you so choose) contact Dr. Frederick Nelson Nakwagala, Chairperson Mulago Hospital Research & Ethic Committee on mobile phone number +256 – 772325869.

The UCT FHS Human Research Ethics Committee on 021 406 6338.

K. What your signature means

Your signature or thumb print below means that you have understood and are satisfied with the explanation given to you about this study and that you have voluntarily agreed to participate in it.

L. Consent statement

I have read or listened to the above information. I have asked questions and received answers

I consent to participate in the study.

_____

Printed name of research participant

_____ _____

Signature or thumbprint of research participant Date

_____ _____

Name and signature of person obtaining consent Date

Appendix Fourteen, CEBU Study Assent Form for Children in the Study- English Version: AE/24/10/2022

Protocol Title: Co-creating a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda (CEBU)

Protocol Number: 1865664

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Introduction

Dear Participant,

I, Francis Ekwan am a PhD student who is aiming to develop a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda (CEBU).

I invite you to participate in a Participatory Action Research (PAR) with a goal to collect data about your thoughts, feelings, and perceptions of the current intervention programme at the KWB-HTC, Uganda. This data will be collected using video recording as you get involved in the different activities in KWB-HTC. Thus, this form will explain the details of the study and what you will do as a participant. I am ready to answer any questions that you may have about this study.

Why the study and how the study will be performed

The reason for doing this study is to come up with something called CEBU that allows children with brain injury to attend or get involved in doing different activities in Uganda. As a selected participant, you will take part in two activities:

KWB-HTC monthly visits (four months).

Video Record Assessment (VRA) of Children with Brain Injury.

Permission to carry out the study

This study has been given permission to go on by all bodies concerned. The bodies that gave permission for this study include: University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (HREC), Mulago Research Ethics Committee (MREC), and the Uganda National Council for Science and Technology (UNCST).

Risks of participating in the study

There is a risk of taking this study to be a form of treatment and yet it is not. There is also another risk of getting COVID-19 and Ebola infection if nothing is done to prevent it. In addition, other people may get to know you. To manage the risk of taking this study to be a form of treatment you will be given information about participatory action research also referred to as PAR, causes, and effects of brain injury prior to video recording. To manage the risk of getting COVID-19 and Ebola infection the researcher has developed the risk management plan/standard operating procedures (SOPs) on COVID-19 and Ebola prevention and control for research staff and participants' safety. The PI will ensure that every one taking part in the study follows the SOPs. To ensure other people do not get to know too much about you, all research activities will take place in a setting where other people who are not part of the study will not be allowed. The researcher will also give you non real name to stop others from knowing your real name.

Important to note is that as a researcher/PI, I am obliged to report certain incidents or observations like abuse.

In case you bring out something that can be taken as serious information during this study, that information will not be linked to your name. This additional measure is to prevent the risk that you could, on the basis of your statements, be later identified by others – resulting in a risk to privacy. Similarly, all what will go public from the study, and other sharing of information outside of the

research will be made without using your real name to ensure that nobody gets to know you as the one who shared the information. In addition, you will be reminded that while participating in this research you are doing so on your own behalf, representing yourself as an individual child.

There is a probability of some minor risk of not feeling good in participating in the monthly KWB-HTC research visits. The design of the monthly KWB-HTC research visits is not intended to cause any problem. If at any time you feel bad with any planned research activity, you may choose not to participate.

There are smaller risks posed to a child with brain injury involved in this study. It is possible that the child may not feel fully good during the KWB-HTC research visit time with other participants. The issue of not feeling good may be because of therapy work and this should not worry you because it goes with therapy ending.

E. Benefits of participating in the study

This study will empower you with appropriate knowledge concerning PAR, causes, and effects of brain injury.

The use of CEBU will increase activity attendance and involvement of children with brain injury. The Researcher/PI will devise ways to integrate the CEBU with existing health services, needs assessment, and helping a wider community including children with brain injury and their caregivers access the right information and services.

F. Privacy and confidentiality

All the details obtained from each child with brain injury in form of video clips, photos, KWB-HTC form among others will be kept in a lock at OTD-M where other people may not access except the researcher. Any picture/video details will only be shared public with permission from you the participant.

The research findings may be presented in meetings for people who want to learn about our work or shared widely through what is called journal. However, these presentations and journal will never include your name, address, or other identifying information about you.

G. Other thing you need to know

As the researcher will not pay you fully, another thing you can do is not to participate. The researcher may also stop you from the study if it is in your best interest. You may also be stopped from this study without your further assent if you do not follow the instructions given to you by the researcher, or if you fail to keep your scheduled research appointment time.

H. Re-imbursement and compensations for participation

You will receive UGX. 50,000-100,000 (R 165-330) to cover transport, time you give to the study, and lunch during the monthly KWB-HTC visits. Drinks and snacks will be provided during group discussions. Being a qualitative research study, there is no risk of you getting hurt in this study. Thus, no need for the UCT No-fault insurance cover for you.

I. Contact information

If you have any questions about the research, your right as a participant, or in case of research related injury, please contact the PhD student or research supervisor at the contact information located on the first page of this assent form.

You are free to refuse to participate in this research project or to withdraw your assent and stop participation in the project at any time without penalty or loss of benefits to which you are otherwise supposed to get.

J. Participants rights.

If you have any questions or problem about the study and would like to talk to someone other than the researcher(s), you are encouraged to contact Dr. Frederick Nelson Nakwagala, Chairperson Mulago Hospital Research & Ethic Committee on mobile phone number +256 – 772325869.

The UCT FHS Human Research Ethics Committee on +2721406 6338.

K. What your signature means

Your signature or thumb print below means that you have understood and are happy with what has been shared about this study, that you have your parent's permission to participate in the study, and that you have voluntarily agreed to participate in it.

L. Assent statement

I have read or listened to the above information. I have asked questions and received answers I assent to participate in the study.

_____

Printed name or parent if the child not capable to assent

_____ _____

Signature or thumbprint of child or parent if child not of sound mind Date

_____ _____

Name and signature of person obtaining assent Date

Appendix Fifteen, CEBU Study Agreement of Confidentiality for GPG/CPG members-English Version: CAGC/24/10/2022

Protocol Title: Co-creating a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda (CEBU)

Protocol Number: 1865664

I, the undersigned person, acknowledge that

In my role as participant `involved in the CEBU study, taking part in the KWB-HTC visits, general participants' and core participants' group meetings, I will be accessing different documents, photos, video clips, medical forms, disability assessment tools, and note books for documenting actions, observations, and reflections. These documents, photos, video clips, medical forms, disability assessment tools, and note books are owned solely by UCT, CEBU study and I will have access to confidential information during the period I am taking part in the study.

In performing my duties, I agree not to disclose any confidential information pertaining to this CEBU study, or to use that confidential information other than as a participant during the study period, or to use that confidential information for possible personal financial gain, without prior approval from the PI.

This agreement is the way to survive the termination of my association with CEBU study.

IN WITNESS, I have signed this Agreement on the date written below.

Date: Signature:

Print Name:

Credentials, Title, and/or Position with an Organization/Institution:

Appendix Sixteen, CEBU Study Agreement of Confidentiality for Research Assistant-English Version: CADCS/24/10/2022

Protocol Title: Co-creating a Culturally Relevant Programme for Enabling Participation of Children with Brain Injury in Uganda (CEBU)

Protocol Number: 1865664

I, the undersigned person, acknowledge that

In my role as Research Assistant involved in the CEBU study's KWB-HTC visits, general participants' and core participants' group meetings, administration of interview forms, and other assigned duties, I will be accessing different documents, photos, video clips, medical forms, disability assessment tools, and note books for stakeholders. These documents, photos, video clips, medical forms, disability assessment tools, and note books are owned solely by UCT, CEBU study and I will have access to confidential information during the period I am taking part in the study.

In performing my duties, I agree not to disclose any confidential information pertaining to this CEBU study, or to use that confidential information other than as Research Assistant during the study period, or to use that confidential information for possible personal financial gain, without prior approval from the PI.

This agreement is the way to survive the termination of my association with CEBU study.

IN WITNESS, I have signed this Agreement on the date written below.

Date: Signature:

Print Name:

Credentials, Title, and/or Position with an Organization/Institution:

Appendix Seventeen, Risk Management Plan for the control and prevention of Ebola-Research Staff & Participants' Safety (Version: SOPE/24/10/2022)

#:	CEBU-SOPE # 002/22
TITLE:	Risk Management Plan for Ebola
EFFECTIVE:	Date of study approval
PURPOSE:	To describe the process of ensuring safety of participants and staff against Ebola transmission and referral of suspected cases.
SCOPE:	This SOPs applies to all study staff, study participants and contracted vehicle or boda-boda drivers.
RESPONSIBILITY:	It will be collective responsibility of the project team, participants, and all engaged in the research process to ensure compliance to this SOPs at all times.

1. **Introduction:**

Because Ebola infection is one of the risks involved in this study, the PI, CEBU study has developed this SOPs (risk management plan) in order to assist the study participants and research team manage the risk of contracting Ebola infection as they get involved in CEBU research activities. In addition, the PI will ensure participants are regularly updated about guidelines issued by the World Health Organization (WHO) and the Uganda Ministry of Health (MOH) in the control of transmission of Ebola and referral of suspected Ebola cases.

2. **Supplies**

The following supplies will be made available by the PI, CEBU study prior to the start of the study.

i. Cloth or disposable masks
ii. Gloves (surgical and disposable)
iii. Alcohol based sanitizer.
iv. Hand washing facilities (soap, water and basin)
v. Water containers
vi. Temperature monitoring gun
vii. JIK
viii. Bio-hazard bag

A) General Considerations about CEBU Ebola Risk Management

1. The PI, CEBU study will write a letter to Mulago National Referral Hospital Ebola task force two weeks prior to the start of CEBU study. The letter will detail the researcher's role in the prevention of Ebola infection during our planned CEBU research activities and the roles of the Hospital task force.
2. The PI, CEBU study will work closely with Mulago National Referral Hospital Ebola task force to ensure that all planned research activities are implemented in ways that do not pose risk of spreading Ebola infection. For instance, the PI will organize a training on Ebola infection to be performed by Ebola task force/IPC- Mulago National Referral Hospital for all CEBU research team and participants.

B) General Procedures in Regards to Ebola Prevention

- All research team members including participants will have a training on Ebola prevention and control measures.
- The CEBU research site will display health education materials and MoH guidelines on Ebola prevention translated in the local language.
- All study participants and staff who come to the study site/office will wash their hands with soap and water for at least 20 seconds or use hand alcohol-based sanitizer and will have their temperature taken.
- All study staff, contracted vehicle or boda-boda drivers, participants including children with brain injury who are above six years will wear face masks provided by the PI at all times except when they are having a refreshment.
- All study team members and participants will be required to practice frequent hand washing/sanitizing, including before and after each therapy session interaction with a child with brain injury.
- All study team members and participants will be required to register their Ebola case contacts, indicating the following information:

i. First name
ii. Family name
iii. Sex
iv. Age
v. Relation with case
vi. Date of last contact with case

vii. Contact type- touched bodily fluids of case (blood, vomit, saliva, urine, stool), had direct contact with the dead body of case (alive or deceased), touched or cleaned the clothing, linen, or plates of case, slept or ate in the same house as case
viii. Name of family head
ix. Address
x. Town/village
xi. Health zone
xii. Telephone number
xiii. Health personnel (Y/N), if yes, structure?

- The study will maintain Ebola infection prevention standards in the study site by sanitizing all surfaces and equipment e.g., tables, therapy mats, chairs, work tops, door handles etc with hypochlorite or as will be guided by Infection Control Committee- Mulago National Referral Hospital. The study site including the study office will be cleaned with JIK and sanitized every day before any form of engagement with participants and research team.
- Any tissue used for sneezing or wiping any form of body fluid or excrete from any study participant/team must be disposed-off properly in the bio-hazard bag.
- If a participant is suspected to have Ebola, the PI will immediately refer to the Mulago National Referral Hospital Ebola task force treatment point for Ebola confirmation and care
- Hugs and handshakes among study participants and or study staffs will be avoided.

Approved by:

…….. **…….……**

Principal Investigator- CEBU STUDY **DATE**

Document Change history:

SOPs # and Version	Effective Date	Suspended Version	Review Date	Reason for review	Outcome of Review
#002/22 V1.0	Date signed				☐ No change ☐ New version issued

Appendix Eighteen, Risk Management Plan for the control and prevention of COVID-19-Research Staff & Participants' Safety (Version: SOPC/24/10/2022)

#:	CEBU-SOPC # 001/22
TITLE:	Risk Management Plan for COVID-19
EFFECTIVE:	Date of study approval
PURPOSE:	To describe the process of ensuring safety of participants and staff against COVID-19 transmission and referral of suspected cases.
SCOPE:	This SOPs applies to all study staff, study participants and contracted vehicle or boda-boda drivers.
RESPONSIBILITY:	It will be collective responsibility of the project team, participants, and all engaged in the research process to ensure compliance to this SOPs at all times.

1. **Introduction:**

Because COVID-19 infection is one of the risks involved in this study, the PI, CEBU study has developed this SOPs (risk management plan) in order to assist the study participants and research team manage the risk of contracting COVID-19 infection as they get involved in CEBU research activities. In addition, the PI will ensure participants are regularly updated about guidelines issued by the World Health Organization (WHO) and the Uganda Ministry of Health (MOH) in the control of transmission of COVID-19 and referral of suspected COVID-19 cases.

2. **Supplies**

The following supplies will be made available by the PI CEBU study prior to the start of the study.

i. Cloth or disposable masks
ii. Gloves (surgical and disposable)
iii. Alcohol based sanitizer
iv. Hand washing facilities (soap, water and basin)
v. Water containers
vi. Temperature monitoring gun
vii. JIK
viii. Bio-hazard bag

A) General Considerations about CEBU COVID-19 Risk Management

1. The PI, CEBU study will write a letter to the Mulago National Referral Hospital Covid-19 task force two weeks prior to the start of the CEBU study. The letter will detail the researcher's role in the prevention of Covid-19 infection during our planned CEBU research activities and the roles of the Hospital task force.
2. The PI, CEBU study will work closely with Mulago National Referral Hospital Covid-19 task force to ensure that all planned research activities are implemented in ways that do not pose risk of spreading Covid-19 infection. For instance, the PI will organize and facilitate a training on Covid-19 pandemic for all CEBU research team and participants.

B) General Procedures in Regards to COVID-19 Prevention

- All research team members including participants will have a training on Covid-19 prevention and control measures.
- The CEBU research site will display health education materials and MoH guidelines on COVID 19 prevention translated in the local language.
- All study participants and staff who come to the study site/office will wash their hands with soap and water for at least 20 seconds or use hand alcohol-based sanitizer and will have their temperature taken.
- All study staff, contracted vehicle or boda-boda drivers, participants including children with brain injury who are above six years will wear face masks provided by the PI at all times except when they are having a refreshment.
- All study team members and participants will be required to practice frequent hand washing/sanitizing, including before and after each therapy session interaction with a child with brain injury.
- A social distance of at least 2 meters will be maintained in all general participants' and core participants' group meetings where possible, except during physical examination of a child with brain injury or direct engagement during therapy session happening in the KWB-HTC where strict adherence to mask use by involved persons.
- All study team members and participants will be required to register their COVID-19 case contacts, indicating the following information:

i. First name
ii. Family name
iii. Sex

iv. Age
v. Relation with case
vi. Date of last contact with case
vii. Contact type- touched bodily fluids of case (blood, vomit, saliva, urine, stool), had direct contact with the dead body of case (alive or deceased), touched or cleaned the clothing, linen, or plates of case, slept or ate in the same house as case
viii. Name of family head
ix. Address
x. Town/village
xi. Health zone
xii. Telephone number
xiii. Health personnel (Y/N), if yes, structure?

- The study will maintain Covid-19 infection prevention standards in the study site by sanitizing all surfaces and equipment e.g., tables, therapy mats, chairs, work tops, door handles etc with hypochlorite per MOH guidelines. The study site including the study office will be cleaned with JIK and sanitized every day before any form of engagement with participants and research team.
- Any tissue used for sneezing or wiping any saliva if any from any study participant/team must be disposed-off properly in the bio-hazard bag.
- If a participant is suspected to have Covid-19, the PI will immediately refer to the Mulago National Referral Hospital Covid-19 task force treatment point for Covid-19 confirmation and care.
- Hugs and handshakes among study participants and or study staffs will be avoided.

Approved by:

…….. **…….……**

Principal Investigator- CEBU STUDY **DATE**

Document Change history:

Sop # and Version	Effective Date	Suspended Version	Review Date	Reason for review	Outcome of Review
#001/22 V1.0	Date signed				☐ No change ☐ New version issued

Appendix Nineteen, Research team, participants' acknowledgement of Risk Management Plan/SOP for Covid-19 and Ebola

I acknowledge that I have read, understood and agree to follow this Risk Management Plan/SOPs.

Name	Signature	Date