SOUTH AFRICAN JOURNAL OF OCCUPATIONAL THERAPY

VOLUME 53, NUMBER 3, DECEMBER 2023, ISSN ONLINE 2310-3833

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Journal Web site: https://sajot.org.za/index.php/sajot
ISSN Print: 0038-2337
ISSN On-line: 2310 -3833

EDITORIAL COMMENT

ISSN Oline2310-3833

DOI: https:/doi.org/10.17159/2310-3883/2023/vol53n3a1

South African Journal of Occupational Therapy .Vol.:53(3). December 2023

Standardised assessment: The crucial first step towards evidence-based practice

"What can be asserted without evidence, can be dismissed without evidence"
(Christopher Hitchens)

As SAJOT was first published in August 1953, this edition marks 70 years of publication for the journal. The first 10 years mainly featured papers on different facets of occupational therapy, and it was only in the late 1960's that the first scientific articles were being submitted and subsequently published (approximately 2 per edition). Although the number of scientific articles published has increased significantly since then, various appeals for more evidence-based research to be carried out and disseminated have been made not only from the SAJOT editorial team quite recently, but also from the South African Academy for Science back in 2014. In their review of the SAJOT in 2014, they stated that "there is a lack of articles reporting on the effectiveness of occupational. therapy interventions in most areas of practice. An increase in experimental and outcomes research that reports on evidence of effective interventions would make the journal more balanced. This research would probably only happen if universities were encouraged to put greater emphasis on these types of study designs in their research foci" [169].

Based on the mapping review of research published in the SAJOT (featured in this edition) Hendricks, Buchanan and Clark[2] found that between January 2009 and December 2021, only 51.2% of articles published used a quantitative approach, of which 31.3% were Level III-3 evidence studies, as classified according to the hierarchy of evidence described by the Australian National Health and Medical Research Council (NHMRC)[2].

Clearly, we are not quite there yet. However, conducting higher level, moreevidence-based research, requires valid, reliable, and standardised assessment practice.

In multi-cultural, multi-lingual countries such as South Africa, assessment tools developed and standardised in first world - mainly English-speaking countries - pose a major stumbling block. In order to conduct non-discriminatory assessments, various methodological challenges and implications need to be carefully considered, such as cross-cultural equivalence or construct, method, and item bias[3].

In this modern era, globalization and migration have increased the multi-cultural nature of most populations. For occupational therapy, this not only has implications for assessment in the clinical field, but in many cases, culturally biased curricula in educational institutions have also imposed a rethinking of educational practices[4] Many socio-cultural barriers are faced by occupational therapists and educators, as the assessment tools largely reflect the culture, language, and values of the dominant society, ignoring the socio-cultural differences andbackgrounds of students' and clients' ethnic backgrounds[5]. It is therefore encouraging to see that South African occupational therapists are taking up the challenge.

Three of the articles featured in this edition focus on assessment practices and instruments. Breytenbach et al set out to determine the content validity of the Modified Barthel Index for the assessment of ADL in stroke patients in South Africa[6]. They highlight the various aspects of content validity as it relates to language, clarity, content completeness and appropriateness, and make recommendations for the revision of the MBI for use with the stroke population of a multi-lingual, multi-cultural society. In another article, Naude, Becker and Uys[7] demonstrate a methodology for translating and adapting the administration instructions of the Developmental Test of Visual Perception 3rd Edition for isiZulu-speaking children. To advance the authenticity of assessment within a multi-lingual context, the methodology employed in this article provides a useful framework for cross-cultural adaptation of assessment procedures and instruments in other contexts. In the third article, the authors used a cross-sectional study design to investigate preferred paediatric hand function assessment practices of occupational therapists in South Africa[8]. They found that therapists in some cases, were not adequately trained in some standardised assessments and recommend the refinement of existing tools, and the development of a standardised, contextually relevant paediatric hand function assessment tool[8].

The degree of racial–ethnic and social diversity in South Africa demands the development of tests and assessment practices that will enable researchers to provide high-level evidence of the services they render.

I trust that the methodologies applied in the above three articles will provide adequate guidelines that may be used for test development, refinement, and application in other fields of practice as well.

We can only provide evidence if we can measure.

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[RESEARCH ARTICLE]

Content validity of the modified Barthel Index for stroke patients in an African country

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KEYWORDS

nominal group technique, Occupational Therapy Practice Framework (OTPFIII), Functional Independence Measure (FIM), neurorehabilitation, activities of daily living

HOW TO CITE THIS ARTICLE

Breytenbach FC, Freeme JD, de Witt PA, Franzsen D. *Content validity of the modified Barthel Index for stroke patients in an African country.* South African Journal of Occupational Therapy, December 2023, Vol 53, No 3
DOI : https://doi.org/10.17159/2310-3833/2023/vol53n3a2

ARTICLE HISTORY

Submitted: 16 February 2021
Reviewed: 25 November 2021
Revised: 21 June 2023
Accepted: 6 July 2023

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DATA AVAILABILITY

From the corresponding author

FUNDING

None to declare

ISSN On-line 2310-3833

ABSTRACT

Background: The Barthel Index is considered the global gold standard for assessing performance in activities of daily living (ADL) tasks, but there has been little research undertaken on this outcome measure for a stroke population in a low to middle income country. The study aimed to determine the content validity of the modified Barthel Index (MBI) for assessing the ADL of stroke patients in an African country.

Method: A mixed methods design using the nominal group technique was utilised. The study sample consisted of occupational therapists (n=11) and physiotherapists (n=4) with four or more years' experience working in the field of adult neurorehabilitation in South Africa. Each of the four focus groups analysed the content validity of the MBI using five questions based on the Table of Specifications methodology. Data analysis followed van Breda's steps to analysing multi-group nominal group technique to establish themes arising from each question and were presented according to final rank scores.

Results: The findings highlighted aspects of content validity of the MBI related to language, clarity, content completeness and appropriateness that require revision.

Conclusion: This study provides recommendations for the revision of the MBI to improve its content validity for the South African stroke population.

IMPLICATIONS FOR PRACTICE

- Methodology can be replicated in other multi-cultural and language countries
- Training on administration of the MBI can overcome barriers related to language and item clarity where English is a healthcare worker's second language
- The MBI is currently most suited to environments with water and sanitation infrastructure
- A future study implementing recommendations for revision of the MBI for the African stroke populations is suggested

INTRODUCTION

Stroke is a leading cause of disability in South Africa, resulting in a high population of people dependent on caregivers to assist them with their activities of daily living (ADL)[1]. The Barthel Index (BI) is considered the international gold standard for asessing one's independence in ADL namely feeding, chair/bed tranfers, groming.toileting, bathing, ambulation (walking or wheelchair mobility), stair-climbing, dressing and bowel and bladder management[2]. One version of the BI - the modified Barthel Index (MBI) - has been studied in various developing countries providing insight into the contextual and cultural factors that affect validity [3-5]. Despite being developed and adapted in a Western

country, the fact that the MBI is an easy-to-administer, cost-free, accessible, and a brief outcome measure, made it a potentially fitting tool for the African context[3]. This study aimed to determine whether the MBI accurately reflects the current ADL domain and its appropriateness for the South African stroke population.

Literature review

Stroke rehabilitation aims to promote the recovery and functional independence of survivors to reduce caregiver burden and restore quality of life. One of the primary areas of focus in acute stroke rehabilitation[6] is independence in ADL as this is needed for basic independent survival and is often the greatest need of the client. To gain a full picture of a patient's ADL performance, therapists need valid and reliable outcome measures to generate objective results to set realistic rehabilitation goals. Furthermore, these outcome measures can be re-administered throughout the rehabilitation process to monitor a patient's gradual improvement and evaluate the efficacy of treatment rendered.

The BI, developed in the United States of America, was first published in 1965 as an outcome measure scoring a patient's functional improvement during rehabilitation[7]. The original BI is a 10 item ADL index, which scored a patient as either *'independent'* or *'dependent'* in the following tasks: feeding, wheelchair transfers, grooming, toilet transfers, bathing, walking, stair climbing, dressing, and bowel and bladder continence. The problem with the BI is that *"it fails to quantify the quality and quantity of assistance"* [8,7,4] needed in the listed tasks. That is, the amount of assistance required in a task can vary, from total physical assistance to just needing supervision. It would therefore be important for a tool to be sensitive to a patient's gradual improvement in such tasks to measure the efficacy of their rehabilitation. In response to this need. In 1989, Shah et al. published a modified BI (MBI) to improve the sensitivity of the BI by introducing three categories of assistance and descriptions for each item[8]. Through the adoption and translation of the MBI worldwide, research has identified some items of the instrument to be problematic or culturally loaded[3,4]. The studies highlighted that the MBI descriptions only considered western tools in the ADL tasks (e.g., knife and fork to feed, western bath, etc.) which may not be appropriate in another nation due to varying people groups, cultures, environments, and languages. Although the most widely recognized and used versions of the BI were published in English[7,8], the South African National Department of Health adopted 3 of the 11 South African languages for the national language policy, namely isiZulu, Sesotho and English[9]. This emphasizes the importance of determining whether the MBI is a valid ADL assessment tool for stroke patients in South Africa.

Validity of the BI

An outcome measure's instrument validity determines whether the tool accurately measures what it is supposed to measure10. The strength of the tool's validity can be determined in several ways; most commonly through analysis of its face validity, criterion-related validity (predictive and concurrent validity), construct validity and content validity[10]. The construct validity for the BI is well-established[11,12] and it has also been shown to have adequate to good criterion-related validity[11,13,14]. The re is also evidence indicating an excellent correlation between the MBI and Functional Independence Measure (FIM); a widely used ADL measure[15].Despite themultiple validity studies on the BI and its versions, a rarely reported type of validity is content validity. Content validity is seen as the basis for determining other types of validity, since it compares the representativeness of the items to the framework which you are assessing[16]. It is essential to regularly revise test content to ensure it accurately reflects current theory and frameworks. That said, there is no record or description of the framework on which the MBI is based.

One framework by which the ADL construct is defined is the Occupational Therapy Practice Framework 3rd edition (OTPFIII)[17]. The OTPFIII has been used as a framework to outline all aspects of ADL functioning worldwide. The International Classification of Functioning, Disability and Health (ICF) is used as benchmark for the terminology and criteria in the OTPFIII so that a universal language by which occupation al therapists assess and treat clients ca n be establish ed. Furthermore, the OTPFIII forms a framework which outlines all elements within each domain or 'area of occupation' which overlap the ICF's 'Activity' and 'Participation' fields. A therapist's chosen outcome measure for assessment of a stroke patient's ADL functioning should reflect this current ADL framework to ensure it remains relevant and assesses all aspects of the ADL domain. Each ADL item listed in the OTPFIII is described below and compared to the content in the MBI and the context of the South African population:

(i) Bathing,showering

According to the OTPFIII, 'bathing and showering' is an ADL activity which encompasses *"obtaining and using supplies; soaping, rinsing, and drying body parts; maintaining bathing position; and transferring to and from bathing positions"*[17:S19]. The MBI includes 'bathing self' as an item and requires the person to be able to *"use a bathtub, a shower, or take a complete sponge (bed bath) bath. The patient must be able to do all the steps of whichever method is employed without another person being present"* [8,7,8]. In a Japanese and Chinese study, the MBI bathing item was criticized for being a culturally loaded item as it does not include various methods of bath ing[3]. Th is is true for many other countries, as many rural dwellers bathe themselves by using plastic basins or zinc bathtubs. According to the 2021 General Household survey, only 45.2% of South African households have plumbing inside their homes, with the remaining 54.8% of households sourcing water from outside, neighbour, or communal taps[18]. Zinc bathtubs and basins are used as a substitute for baths in households without bathrooms or indoor plumbing and 20-liter water containers are commonly used to carry water from a main water source (communal/ yard tap) into homes to fill these tubs and basins[19]. Therefore, the MBI does not account for obtaining supplies (water) as described in the OTPFIII.

(ii) Toileting (Bowel and bladder management)

Toileting is grouped with toilet hygiene in the OTPFIII and is described as the "intentional control of bowel movements and urinary bladder and, if necessary, use of equipment or agents for bladder control"[17:S,19]. The highest score demands the patient's intentional control of the bowels, as having no accidents,

and can use a suppository or take an enema when necessary. One study suggested that the bowel control item is a likely measurement of another construct (i.e., not measuring ADL, but physiological body functions)[2]. This finding is supported by two other studies that found the continence items to misfit the single dimension model[4,20]. A South African study found that in stroke survivors, the bowel and bladder continence items scored higher than any other items on discharge and at more than six weeks post-discharge[21]. This concurs with two other studies[2,3]. These studies suggest content misfit and disproportionate ease of bowel and bladder continence as compared to other items. Although it has been suggested that the continence items should be removed from the MBI[2] in some African cultures, bowel and bladder cleansing is an important activity. Gastrointestinal cleansing rituals are performed to rid the person of spiritual possessions to restore health and spiritual harmony through ingesting herbal laxatives, emetics, or administering enemas. Despite the lack of literature in these bowel and bladder cleansing rituals, 80% of the South African black population use the services of traditional healers[22], and therefore the everyday practice of this must not be overlooked.

(iii) Toilet hygiene

The OTPFIII details toilet hygiene as *"obtaining and using supplies, clothing management, maintaining toileting position, transferring to and from toileting position, cleaning the body, and caring for menstrual and continence needs"*[17:S,1]. The OTPFIII states that toilet hygiene includes using assistive devices such as catheters, colostomies, etc. Toilet hygiene is an ADL item under 'on and off the toilet' in the MBI; the patient must be able to get on and off the toilet, undress, and dress, prevent soiling of clothes and use toilet paper independently[8]. It also includes that if the patient requires a bed pan, commode, or urinal, they must be able to empty it and clean it[8]. This item does not include obtaining supplies as described in the OTPFIII, which is a crucial aspect of toileting in many developing nations (e.g., fetching bucket). Authors have suggested this item is culturally loaded since it assumes a western toilet is used[3,23]. Although the majority of South Africans (64.8%) have access to flushing toilets18, the remainder of the population uses government subsidized pit latrines which are non-flushing toilets within a small, sheltered cubicle situated within 200 meters from the house. Others rely on using buckets which are emptied by municipal sanitary personnel or poured into a dug out hole19,24. Some areas have no sanitary infrastructure and individuals use the bush18. Additionally, not only does the structure of toileting in many African countries differ, but also the position and custom required to toilet. For example, traditional Indian people use flushing squatting toilets and clean by washing themselves, whereas Africans and Caucasians sit on a western toilet or bench and clean themselves by wiping with paper.

It is a concern that menstrual care has never been included in any version of the BI, this is especially important since Africa has a younger stroke population25. Additionally, neither the MBI nor one of the professional frameworks consider whether the patient can get rid of the toilet waste or access the toilet – a crucial aspect of toileting in countries without sanitation infrastructure.

(iv) Dressing

Dressing encompasses "selecting clothing appropriately, obtaining clothing from storage area; dressing and undressing in a sequential fashion; fastening and adjusting clothing and shoes; and applying and removing personal devices, prostheses, or orthoses"[17 S,1]. The MBI awards full score for the 'Dressing' item to a patient who can put on, remove, and fasten clothing, tie shoelaces, or put on, fasten, remove corsets and braces, as prescribed[8]. Notably, the MBI excludes the task of selecting appropriate clothing and obtaining it from a storage area, as described in the OTPFIII. One study comparing the inter-rater reliability of the 100-point BI and MBI to the Functional Independence Measure (FIM), found the 'dressing' item received the lowest verage kappa scores for inter-rater reliability in both versions of the BI and this was attributed to possible ambiguity in the definitions[15]. The authors therefore recommended revision of the definitions and that dressing be separately scored for upper and lower body[15].

(v) Swallowing/Eating

Succeeding in the act of feeding, eating is "the process of keeping and manipulating food/fluid in the mouth and safely swallowing it" as described by the OTPFIII[17 S,1]. Eating is not listed as an item in any versions of the BI, probably because it is considered a body function, not an ADL item. This is debatable since bowel and bladder continence are included items; however, no literature has argued this.

(vi) Feeding

Feeding is an ADL described as "the process of setting up, arranging, and bringing food or fluids from the plate or cup to the mouth"[17:S,1]. In the MBI, the patient should be able to feed themselves if the food is set-up and the patient must put on an assistive device if needed, cut food, and if desired, use salt and pepper, spread butter, etc[8]. In the literature, the feeding item consistently shows moderate to very good agreement for inter-rater reliability across all versions of the BI[15,26,27]. One study criticized the MBI for being culturally loaded since it implies Western utensils are used, as opposed to other utensils such as chopsticks for Chinese populations[3]. Similarly, African, and Indian ethnic groups do not necessarily use Western utensils and often eat from communal plates using one or both hands.

(vii) Functional mobility

Functional mobility is a broad ADL encompassing one's ability "to move from one position or place to another" as described in the OTPFIII[17:S,19]. Although this activity is integrated into other ADL, it is comprised of the following activities: in-bed mobility, wheelchair mobility, transfers (wheelchair, bed, car, shower, tub, toilet, chair, and floor), walking, and carrying objects[17]. Four items of the MBI relate to mobility: namely On and off the toilet (toilet transfers), Stairs, Ambulation (or Wheelchair management), and Chair/bed transfers. The MBI excludes some functional mobility items listed in the OTPFIII such as in-bed mobility which is a common early rehabilitation goal in acute stroke rehabilitation. That said, the chair/bed transfers and ambulation items in the 20-point BI were considered two of the three main predictors of total BI score, indicating that priority mobility areas are included[28]. Africa's unforgiving terrain, space limitations (overcrowding) and informal dwellings in both urban and rural areas act as additional environmental barriers to the mobility impaired. One author commented that the physical environment can pose a threat to the validity of MBI since differing natural and built environments may not mirror that of developed nations[3].

(viii) Personal device care

Personal device care is listed as an ADL under the OTPFIII and involves "cleaning and maintaining personal care items"[17:S,19] such as hearing aids, orthotics, glucometers, etc. Although 'personal device care' is not listed as an ADL item in the MBI, device use is integrated into each item's description. In most parts of South Africa, long waiting lists and delayed provision of assistive devices are common due to frequent budget constraints and the lack of therapists[29]. Furthermore, care and maintenance services are scarce, particularly in rural areas[29], leaving patients responsible for the care and maintenance of their devices, emphasizing the needed independence in this area. However, the ability to perform this task is not applicable to all patients as some may not use assistive devices, or the caregiver assumes the role of caring for the device. Therefore, whether the item should be included in the MBI is debatable.

(ix) Personal hygiene and grooming

'Personal hygiene and grooming' as described by the OTPFIII, involves *"obtaining and using supplies; use of cosmetics; hair, nail, skin, ear, eye, and nose care, applying deodorant; oral hygiene; and the cleaning, and inserting of orthotics and prosthetics"*[17:S,19]. In the MBI, the patient should be able to wash their hands and face, comb hair, clean teeth, and shave. The MBI most noticeably excludes nail care, skin care and the use of dental orthotics. The MBI includes obtaining and using the supplies, and states that a female patient must apply her own make-up, if used, but need not braid or style her hair. Interestingly, hair styling is explicitly excluded from the MBI although it is included in the OTPFIII.Initial hair styling in African women is done by another person/professional, but daily maintenance, such as clipping in weaves, is an important daily task to preserve the style. Certain practices in personal hygiene and grooming in African cultures and religions extend beyond what is understood in a western context. For example, 'applying cosmetics' would include traditional mud, clay and natural dyes which are used to ceremoniously decorate the faces and bodies of men and women.

(x) Sexual activity

Sexual activity is included as an ADL in the OTPFIII and is described as *"any activity that results in sexual satisfaction"*[17:S,19]. Compared to the OTPFIII, not all versions of the BI include sexual activity. The need for its inclusion for the African context is debatable. One South African study excluded sexual functioning from both urban and rural versions in the development of an ADL outcome measure because participants from both cohorts felt shocked and uncomfortable if asked about their sexual functioning as it was not considered culturally appropriate[30]. One of the effects of this attitude results in sex being a frequently forgotten area in ADL assessments.

Two global ADL frameworks, namely the ICF and OTPFIII, form the foundation of current ADL theory, outlining the tasks that constitute this domain. The BI is considered the benchmark ADL outcome measure; however, it is essential that this outcome measure reflects current theory. Furthermore, ADL outcome measures should also be appropriate and contextually relevant for the population it is testing. In this literature review, each ADL task listed in the OTPFIII was defined, analyzed for the stroke population, and then compared to the content of the MBI. The literature review highlighted the strengths and weaknesses of the MBI and its appropriateness for the African population. This emphasized the need to determine the content validity of the MBI for stroke patients in South Africa.

METHODOLOGY

Study design

Content validity is established by gaining a consensus among experts whether an assessment tool is an accurate representation of the framework that it is measuring. This study investigated whether the MBI ADL items mirrored the OTPFIII framework ADL items. Although content validity can be established through quantitative or qualitative research designs, a mixed methods approach is preferred as it allows for quantification of the group consensus as well as providing qualitative insights from experts regarding the population and context in which the tool will be used[31]. A nominal group technique (NGT) using a consensus-generating participatory methodology was chosen for simultaneously collecting of qualitative (test contents) and quantitative (ranking of test items) data from experienced clinicians in focus groups[32]. The Table of Specifications (TOS) was used as a universal methodological structure as it uses a two-way chart to align all the topics of the MBI, as well as the number of items associated with each topic, to with all concepts that need to be assessed with a particular ADL topic[31]. Thus, qualitative data were collected from the participants in small groups while the more quantitative data were collected through a consensus seeking process.

Ethical considerations

Ethical clearance was obtained through the University of the Witwatersrand Human Ethics Committee to undertake this study (Certificate no. M130810). Permission to undertake the study was also given by the publishers of the MBI. Participants who met the inclusion criteria were recruited using a written invitation in an information sheet that detailed the research's nature, scope, and anticipated data collection time. The voluntary nature of participation was stressed as were the processes that were followed to maintain confidentiality throughout the research process. Participants who agreed to participate gave written consent and consent for the focus groups to be audio-recorded.

Study population and sample

The population was defined as experienced rehabilitation healthcare workers (HCWs) including occupational therapists and physiotherapists working in the field of neurological rehabilitation in Gauteng, South Africa. A snowball sampling method was chosen due to the poorly defined population parameters of occupational therapists and physiotherapists working in neurorehabilitation with four or more years working experience[33].

Data collection

A demographic questionnaire developed for occupational therapists from the same population was used[34]. To ensure this questionnaire was unbiased between professions, it was completed by two physiotherapists to ensure the questions were clear and easy to understand. Suggested changes made by the participants were implemented. This was completed by all participants at the beginning of the NGT groups.

Four NGT groups, of three to six participants each, were held over 10 months. Each group had a mix of both professions. The discussions were approximately 90 minutes in duration. Before the group, participants who consented to participating were given a chance to peruse the MBI. The first author facilitated the groups. Group participants were posed 5 questions: i) Who should administer the MBI? ii) What language should the MBI be in? iii) How can we rephrase the MBI to make it clearer and more understandable? iv) Compare the OTPFIII to the MBI. Are there any items of the MBI you would include/exclude? v) How do South African ADL differ from western ADL?

The NGT followed four steps of the TOS for each question asked:

Generating Ideas: The facilitator presented the question to the group in written form and read it to the group. All participants were directed to silently generate ideas in brief statements on their notepads.

Recording Ideas: Participants engaged in a round-robin feedback session (without debate); each statement was typed by the facilitator and projected onto a screen.

Discussing Ideas: Discussion regarding each statement was then facilitated to determine clarity, importance, and consensus. Participants discussed each item in-depth (if found to be important) and compared it to current theory (OTPFIII) and clinical experience.

Voting on Ideas: Participants each choose five statements from the list of statements generated that they found the most important regarding that question. Each participant voted privately on their voting cards by prioritizing the statements from one to five (one being the 'most important'). Each voting card was collected, and the votes were tallied to identify the ideas rated highest by the group. At the end of the session all group statements and voting cards were collected

Data analysis

All data from the demographic questionnaires were entered into Microsoft Excel. Univariate analysis was done to describe the central tendency (mean, median), range and present frequency distributions of demographic data. Van Breda's seven steps to analysing multi-group NGT data was used for the current study[32]. This data analysis process is recommended for analysis of combined qualitative and quantitative data required for the current study[35].

i). Each statement generated over the four NGT groups was listed on a Microsoft Excel spreadsheet with its accompanying group number, summed scores received from votes (highest vote = 5 points, lowest vote = 1 point), the average score (sum of scores/number of persons in the group) and then arranged according to importance (highest averages for scores for each group listed first).

ii) All statements were thoroughly perused, and similar statements were grouped together into themes whilst ensuring that all themes were mutually exclusive and collectively exhaustive. This process was repeated several times until the researcher was satisfied that all statements were allocated a theme, and all necessary themes were generated and distinct from one another. Each theme was named, defined, numbered, and typed next to each . No new themes arose in the fourth NGT group and therefore, data saturation was reached.

iii). Four volunteers not involved in the data analysis were asked to peer-review the previous step. The themes and their descriptions were provided, and each volunteer worked independently to allocate a theme to each statement. Once all completed lists were returned to the researcher, the group of volunteers convened to discuss any discrepancies. Themes were added, divided, combined, and re-defined by the group until consensus on each theme-statement pairing was reached.

iv).The researcher summed the scores of ranked importance, ranked frequency, ranked average producing a final rank score. Final rank scores were arranged in descending order from most to least significant.

RESULTS

The sample consisted of 15 participants, 11 (73.3%) registered occupational therapists and four (26,7%) physiotherapists working in the city of Pretoria or Johannesburg, South Africa. All participants (n=15) were working in the neuro-rehabilitation field in government, private or academic facilities at the time of data collection. As can be seen from Table I (below), the mean number of years that the participants had worked was 13.7 years and the mean number of years in work in the neurorehabilitation field was 10.1 years. Participants reported that only 13% (n=2) had had training in the BI during their undergraduate training but 73% (n=11) had had experience with the BI while working.

Table I: Participant demographics

	Mean	Median	Range
Working experience (n=15)	13.7 years	10 years	4-41 years
Working in neurorehabilitation (n=15)	10.1 years	8 years	4-30 years
	Yes	**No**	**Unsure**
Undergrduate training in BI (n=15)	13.3% (n=2)	80% (n=12)	6.7% (n=1)
Experience with BI (n=15)	73.3% (n=11)	20% (n=3)	6.7% (n=1)

Administrators and language of the test

Participants considered therapists (occupational therapists and physiotherapists) and nurses to be the persons who should administer the MBI. The theme 1B - 'Therapists and nurses' was ranked highest of the five themes in terms of importance and frequency of statements with a final rank score of 14/15. For the question "What language should the MBI be in?" theme 2B - 'English for HCWs' was ranked highest overall with a final rank score of 14/15 indicating that participants agreed that the MBI should remain in English since HCWs typically administer the MBI. The second highest final ranked theme was 'Translate MBI into all SA languages'(score 10.5/15).

Instrument clarity

Six themes arose from the list of 22 statements generated by the four NGT groups in response to the third question, "How can we rephrase the MBI to make it clearer and more understandable?". The overall highest ranked theme was theme 3A – 'Quantify amount or type of assistance' with a final rank score of 16/18. The statements contributing to this theme emphasized the importance of quantifying the amount of assistance given to the patient using percentages. One statement suggested including a key on the document to improve the reliability of what is understood by words such as 'minimum', 'moderate' and 'maximum' assistance, which was frequently raised in the groups and often compared to what is used in the FIM. Theme 3B – 'Use simple contextually relevant words or explanations'- obtained the highest rankings in importance (ranked 6/6) and frequency of statements (ranked 6/6) with a final rank score of 15/18. Table II (adjacent) lists substitutions for difficult words as suggested by participants.

Table II: Suggested word substitutions for the MBI

Current terminology	Substitution
Propel	Push
Terrain	Ground
Attendant	Helper/person
Assistance	Help
Ascend	Going up
Descend	Going down
Ambulate	Walk
Incontinence	Unable to control bladder/bowel - makes accidents

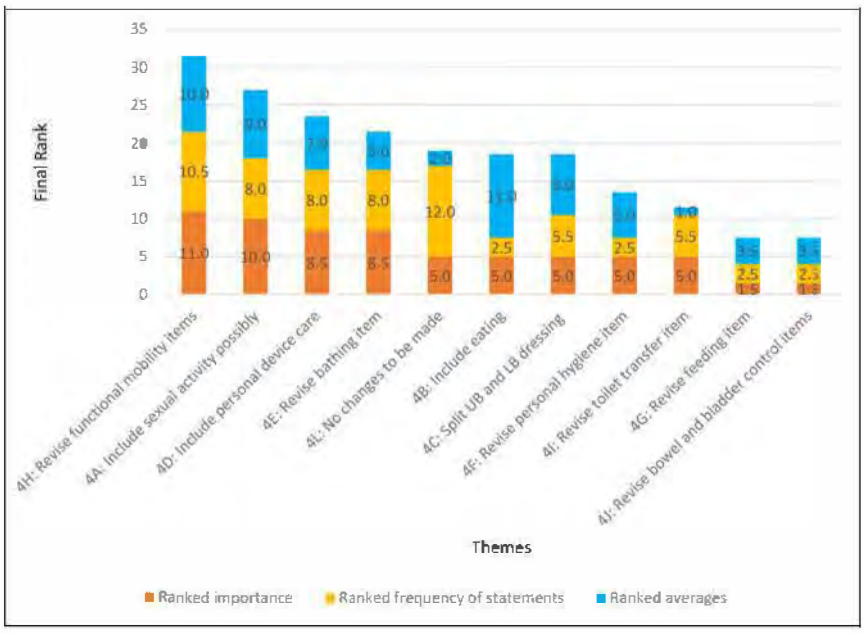

Figure 1. Themes arising from Question: 'Are there any items of the modified Barthel Index you would include/exclude?', ordered according to final rank

Content areas: Completeness

Twelve themes arose from the list of 34 statements generated by the four NGT groups in response to the question "Compare the OTPFIII to the MBI. Are there any items of the MBI you would include/exclude?". As shown in Figure 1 (avove), the highest ranked themes were 'functional mobility' (final rank 31.5/36), 'sexual activity' (final rank 27 /36), and 'personal device care' (final rank 23.5/36) respectively. The theme with the highest ranked frequency of statements is theme 4L which grouped statements that referred to aspects of the MBI that should not be changed.

Content areas: Appropriateness

Seven themes arose from a list of 32 statements generated by the four NGT groups in response to the question "How do South African ADL differ from Western ADL?". As reflected in Figure 2 (page 9), two themes were awarded a considerably higher final ranking compared to other themes; theme 5B – 'Resource barriers' – and theme 5A – 'Accessibility barriers' – scored 19/21 and 18.5/21 respectively, with the 'Resource barriers' theme having the highest ranked importance and frequency of statements, and the 'Accessibility barriers' theme having the highest ranked average.

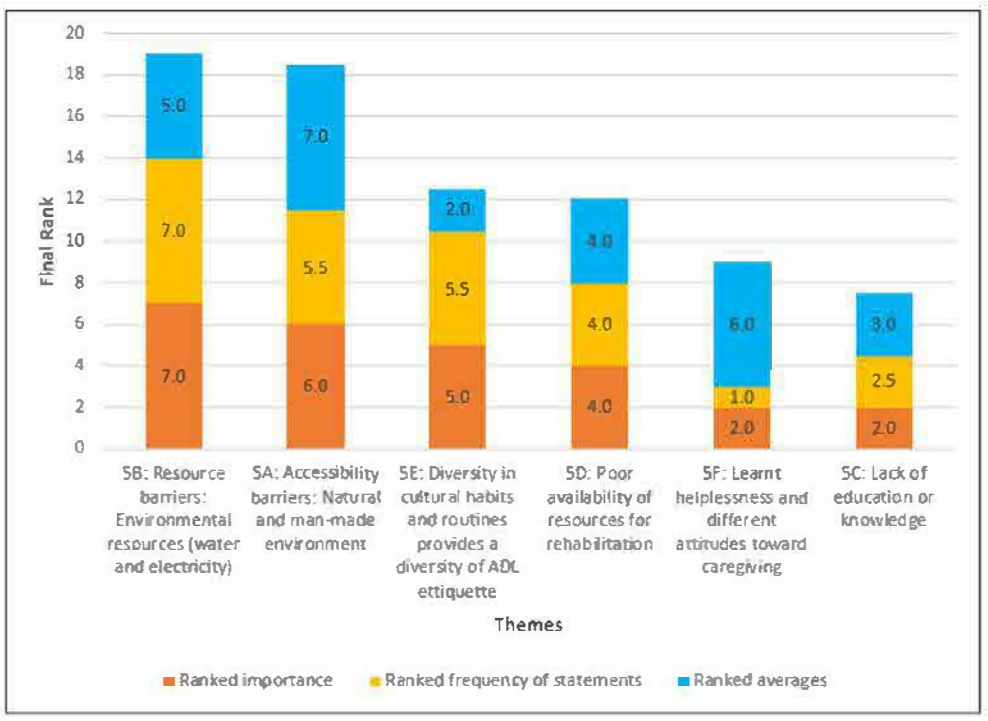

Figure 2. Themes arising from Question: 'How do South African activities of daily living differ from Western activities of daily living?', ordered according to final rank

DISCUSSION

The participants in this study (n=15) comprised of occupational therapists and physiotherapists working in the field of neurorehabilitation in various settings with an average of 13.7 years working experience. While a nominal group technique typically requires a single group with between 4-7 participants, 15 participants were recruited into this study to hear the voices of clinicians in different contexts. Eleven participants were occupational therapists (73.3%) which may have created a bias toward occupational-therapy focused themes, while only four physiotherapists were included, possibly placing less emphasis on mobility items. While majority (73.3%) of participants had used the BI in practice, most (80%) participants had not received undergraduate training of the tool. This finding highlights the need for a valid ADL measure that can be understood on first impression and the need for formal training in university curricula.

Language and administrators

The first question regarding who should administer the MBI aimed to orientate the participants and reach a consensus on who should administer the tool – since the language of a tool is dependent on who will be administering it. In this study, participants voted that occupational therapists, physiotherapists and nurses should be the persons who should administer the MBI to stroke patients. Similarly, nurses, therapists and physicians are the primary administrators of the BI globally[27]. Although the BI can be self-administered or completed by patient caregivers, participants were of the view that experienced clinicians would score items most reliably based on direct observation. This finding is supported by Waeherens et al.[36] who found self-report scores to be higher than those completed by observation. This finding lent itself to the researcher's second question to the group, "What language should the MBI be in?" since South Africa is a multilingual nation. Participants reported English to be the most common language in their work setting and therefore voted for the MBI to remain in English. However, all participants were working in Gauteng which may not be representative of all South African healthcare settings. The participants decision for the tool to remain in English was also practical as translation into all official languages will be costly and time-consuming. Further research is needed to determine the effect of training on the inter-rater reliability of the MBI in South Africa as English not everyone's primary language. If training is found to improve the inter-rater reliability of the tool, it is recommended that standardized directions or training options that are feasible for the African population be developed. It is important to note that although the BI is an observation-based tool and doesn't require translation into a patient's home language, the stroke survivor should still have a clear grasp of what the HCW is using the tool for to provide informed consent[37]. Translation of the tool description or the use of a translator would be of help to address this concern.

Instrument clarity

To determine a tool's content validity; clarity, statement fit (item appropriateness), redundancy and consistency must be inspected[38]. Clear and simple wording ensures that the items are easy to understand and make sense[38]. The third question posed to the group, "How can we rephrase the MBI to make it clearer and more understandable?" resulted in theme 'Quantify amount or type of assistance' being ranked highest overall. The MBI uses a variety of methods in describing assistance, such as using descriptors for instance "minimum /moderate/ maximum", or of the number of people required, e.g., "two attendants" or "one person". This varying phrasing was perceived as vague and inconsistent by participants.

Participants suggested that, to improve understanding and clarity in the MBI, the amount of assistance required in each item must consistently be quantified either through percentages or the number of persons required to assist in the task. However, this method of quantifying the degree of assistance can still be subjective.

In terms of clarity participants suggested that the MBI's language may not be clear and appropriate for the South African population since English is many people's second language. This finding is supported by several studies in countries where English was not the primary spoken language[3,4,5,39]. Participants suggested that difficult terminology in the MBI be substituted with more common/simple words, and/or providing definitions of words as shown in Table i (page 8) This theme was the most discussed and most voted theme across the four NGT groups, emphasizing the urgency participants placed on the need to improve the clarity of the MBI.

Content areas: Completeness

As summarized in the literature review, four of the nine ADL tasks in the OTPFIII are not included in the MBI. Throughout the four NGT groups, all these items were suggested to be included in the MBI; functional mobility was ranked highest, followed by sexual activity, personal device care and lastly, eating.

The first suggesting revision of functional mobility items highlighted that the MBI should encompass all aspects of functional mobility. The statements receiving the highest ranked votes for this theme were statements pertaining to the inclusion of 'in-bed mobility' as an item, confirming in-bed mobility as an important and common rehabilitation goal. The current study highlighted that when the accessibility barriers in

the community are considered, mobilizing becomes more challenging and time-consuming compared to Western environments. Specifically, rough terrain, space limitations, poor accessibility, far distances to toilets and a lack of housing fixtures makes this ADL more physically demanding. Therefore, the content description of the items should accommodate for aspects of the African environment that affects mobility to improve the validity and sensitivity of the tool.

Secondly, statements contributing to the sexual activity item was ranked third highest in the fourth question posed to the groups – suggesting that it should be considered for inclusion in the MBI. All statements contributing to this theme identified that sexual activity may not be applicable to some patients and would be difficult to gain information regarding functioning in this area. However, the literature recognizes sexual activity as. an important, but frequently overlooked aspect in neurorehabilitation[4]. Therefore, one must be aware that results may be biased by therapists in this study's NGT groups since the literature indicates that therapists are reluctant to approach this subject and therefore neglect it in therapy[4]. This item remains a controversial topic and it is recommended that future studies investigate the opinions of South African stroke survivors to determine whether this is a need in their rehabilitation.

Thirdly, 'Include personal device care' was ranked the fourth highest theme in the fourth question posed to the groups. As was the case with sexual activity, personal device care is a debatable item to be included in the MBI as it may not be applicable to all patients. Furthermore, there is a multitude of varying types and models of assistive devices and therefore scoring for this item would be difficult and possibly unreliable. It is recommended that future studies investigate the opinions of stroke survivors in South Africa and other diverse countries to determine whether this is a need in their rehabilitation.

Lastly, 'Include eating (swallowing)' was ranked the least important theme amongst the four 'missing' ADLs from the MBI. 'Include eating (swallowing)' was ranked lower than theme 4L 'No changes to be made to the MBI'. Therefore collectively, participants felt it was more important for the MBI to remain as is than to include 'eating (swallowing)' as an item. Participants voiced concern that speech and language therapists typically perform swallow assessments, and an unsafe assessment could result in aspiration since many stroke patients are prone to dysphagia. Therefore, it is not recommended to include eating as an ADL item in the MBI.

Content areas: Appropriateness

Two themes that strongly emerged from the question "How do South African ADL differ from Western ADL?" – were 'Resource barriers' and 'Accessibility barriers', with respective final rank scores of 19/21 and 18.5/21. Participants discussed how a lack of resources (access to water and electricity) acts a barrier to some South African's performance in their ADL making tasks more difficult and time-consuming. For example, one may pour bathwater from an indoor tap, drain it once complete, and have materials readily available at the bath/shower.However, this is not the case for 54.8% of the South African population who need to fetch water from a yard or communal tap, carry the water in a bucket or container, and fill a basin or zinc tub/basin to bath[18]. Thereafter, the tub or basin must be carried outdoors to be emptied. The MBI does not include 'obtaining supplies' as part of the bathing as escribed in the OTPFIII, indicating incompleteness of the content of the tool. Additionally, South African ADL are more difficult due to accessibility barriers, that is differences in the natural environment and man-made environment. Rough terrain in rural areas, limited and crowded space in homes, toilets built outside, and a lack of indoor fixtures make tasks more difficult to complete due to the physical demands needed to overcome barriers such as one requiring better balance when walking over an uneven surface, or increased strength and endurance to walk or push a wheelchair to access an outside toilet. With such a large portion of the population relying on these environments, it emphasizes the stark environmental differences between developed and developing countries and the need for the MBI to not assume a contextual bias. It is recommended that each item description of the MBI consider all environments needed to complete ADL.

Limitations of the study

The demographic profile of the group consisted of almost three quarters of participants being occupational therapists due to the sampling method which may create a bias toward occupational-therapy focused themes. Future studies should ideally include an equal number of occupational therapists, physiotherapists, and nurses, as these HCWs most commonly administer the MBI.

In the NGT groups, the researcher undertook the role of the group facilitator as well as being the scribe which caused frequent breaks which interrupted the flow of thought and debate - in future it is recommended that a research assistant is used. Demographic data should have been checked for normality. The fourth and fifth question posed to jurors could have been phrased around the content of the MBI and how ADL tasks are performed rather than as a com parison to generate more statements and insight from the groups.

CONCLUSION AND RECOMMENDATIONS

The Barthel Index has endured a lot of criticism for not being culturally sensitive enough, however it remains the most feasible ADL outcome measure for the South African population since it is cost-free, brief, accessible, and does not require formal training.The findings of the current study highlighted aspects of the MBI's content related to language, clarity, completeness, and appropriateness that require revision.

The following recommendations list summarized the findings from this study and serve as a guideline to future studies that aim to standardize the MBI for the South African stroke population.

Administrators: The MBI should be designed for use by nurses, occupational therapists, and physiotherapists.

Language: The MBI should remain in English, however item description revision was recommended.

Items: Each item description in the MBI referring to assistance must quantify the amount of assistance required (e.g., extent of task completed by therapist in percentage). Complex or contextually unfamiliar terminology should be substituted by simpler words as suggested in the results. Where terminology *cannot* be substituted by simpler words are given a longer explanation or a 'definition sheet' be provided as an appendix to the tool.

Revision: Bathing and dressing items to be revised. The item name should be changed from 'bathing self' to 'washing' and should include obtaining supplies (fetching and emptying bathwater) as this is relevant to rural areas. The bathing item should include zinc tub and basin as options. The dressing item should be split into two sections, namely, 'Upper-body dressing' and 'Lower-body dressing'.

Training: South African universities training occupational therapists, physiotherapists and nurses should include the MBI in their curriculum.

Content: Each item of the MBI should consider all environments and fixtures needed to complete ADL and score the difficulty accordingly.

Additional items: Although no items were suggested for deletion, additional items to be added to the MBI relating to functional mobility were suggested for inclusion: All aspects of functional mobility should be included in the MBI, such as in-bed mobility, and the content description of the functional mobility items should accommodate aspects of the South African environment that affects mobility (e.g. ability to walk over rough terrain).

It is suggested that a future study implementing the abovementioned recommendations be conducted and a new version be developed for the African stroke population.

Author Contributions

Fiona Breytenbach devised the main conceptual idea, collected, and analysed the data and wrote the initial draft of the manuscript. Juliana Freeme supervised the research, assisted with conceptualisation, methodology and provided key literature and critical feedback on draft manuscript. Patricia de Witt and Denise Franzsen consulted during data collection and analysis, and critically reviewed the manuscript.

Competing Interests

The authors have no competing interests to declare.

Acknowledgements

We want to thank all participants for your contribution to this study and the following hospitals for the use of their premises; Steve Biko Academic Hospital and Mediclinic Muelmed Hospital. Thank you to co-author Juliana Freeme for your guidance throughout the research process and the OT teams at Kalafong Provincial Tertiary Hospital and Chris Hani Baragwanath Academic Hospital for your continued assistance and support.

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RESEARCH ARTICLE

Collaboration within a curriculum of support in the classroom: occupational therapists' and educators' perceptions and experiences

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KEYWORDS

inclusive education, learning barriers, classroom approach, trans-disciplinary collaboration, mainstream school, qualitative research

HOW TO CITE THIS ARTICLE

Arendse P, Hess-April L. *Collaboration within a curriculum of support in the classroom: occupational therapists' and educators' perceptions and experiences.* South African Journal of Occupational Therapy. December 2023, Vol 53, No 3
DOI: https://doi.org/10.17159/2310-3833/2023/vol53n3a3

ARTICLE HISTORY

Submitted: 18 May 2022
Reviewed: 22 September 2022
Revised: 16 May 2023
Accepted: 16 August 2023

EDITOR

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DATA AVAILABILITY

From the corresponding author

FUNDING

The National Research Foundation is acknowledged for supporting a scholarship for the principal author towards her Masters, from which this paper emanates.

ISSN On-line 2310-3833

ABSTRACT

Introduction: According to South Africa's key education policies, all children can learn and need support, necessitating collaboration between occupational therapists and educators. Collaboration between occupational therapists and educators within the classroom is however a relatively new practice in South Africa and there is a dearth of literature that report on studies in this regard. The aim of this study was thus to explore occupational therapists' and educators' experiences in adopting a classroom approach in three primary mainstream schools in the Metro North education district in the Western Cape.

Methodology: A qualitative research approach and exploratory descriptive design was utilised. Data collection included semi- structured interviews and focus groups with educators and occupational therapists who participated in the curriculum of support in the classroom programme. Thematic data analysis was conducted.

Findings: Three themes highlighting the meaning and value the participants assigned to classroom collaboration, and factors that facilitate or limit the implementation of the curriculum of support emerged from the analysis.

Conclusion: The study is useful in expanding the understanding of the changing role of occupational therapists within the context of inclusive education and contributes to the development of educator support strategies utilising the whole classroom approach. This approach entails the educator and occupational therapist working together in implementing activities in the classroom to all learners. These learning activities are based on curriculum themes and occupational therapy principles and components.

IMPLICATIONS FOR PRACTICE

Occupational therapists' roles in the education practice context are expanding from traditionally working in special school settings to providing support to educators within public mainstream schools. The role of the occupational therapist within public mainstream schools is evolving from a consultative role and providing input into the individual support of learners to providing hands-on support to educators and collaborating with them within the classroom.

INTRODUCTION

Occupational therapist- educator collaboration within the classroom has gained momentum in South Africa since the move towards inclusive education and the development of related policies to ensure that the needs of vulnerable learners are addressed[1]. The policy on screening, identification, assessment and support (SIAS) standardises procedures to identify, assess and provide learner programmes for those who require extra support in an effort to enhance classroom and school participation and inclusion[1]. The SIAS aims to improve learner access to quality education and is aligned to the Integrated School Health Policy to ensure early identification of learners who experience barriers to learning and ensure the provision of effective support[2]. Likewise, the recently developed National Strategy for Learner Attainment (NSLA) is an overarching tool that informs provincial and district programmes to improve overall learner performance in line with the Action Plan toward Schooling 2030[3]. The action plan speaks to curriculum delivery and support in schools and highlights a differentiated approach with particular focus on learners who experience barriers to learning. Prominentbarriers to learning identified in South Africa are emotional challenges, behavioural challenges, reading, spelling and language difficulties, intellectual disabilities, mathematics and perceptual challenges[3]. Poor participation in school related tasks due to barriers or difficulties in learning, contribute to poor educational outcomes[4]. Consequently, a high number of learners require support within public mainstream schools[3].

In South Africa, a study conducted to explore educators' understanding of inclusion and barriers to learning highlighted that they are expected to develop strategies to provide quality educational opportunities for learners who have diverse needs[4]. For this reason, occupational therapist-educator collaboration in facilitating inclusive education in mainstream schools has become imperative[5].

This is particularly significant in the post COVID-19 lockdown period and its influence on learners, particularly in relation to the loss of knowledge and skills suffered by the learners as a result of disruptions in the school calendar. Collaboration implies occupational therapists and educators working together to address learning needs in an effort to make the curriculum accessible to all learners[5]

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There is however a need for a better understanding of this process of collaboration and how occupational therapists and educators can work together within a classroom approach. This article reports on a study that explored occupational therapists' and educators' experiences in adopting a classroom approach to enhance inclusive education in three primary mainstream schools in the Metro North education district in the Western Cape.

Literature review

Primary school learners are expected to engage in a wide variety of scholastic tasks that involve activities that require fine and perceptual motor skills (e.g. handwriting and copying from the board), gross motor skills (e.g. kicking, jumping, hopping, throwing, catching) and social skills (e.g. socialization and personal care activities)[6,7]. Learners with learning difficulties may however experience challenges in accomplishing these tasks with subsequent social, vocational, academic and psycho-emotional consequences[7].Occupational therapists enable learners who experience learning difficulties by addressing the underlying components of function; by adapting learning and teaching strategies utilised in the classroom, or by adapting aspects of the school environment[6]. Successful intervention however requires collaboration between educators and occupational therapists to work as teams in order to offer support and make education inclusive to those learners with barriers to learning in the classrooms - as has been the case in some public special schools in South Africa[8].

Two studies that explored elementary teachers' perceptions of the value of collaboration with occupational therapists in the United States validated the need for improved occupational therapy supports in the school environment[9,10]. These studies further highlighted that teachers perceived collaboration with the occupational therapist as valuable for providing effective classroom strategies and a positive influence on student success[9,10]. Thus, a growing body of literature presents compelling evidence for the benefits of collaboration among educators and occupational therapists as educators perceive occupational therapists to be playing an important role in providing support within a school setting[9,10,11,12].

Addressing the diverse needs of learners and the learning barriers they encounter in the classroom is generally experienced as challenging by educators[12,13,14]. A study conducted in selected Fort Beaufort district primary schools in South Africa established that teachers experienced lack a of parental participation, heavy workload, inadequate training, and lack of resources in implementing the inclusion of learners with special education needs[13]. However, a shift from a focus on individual student goals, to consultative services focused on capacity building of educators, can enhance occupational therapy service delivery within schools and effect change for a diverse learner population[15,16].

There is however an apparent paucity of evidence to describe how school participation is enabled in South Africa. A South African study that explored the collaborative relationship between educators and occupational therapists in junior primary mainstream schools in Kwazulu Natal indicated that educators regarded collaboration with occupational therapists as instrumental in developing their ability to identify learning barriers[5]. Working together with educators in adopting a whole classroom approach is therefore important

in improving the educational outcomes of learners who experience barriers to learning[14,15]. While collaborative consultation between occupational therapists and educators is regarded as a vital tool for assisting learners who experience learning barriers[8], there are factors that may negatively influence such collaboration. These include a key barrier related to how services are designed and implemented across health and education, with different underlying philosophies to practice[8]; educators' poor understanding of occupational therapy services and the concept of inclusive education[16,17,18]; as well as time constraints and limited contact between educators and occupational therapists[5,12,17].

Studies that explore occupational therapist-educator collaboration in the classroom can be useful to guide the development of collaborative relationships and transdisciplinary interventions to enhance inclusive education. Nevertheless, a dearth of literature exists that reports on studies that explore collaboration between occupational therapists and educators while making the curriculum accessible to all learners. This article reports on a broader study that aimed to explore educator-occupational therapist collaboration in the implementation of a curriculum of support in the classroom programme to address learning support strategies in three primary mainstream schools in the Metro North education district in the Western Cape. In particular, we discuss one of the objectives of the study, i.e. to explore and describe occupational therapists' and educators' perceptions and experiences regarding trans-disciplinary collaboration within the classroom.

Curriculum of support in the classroom program: Overview

An occupational therapy intervention programme was implemented in the Metro North Education District in the Western Cape in 2012 but has gained recent momentum because occupational therapists working in Special Schools are required to perform an outreach function in mainstream schools by the Western Cape Education Department (WCED). The programme was specifically designed for Grade R and Grade 1 'at risk' learners. The district- based support team (DBST) that includes an occupational therapist, meets to select the public mainstream schools where the programme will be implemented. This is followed by a series of workshops with educators where after the programme is implemented in each school and monitored by the DBST. In this programme, occupational therapists and educators work collaboratively to support learners who experience barriers to learning. The four key components of the programme are 1) Training of educators and therapists in the Grade R Curriculum Assessment Policy Statement (CAPS)[19] 2) Collaborative design of a developmental support and stimulation programme; 3) Training of educators in the utilisation of the support and stimulation programme and 4) Implementation of the support and stimulation programme.

While the Grade R CAPS[19] informed the design of the training programme, the Grade R as well as Grade 1 educators participate in the programme. Instead of merely providing instructions, occupational therapists join educators in the classroom and facilitate relevant skills as guided by the CAPS.

This is generally preceded by educators attending interactive workshops that are presented by the occupational therapists. Following the workshops, the occupational therapists join educators in the classroom to implement the stimulation programme over an 8-week period. The occupational therapist spends 1 hour with each Grade R practitioner and Grade 1 educator in their classrooms, with support to a minimum of 3 educators provided in the classroom per week. The 8-week programme covers the following; 1) occupational therapists demonstrate the activities of the specific theme with learners to the educator in the classroom, 2) the educator presents a theme to the occupational therapist who acts as facilitator and 3) the educator presents the theme with minimal facilitation from the occupational therapist. Activities concentrating on skills development inclusive of stimulation programmes focussing on auditory, listening, perceptual, language and gross and fine motor skills are geared towards the theme and aim for the week (Table I, below) and also involves setting developmental outcomes, activity requirements, structuring and grading.

Table I: Themes for Term 1 & 2

Term 1		Term 2	
Week	Theme	Week	Theme
Week 1	My body	Week 11	Weather
Week 2	My school	Week 12	Autumn
Week 3	My classroom	Week 13	My home
Week 4	My family	Week 14	Pets
Week 5	Summer	Week 15	Safety
Week 6	Healthy living	Week 16	Educators choice
Week 7	Shape and colours	Week 17	On the farm
Week 8	Days of the week	Week 18	Sight and sound

METHOD

Research setting

The research setting for this study was three primary mainstream schools in the Metro North education district of the Western Cape with large learner totals in the classrooms. The three schools are located in two townships geographically located on the outskirts of Cape Town i.e. two schools in Atlantis and one in Delft. The Atlantis and Delft townships are characterised by poor socio-economic conditions, i.e. poverty, a high rate of unemployment and crime. Many learners come from single-parent homes, grandparent homes and foster homes where families are dependent on government grants. The learners have a general lack of stimulation at home. All three schools benefit from the National School Nutrition Programme (NSNP). The schools are generally under-resourced; classes are large, and educators often buy resources from their own funds as parents very seldom can afford to buy stationery for their children. The two schools in Atlantis are government funded and classified as non - fee paying schools. The two schools in Atlantis each have an average of 1300 learners attending and 33 teaching staff

that includes heads of departments, deputies and principals. The school in Delft is also a non - fee paying school which means that parents are exempted from paying school fees. The school accommodates 1177 learners and also has 33 teaching staff. The grade 1 pass rate at all three of these schools was identified as a concern by the education circuit manager in the district. Accordingly, the DBST also identified that the three schools required additional support for the learners.

Research Design

A qualitative research approach[20] within an exploratory descriptive study design[21] was utilised to explore collaboration between educators and occupational therapists in the curriculum of support within the classroom programme.

Sampling

The study population comprised all occupational therapists and educators who participated in the curriculum of support in the classroom programme. Purposeful sampling[21] was utilised to select a sample of six educators and three occupational therapists (Table II, below). The criteria for selection of the sample included Grade R and Grade 1 educators and therapists who were involved with the compilation of the manual for the programme; Grade R and Grade 1 educators and therapists who participated in the implementation of the programme in the three primary mainstream schools.

Table II: Participants and their communities

PARTICIPANT NUMBER	PARTICIPANTS	COMMUNITY IN WHICH PRIMARY SCHOOLS AND THERAPISTS ARE LOCATED	BASE SCHOOL
E 1	Grade R educator	Atlantis school 1	Atlantis school 1
E 2	Grade 1 educator	Atlantis school 1	Atlantis school 1
E 3	Grade 1 educator	Delft school 2	Delft school 2
E 4	Grade R educator	Delft school 2	Delft school 2
E 5	Grade 1 educator	Atlantis school 3	Atlantis school 3
E 6	Grade R educator	Atlantis school 3	Atlantis school 3
OT 1	Occupational therapist	Atlantis	Special School in Atlantis
OT 2	Occupational therapist	Atlantis	Special School in Atlantis
OT 3	Occupational therapist	Delft	Special School in Belhar

Data collection methods

Semi- structured interviews and focus groups were utilised as data collection methods. Individual semi-structured interviews were used to gain participants' views, feelings, perceptions and experiences[17] about the curriculum of support and educator-occupational therapist collaboration. The interviews were conducted with two educators in each of the three mainstream schools as well as with the three occupational therapists who were based at public special schools and performed an outreach function in the public mainstream schools of which two were in Atlantis and one in Delft. The occupational therapists were based at Public Special Schools in the Metro North Education District and implemented the curriculum of support programme at three Primary schools in the same district.

This was part of an initiative taken by the Department of education to address inclusive education in public mainstream schools. Two occupational therapists were based at a special school in the Atlantis area and implemented the programme in two separate Primary schools in that area. One occupational therapist was based in a special school close to the Delft area and thus implemented the programme in a Public school in the Delft area. Interviews were conducted until data saturation occurred i.e. no new information materialised. Interviews lasted for about 45 minutes to an hour. The focus of the interviews ranged from the participants' understanding of inclusive education to their perceptions and experiences of collaboration in the classroom (Table III below).

Table III: Interview guide for educators and occupational therapists

1	What is your understanding of inclusive education?
2	How do you understand the role of occupational therapists in respect of inclusive education in primary mainstream schools?
3	What are your perceptions regarding the curriculum of support in the classroom programme?
4	How do you experience working with the educator / occupational therapist in the curriculum of support in the classroom programme?
5	How did you find working collaboratively within the classroom?
6	What did you find to be the biggest challenge when implementing the programme?
7	What did you find most rewarding when implementing the programme?

Focus groups are advantageous as it allows a space where people can get together to jointly discuss issues and thus create meaning collectively[20]. In this study, the issues focussed on occupational therapists and educators' perceptions and experiences regarding trans-disciplinary collaboration within the classroom. The purpose of the focus groups was thus to explore issues that surfaced in the individual interviews regarding participants' perceptions and experiences with the curriculum of support programme and required clarification or a more in-depth exploration . Thus, the focus group guide for educators (Table IV below) and occupational therapists (Table V, page 17) was compiled after a preliminary analysis of the interviews, allowing for similar and opposing opinions to surface. One focus group was conducted at each of the three primary mainstream schools with the Grade R and Grade 1 educators and one focus group was conducted with the occupational therapists. Each focus group lasted for about one hour. All interviews and focus groups were audio taped and transcribed verbatim for the purpose of data analysis. The thematic data analysis framework[21] was utilised to analyse the interview and focus group transcripts.

Table IV: Focus group guide for educators

1	Do you think this programme adds value to effective classroom management? Please substantiate your answer.
2	Would you include the activities of the Programme as part of your planning? Please substantiate your answer.
3	What, for you as educator, signifies general improvement in the learners, post implementation of the programme?
4	What did you perceive to be the impediments of the smooth implementation of the Programme?
5	Will you continue to work together with occupational therapists, in the future, in order to address learner needs? Kindly substantiate your answer.

Table V: Focus group guide for occupational therapists

1	In which way is curriculum support vital? Which aspects of curriculum support are most important?
2	Why is it critical that occupational therapists have a sound understanding of the school community and the educator they serve?
3	Why is effective classroom management critical to the success of the programme?
4	What did you perceive to be impediments to the smooth implementation of the Programme for the educators?
5	What, for you as an occupational therapist, signify general improvement in the learners, post implementation of the programme?

Trustworthiness

The Lincoln and Guba[24] framework guided the implementation of trustworthiness strategies. Credibility was ensured through member checking where the preliminary findings were presented to the participants. Transferability was endorsed through a detailed description of the research context, while an in-depth description of the research process from the start of the project to the reporting of the findings allowed for dependability. In addition to a detailed record of the research process, a trail of data and analysis was kept throughout the study and deposited into the university's research repository to allow for an inquiry audit in order to ensure confirmability.

Ethics

This study conformed to ethical standards of scientific inquiry, including ethics approval by the Humanities and Social Science Research Ethics Committee of the University of the Western Cape (REC number - 130416-04) as well as the Western Cape Department of Education. All participants provided formal written and informed consent. Participation was voluntary and participants could withdraw from the study at any time without being penalised. Confidentiality was maintained by securing data in a password protected electronic folder and this will remain stored in the university's research repository for a period of five years following the completion of the study after which it will be destroyed. By referring to participants in terms of allocated numbers, their anonymity is maintained. All participants have access to the findings of this study.

FINDINGS

Three themes with related sub-themes emerged from the thematic analysis: 1) The meaning of classroom collaboration, 2) Factors that facilitate collaborative implementation of the curriculum of support, and 3) Factors that inhibit a collaborative classroom approach to inclusion (Table VI. below).

Table VI: Overview of Themes

THEME	SUB-THEMES
1. The meaning of classroom collaboration.	"Hands on support" The value of collaboration for the learner
2. Factors that facilitate a collaborative curriculum of support.	The importance of social interaction and collegial support The role of classroom management
3. Constraints to a collaborative classroom approach.	Time Challenges Lack of resources

Theme 1: The meaning of classroom collaboration

The first theme highlights the meaning that educators and occupational therapists assigned to collaboration as supported by how they understood working together in implementing the classroom approach.

"Hands on support"

For both the occupational therapists and educators, collaboration implied direct physical i.e. actual 'hands on' support provided by the occupational therapists in the classroom.

"When the programme took place the occupational therapists came in and then gave us hands on training in the classroom...They were an asset in ourclassroom, working with us." **(Interview, E5)**.

The educators' understanding improved when they jointly engaged in demonstrations and discussions on strategies to support learners who experience barriers to learning. Through working together, the educators and occupational therapists were able to observe each other, within their roles, as they together engaged in activities with the learners.

"We would focus on how they were teaching and then transferring skills and equipping the educator to stimulate the children in different ways so that they could access the curriculum" **(Interview, OT3).**

Some educators were positive about their participation and were open to learn within their classroom but some educators were initially hesitant and not as cooperative as others were as they were uncertain about programme expectations.

"There were educators that were very willing and eager to participate andto learn and opened their environment and their space to enter... Some educators were a bit hesitant and not so cooperative like some of the others were because they were not sure about the demands on them" **(Interview, E6)**.

While the educators generally understood the need for the curriculum of support, ensuring an understanding that the classroom support programme was not an 'add on' to the curriculum was key to the collaborative relationship.

"The curriculum of support was directly taken from the CAPS so we made them understand and they could see that the themes t h a t they uhm implemented within their activities and scholastic tasks, what was written up (in the programme) they could see that it linked with the CAPS." **(Focus Group: OT2)**.

Finding some educators more willing to participate than others helped the occupational therapists to appreciate the importance of understanding the school community as this affected collaboration. The occupational therapists emphasised the principle of context first and stressed that they first had to understand the conditions under which educators worked before they could provide relevant and effective support.

"...if you know what the context is, you can know where you can assist and where you need to stand back...it's good to have knowledge about it (context) because when you get to the class and the educator didn't do (the activities) then you have that negative mind-set already...but if you understand the reason why, it makes it better." **(Focus Group: OT1)**.

The value of collaboration for the learner

The educators perceived that the learners enjoyed the different sessions and activities with the occupational therapists evident in their improved behaviour.

"You get learners that have behaviour problems but when you have the occupational therapist here at school, they just have the way of listening to that person...Discipline in my class improved and learners were really listening. Behaviour was better, it wasn't as bad as previously...It (the programme) got learners more involved." **(Interview, E4).**

The educators were aware that the learners looked forward to the sessions and acknowledged that learners improved in sitting posture, gross motor skills and handwriting.

"Some learners always just wandered around during group activities, but now you see them come closer and wanting to be part of what is happening ... You see the kids develop well and those muscles, you can see that the posture is not limp or clumsy anymore and their handwriting is better." **(Interview, E6).**

In their feedback to the occupational therapists the educators expressed that they valued their input as the value of the improved curriculum became evident.

"...with regards to the learning areas of maths and uhm literacy, also the activities for gross motor that we brought in...the educators said thatthere's really improvement within the curriculum" **(Interview, OT2)**.

"So, the programme is a very good programme, the stimulation programme ...it really works and we are using it now in our planning. We continue to implement it." **(Focus Group: E6)**.

Theme 2: Factors that facilitate a collaborative curriculum of support

This theme illustrates the importance of professional and inter-personal relationships in the facilitation of a collaborative curriculum. It further captures the participants' views on the value of factors such as having opportunities and a collaborative space to discuss ideas, challenges and new concepts.

The importance of social interaction and collegial support

The occupational therapists highlighted social interaction and collegial support as important facilitating factors of a collaborative curriculum of support. For the occupational therapists' social interaction with the community, including learners, teachers, heads of departments, deputies and principals, was an important vehicle to being understanding and relevant when implementing the curriculum of support.

"...that social interaction of knowing the school community and the educator that we are serving ...that also came through as having a better relationship even though you are a professional from a different field, ja, sharing as colleagues..." **(Focus Group: OT3)**.

The participants stressed the importance of having a space to express their thoughts and feelings about the successes and challenges they encountered in the classroom. The educators often referred to the feedback sessions they had with the occupational therapists after each implementation session. Educators were encouraged to discuss their successes and challenges and to make recommendations.

"Normally we plan together, the programme in the manual has been worked out according to weeks so we plan and share ideas together." **(Focus Group: E1)**.

"We talk about and work together on those activities that you maybe want to do with the child, how to downgrade and work on the child's level" **(Interview, E6)**.

Reflective sessions after each classroom session as well as after each term with the rest of the DBST and learning support advisors were also highlighted as facilitators of the process.

"We have term meetings with the rest of the metropole north therapists,where we present our feedback. It's good that the broader team and advisors can also hear our experiences" **(Interview, OT2)**.

The role of classroom management

Effective classroom management was highlighted as another facilitating factor of the curriculum of support. The occupational therapists explained that when they came into a class where the educator managed her learners well, they observed that the programme was implemented more efficiently and progress could be seen, particularly in respect of learners' behaviour.

"I would say that effective classroom management is important as it motivates learnerces misbehaviour and it improves discipline and sets routine and consistency"

Focus Group OT1)

Educator preparedness signalled an openness to learning which was appreciated by occupational therapists who could then focus on the transfer of skills. If an educator struggled with managing her learners, the occupational therapist would assist although classroom management is the educator's responsibility.

"Where I saw the ideal classroom management is where I could actually see that the educator did some of the work already the day before or in theweek...It was the second time, third time ...now they are in a space where they can perfect whatever is required and the educator is more comfortable...so it's easy to assist" **(Focus Group: OT3).**

"She (educator) also needs to bring her part into managing the classroom It cannot be the responsibility of the person (occupational therapist) coming in although they would be willing to assist." **(Focus Group: OT1)**.

In relation to the role of classroom management, the educators acknowledged that it was important but simultaneously highlighted that the time they had available sometimes hamper this and their preparedness to work with the OTs in implementing the programme.

"Sometimes available time interfere with being prepared and the OTs are not always happy as the children are not used to the programme because I didn't have time to prepare the class then she still has to assist with that ... and then you've only got maybe 15 mins left to really implement." **(Focus Group: E5)**.

Theme 3: Constraints to a collaborative classroom approach.

Constraints to working together in a collaborative classroom approach as experienced by the participants mainly related to the school context. The participants were asked to reflect on the difficulties they encountered in relation to implementing the collaborative classroom approach.Some educator participants struggled to find time to implement the classroom programme due the demands of the CAPS curriculum, while large learner totals ingrained the inefficiency of the resources that were available to the educators.

Time challenges

Finding time in the timetable to implement the classroom programme proved a challenge for the educators, particularly for grade 1 educators who had curriculum deadlines. Some educators, however, were very curriculum focused because of the outcomes that needed to be achieved within a specific time.

"Educators were more focussed on the curriculum demands and the deadlines that they needed to reach, so they saw the program or the activities as extra work" **(Interview, OT1).**

"So they just expect us to come in there, and expect us to run through the program because it's really time consuming, because we must fit it in betweenlessons" **(Focus Group: E2).**

Gaining support from curriculum advisors was one way in which time challenges could be addressed from the perspectives of the occupational therapists. They felt that in this way they could play a role in monitoring the programme and assist educators to set times to plan and implement the continued programme.

"So yes it's great for them (curriculum advisors) to know about it when they read reports but it's great for them to actually experience it, to be excited to come and see the value in it and then to ensure that the programme continues" **(Interview, OT2)**.

Lack of resources

The mainstream schools were generally characterised by large classes and while it posed a challenge for the educators, it particularly did so for the occupational therapists who were used to working with individual learners or groups of 8 – 12 learners in the special schools.

"So the biggest challenge is the big classes... A big challenge for me is when a class is 50, 56, 59. I think 59 was the biggest class I've ever had to work with." **(Interview, OT3)**

"The space was so limited because the classrooms were small." **(Interview, OT1)**.

Large learner totals meant that educators encountered a shortage of materials and basic equipment as required by the programme. In an effort to cope with the scarcity of resources, educators often brought items from home or used personal finance to buy materials.

"When it comes to apparatus we don't have all the equipment... things that's recommended in the programme manual." **(Interview, E4).**

And the apparatus that is used you have in your classroom or you can bring things from home or your learners can bring it from home...or we just went and bought the items with our own money so that the apparatus were in the classroom. **(Focus Group: E3)**.

The implication for some however was that educators skipped certain activities because of insufficient resources.

"Like the resources we don't have, we will skip them (activities in the programme) we will skip, as we have no choice." **(Interview, E4).**

DISCUSSION

The role of the occupational therapist within inclusive education, in particular within the foundation phase of public mainstream schools in South Africa, is transforming into a much broader role. The SIAS policy promotes district and school based support services by a variety of professionals, including occupational therapists to enhance classroom and school participation, and inclusion of all learners[1]. The implementation of inclusive education policy in South Africa is reliant on school district teams, with the occupational therapist as a member of the team acting as key resource for educator involvement and support. Occupational therapists address underlying components of function by adapting learning and teaching strategies utilised in the classroom[9,10], or by adapting aspects of the school environment[6]; and are perceived as playing an important role in providing support within a school setting[5,14,15,16].

This study thus makes an important contribution to understanding the value of educator-occupational therapist collaboration and hence strengthens the argument for increased allocation of occupational therapy posts within mainstream schools in South Africa.

Based on the rationale that there is a need for a better understanding of how occupational therapists and educators can work together in the classroom, the findings of this study are useful in generating an understanding of how factors important for collaboration could enhance the curriculum of support in the classroom programme. The initial process of programme implementation entailed the DBST meeting to select the public mainstream schools, followed by a series of workshops with educators where after the programme was implemented and monitored by the DBST. It however emerged that a process that entail occupational therapists making an effort to understand the school context, fostering professional and collegial support, providing hands-on support by focussing on learning barriers and specific skills-transfer to educators enhance the process of educator-occupational therapist collaboration. Figure 1 (below) illustrates this process based on the findings of this study.

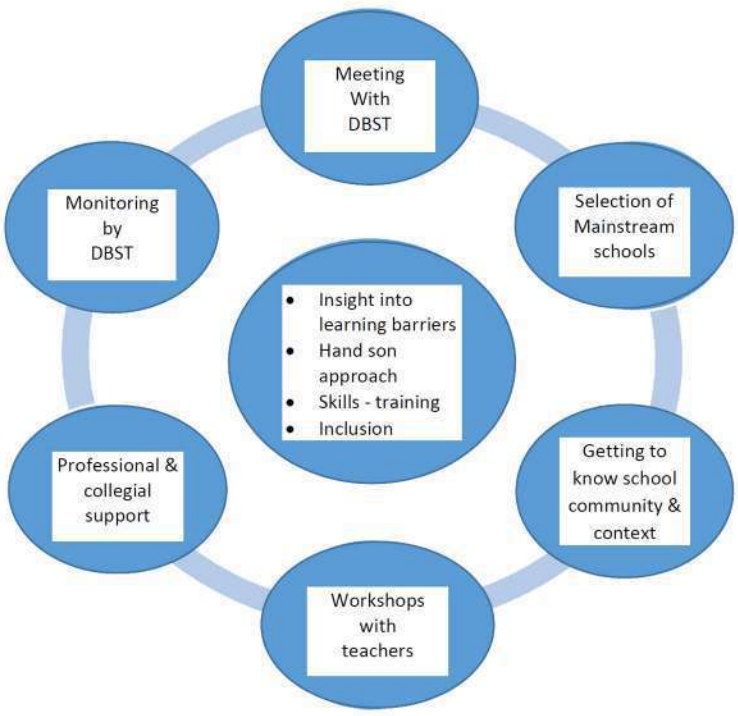

Figure 1 Collaboration within the curriculum of support within the classroom programme

The role of the educator is highlighted in the SIAS policy and identifies educators as the first level of support to the learner in the classroom[1]. Educators are expected to understand learning barriers and the ability to identify learners who require support[25,26]. Educators therefore need to have a comprehensive understanding of inclusion and learner diversity[25,26,27]. Based on educators' feedback regarding the value of the programme, they require opportunities to share their experiences and knowledge and to apply what they have learnt within their own context[25,27].It is evident that educators benefit from hands-on support and demonstrations from occupational therapists to improve their skills and knowledge regarding a classroom approach to the management of learning difficulties.

Collaboration with occupational therapists is imperative for educators teaching in overcrowded classrooms, particularly when drawing up lesson plans. Debriefing sessions and opportunities for social interaction are key indicators for moral support not only for educators but also for occupational therapists who have to deal with large learner totals. Then there are additional challenges to navigate such as limited resources in addition to learners who experience barriers to learning. This is particularly significant in the post COVID-19 period where educators have to address its influence on learners, particularly in relation to the loss of knowledge and skills the learners experienced because of disruptions brought on by the pandemic. The impairment of children's cognitive development was identified as a specific challenge that resulted from the COVID-19 disruptions in schools[28]. This is not only the responsibility of the educator and accordingly, the study holds implications for the DBST. In order to successfully establish an inclusive training and education support system, a DBST needs to be at the foundation of the system[25,26].

Where possible, successes as well as constraints to collaboration should be presented to the DBST and school management team members in order for it to be addressed at management level as a shared responsibility and as part of monitoring programme interventions[29]. The DBST and in particular curriculum advisors, are pivotal in assisting educators in formulating lesson planning, providing demonstration lessons and providing support with classroom management for those who need it to ensure inclusive practices in schools. Thus, they should ensure that the DBST collectively address allocation of time for the implementation of the curriculum of support in the classroom.

The study raises the question of whether occupational therapy education adequately prepares occupational therapists to work with educators within classrooms with all its constraints and thus have clear implications for the formal education of occupational therapists. It is imperative that occupational therapy curricula develop graduate competencies in collaboration. The occupational therapy curriculum should incorporate methods to equip students to work within a whole classroom approach and not only with individuals or small groups as this will enable them to support educators and collaborate with them effectively within the classroom.

CONCLUSION

This study set out to provide an understanding of collaboration whereby occupational therapists entered the classroom and worked with educators promoting and adopting the classroom approach to inclusive education. While a limitation of the study is that it was conducted within three primary mainstream schools in one education district only, the findings showed the value of collaboration in the curriculum support in the classroom programme. This was not just the case for learners, but in particular for educators, who despite constraints like large learner numbers, time constraints and inefficient resources, remained motivated to work towards making learning accessible to all learners and to work towards CAPS outcomes while experiencing professional and collegial support. Collaboration and providing simultaneous support to educators have become even more imperative as educators have to deal with the effects of the COVID-19 lockdown on learners' academic abilities. This study is consequently useful in expanding the understanding of the changing role of occupational therapists within the inclusive education setting.

Acknowledgements
The authors thank the participants for their contributions to this study.

Declaration of conflicts of interest
The authors declare no conflict of interest.

Author contributions
Patricia Arendse conducted the study under the supervision of Lucia Hess-April. Both authors made substantial contributions to the conceptualisation of the research, and the drafting and revising of the manuscript.

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[RESEARCH ARTICLE]

Paediatric hand function assessment practices of occupational therapists in South Africa

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KEYWORDS
paediatric practice, hand function assessment frameworks, psychometric properties, assessment methods, contextually relevant instrument, fine-motor skills

HOW TO CITE THIS ARTICLE
Visser M, Nel M, Bornman C, Kellerman T, Muller Z, Oosthuizen C. *Paediatric hand function assessment practices of occupational therapists in South Africa.* South African Journal of Occupational Therapy. December 2023, Vol 53 No 3
DOI: https://doi.org/10.17159/2310-3833/2023/vol53n3a4

ARTICLE HISTORY
Submitted: 15 February 2023
Reviewed: 8 May 2023
Revised: 11 July 2023
Accepted: 12 July 2023

EDITOR
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DATA AVAILABILITY
From the corresponding author

FUNDING
The authors did not receive funding for this study.

ISSN On-line 2310-3833

ABSTRACT

Introduction: South African occupational therapists' assessment practices of children's hand function are unknown, although the treatment thereof is an integral part of the paediatric scope of practice and clientele. Hand function assessment frameworks and instruments are available, but a lack of contextually relevant, comprehensive standardised instruments was identified. The study aimed to investigate occupational therapists' current paediatric hand function assessment practices and their preferences towards future practice.
Methods: A quantitative, cross-sectional study design using convenient and snowball sampling was employed. An EvaSys© survey system, custom-developed online questionnaire, was used to collect information.
Results: In total, 194 HPCSA-registered occupational therapists participated. All the participants currently rely on informal observations. Although not exclusively designed for hand function, standardised developmental tests were often used. Limited familiarity with and use of the available published hand function assessment instrument was reported. Future assessment preferences supported a standardised, comprehensive hand function assessment instrument for different age groups and paediatric conditions.
Conclusion: This study provides baseline evidence of current and preferred paediatric hand function assessment practices used by occupational therapists. The need for training to use the available published instruments was highlighted. Recommendations towards the refinement of existing or the development of a standardised, contextually relevant instrument for paediatric practice in South Africa are offered.

Implications for practice

This article offers a deeper understanding of available paediatric hand function assessment frameworks, assessment instruments, and practices of occupational therapists. It provides an outline of existing methods therapist use and offers clear directives for how the South African OT would prefer to assess hand function in children. Emphasis is placed on the need for a contextually relevant instrument and future research in refining existing instruments or developing a new instrument is proposed. Additionally, practitioners provided practical suggestions to guide the development of a contextually relevant instrument for potential use in future instrument development research.

INTRODUCTION

Children use their hands as instruments to experience life, express themselves and explore their world[1]. The term hand skills is used interchangeably with terms such as dexterity, fine-motor skills and hand function[2]. Hand skills can be defined as "skills of the hand that are needed to attain and manipulate objects" to interact with the environment and people[2:230]. Hand function is crucial for engagement in early childhood occupations of learning, doing and thinking[1]. Limitations in hand function may cause children to experience difficulties in fine-motor activities, for example, grasping small objects, writing, fastening buttons and using an electronic device[2]. Without hand function skills, children are unable to meet the demands of daily life[2]. Children with several different health conditions can present with various hand function difficulties, causing restriction in activity participation and impairment in quality of life. Thus, children are often referred to occupational therapy, where precise assessment and effective intervention are crucial to address these impairments[3].

In South Africa, research indicates that only 30.4 % of South African pre-schoolers' fine motor are on par for age[4]. Fine motor skills have been identified as one of the predictive components of children's performance in the preschool years[4]. With South African occupational therapists frequently treating young children, it may be important to look at their paediatric hand function assessment practices to ultimately address these difficulties in South Africa children5. Assessment practices refer to the methods of assessment, type of assessments used, the preference, reasons for use/non-use, the frequency of use, the particular context of practice used in and the population being evaluated[6-7].

It is widely acknowledged that assessment is a core professional skill considered an essential first step in the occupational therapy process[8]. Assessment involves determining the factors that support or hinder "health, well-being and participation" through determining the client's current and potential problems[8:24]. Sound assessment instruments are valuable in the decision-making process, guiding intervention planning and augmenting evidence-based practice[8–10]. The use of valid and reliable assessment instruments may assist the occupational therapist to obtain trustworthy information to justify and guide intervention, can be used to evaluate the effectiveness of occupational therapy service and guide clinicians to discover ways of advancing knowledge and practices[9–13].

Moreover, another aspect to consider in the field of assessment practice is the rapidly growing fields of instrument development across disciplines[14]. This has led to the availability of a wide range of emerging assessment instruments, approaches, and methods of great value to the profession, considering the broad scope of services provided by occupational therapists[14–21]. At the same time, occupational therapists need to be thoughtful in their choice of instruments to obtain relevant, valid and reliable information to ensure the best assessment practices[13,15].

The type of instruments used to assess children's hand function has been described in the literature[1–3,10,22,23]. Moreover, the method of assessment seems to be dependent on the availability of instruments. Therefore, it seems that hand function assessments often occur in combination with other more general developmental assessments or are administered as part of informal observations. Nevertheless, despite all the available paediatric hand function instruments described in the literature, it appears that there is no one assessment that (i) includes assessment items to cover all hand function aspects[20]; (ii) displays the characteristics of a systematic and comprehensive instrument development process as previously described[12,13,15]; (iii) provide evidence of the essential psychometric properties[10,24]; and (iv) have been standardised as norm-referenced instruments for a wide age range of children in South Africa[25].

However, little is known about the assessment practices of South African occupational therapists pertaining to paediatric hand function[26,27]. In 2021, South African occupational therapists in-hand manipulation (IHM) assessment practices have been described with regard to current and preferred assessment methods5. Only one international study and no national studies could be located regarding the paediatric hand function assessment instruments selected and used by occupational therapists[28]. Therefore, several questions arose regarding South African occupational therapists' current paediatric hand function assessment practices and their preferences towards future assessment practices.

LITERATURE REVIEW

Considerations when selecting an assessment instrument

The wide range of assessment instruments available, occupational therapists need to be thoughtful when choosing an assessment instrument. From the literature, cognisance of specific considerations is pivotal during any critical evaluation process of potential assessment instruments (to be purchased and used in clinical practice or for research). Foundational to these considerations are (i) instrument evaluation framework/s; (ii) instrument development theory and process; (iii) evidence of the psychometric properties; and (iv) contextual relevance of assessment instruments. Each consideration is briefly described below.

Firstly, occupational therapists should critically review available instruments for appropriateness and performance against an evaluation framework, such as those described by Law[12] or Rudman and Hannah[13]. These frameworks describe five broad categories: clinical utility, standardisation, purpose, psychometric properties and patient's perspective[12,13].

Secondly, instruments should be reviewed to determine whether a systematic theory-based process for instrument development was followed and recorded to substantiate the instrument's scientific soundness[11,14,29,30]. These include the classic test, item response, and multidimensional scaling theories. Many currently available instruments used in occupational therapy have been developed with the classic test theory[16,30].

A third consideration is the evidence of evaluated psychometric properties of the instrument[11,29]. The nature of the psychometric evaluations depends on the type of assessment instrument but generally include reliability (i.e., inter-rater, intra-rater, test-retest and internal consistency), validity (i.e., face, content, construct, criterion, concurrent and predictive validity), and responsiveness (i.e., longitudinal validity)[10,11,13,15,16,29–32].

Lastly, a critical continuous consideration is whether the instrument has evidence of social, cultural, religious, gender and contextual relevance[2,33].

Components of a comprehensive paediatric hand function assessment

Concerning all the different aspects of hand function that can be assessed, three models/frameworks that can serve as conceptual guides toward comprehensive assessment of paediatric hand function have been proposed.

They include the following:(i) the Hand Function Evaluation Model which proposes three levels of assessment: sensorimotor components, developmental progress and function of the hand[34]; (ii) the Functional Repertoire of The Hand Model is based on four key components, namely personal constraints, task parameters, hand roles and hand actions[3]; and (iii) the Children's Hand Skills Framework recommends a comprehensive hand repertoire that can be divided into six distinct categories applicable to the assessment process[22]. The first two categories do not include contact with objects, namely manual gesture and body contact hand skills. The object-related categories include hand skills involving arm-hand use, hand function involving adaptive skills of hand use (such as grasping and in-hand manipulation), hand skills involving bimanual use, and general quality of hand function (dexterity, coordination speed)[22].

The available paediatric hand function assessment instruments

Although this article does not aim to provide a literature review on available hand function assessment instruments, a comprehensive selection and charting of instruments were needed to inform the development of the questionnaire for this study. Therefore, a literature search was conducted in May 2020 to identify all the paediatric hand function assessment instruments that are currently available.

The following databases were searched: Academic Search Ultimate, Africa-Wide Information, CINAHL with full text, eBook collection (EBSCOhost), Health Source: Nursing/Academic Edition, Kovsiecat, KovsieScholar, MEDLINE with full text, Open Dissertations and MEDLINE .

The search was limited to articles written in English that were published from 2010-2022. The search terms used were [instrument] and child*. From these sources, a broad overview of published paediatric hand function assessment instruments was identified, arranged and tabulated according to categories of observational assessment, pathology-specific assessments, pegboard tests and questionnaires in Table I (page 24-25). The study did not include the psychometric properties of each instrument. The following types of instruments were excluded from the table: (i) in-hand manipulation instruments (assessing a small part of hand function); as a recently published scoping review on existing in-hand manipulation instruments is already available[35]; (ii) instruments that assess single occupational performance components (i.e., muscle strength and coordination), for example, the Two-Arm Coordination Tests (TACT)[36] and the Cup-Task and Box-Task test, which is a functional hand and upper extremity muscle-strength test[37]; (iii) paediatric developmental tests such as the Bayley scales of infant and toddler development[38] designed to measure more comprehensive aspects such as motor, cognitive, sensory and socio-emotional and language; (iv) instruments that can be used to assess children's participation, specifically in life situations requiring hand use, such as the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (CAPE/PAC)[39]; (v) instruments currently under development (but not referred to in any publications) such as the GRAB[40] and the Pizza Putty Test[41]; and (vi) questionnaires that assess hand function developed for adult hand injuries but not adapted for children, for example, the DASH (disabilities of the arm, shoulder and hand) questionnaire[42] and the Michigan Hand Outcomes Questionnaire[43].

Table I: A summary of literature on currently available hand function assessment instruments for children.

Name	No. of publications 2010–2022	Subdivisions/ items	Population for which test is developed	Purpose of the test	Age range
Observational assessment					
1. Assessment of Children's Hand Skills (ACHS)[26,33,44]	9	20 hand-skill items and 22 activity items in three categories	Children with and without disabilities	Measures a comprehensive range of hand skills in meaningful occupations that are completed in daily contexts	2–12 years
2. Task-Based Bilateral Fine Motor Skill Assessment (TBA)[45]	1	6 activities	Typically developing South African children	Assess school readiness with regard to fine motor skills in school-based tasks	Grade 0 (5-6 years)
Pathology-/disability-specific					
3. Assisting Hand Assessment (AHA)[46]	785	22 items grouped in 6 clusters	Children with hemiplegic cerebral palsy or obstetric brachial plexus palsy	Measures the effectiveness with which children use their affected hands in bimanual activities	18 months to 5 years

4. Melbourne Assessment of Unilateral Upper Limb Function (MUUL)[47]	175	4 subscale scores 14 tasks and 30 scores	Children with cerebral palsy or neurological impairment	Assess quality of upper-limb movement	2 years 6 months to 15 years
5. Quality of Upper Extremity Skills Test (QUEST)[48]	116	4 domains with 34 items	Children who have neuromotor dysfunction with spasticity (i.e., cerebral palsy)	Measures movement patterns and hand function	18 months to 8 years
6. Manual Ability Classification System (MACS)[49]	1094	5 levels of hand function and independence in performing activities	Children with cerebral palsy	Classifies hand use in handling objects in daily activities	4–18 years
7. Besta Scale[50]	10	3 sections	Children with hemiplegic cerebral palsy	Measures grasp on request and spontaneous use of upper limbs in bi-manual activities	18 months to 12 years
8. Box and Blocks test (BBT)[51]	53	No subtests	Persons of any age with different upper limb disabilities	An outcome measure testing gross manual dexterity of the upper limbs	3–75+ years
9. Both Hands Assessment (BoHA)[52]	27	16 items (11 unimanual and 5 bimanual)	Children with bilateral cerebral palsy (MACS levels I-III)	Describe spontaneous bimanual performance and asymmetry of hand use	18 months to 12 years
Pegboard tests					
10. The Purdue Pegboard Test (PPT)[53]	180	4 subtests	People who are healthy & with physical, neurological and psychological conditions	Assess manual dexterity of the fingers	2.6–89 years
11. Nine-hole Peg Test[54]	146	No subtests	People with various neurological diagnoses, e.g., stroke	Screening fine motor problems	5–65 years
12. Functional Dexterity Test (FDT)[55]	24	No subtests	Typical developing children and adults	Measure in- hand manipulation and tripod pinch	3 years and older
Questionnaires (self-reported /parent-reported)					
13. Children's Hand use Experience Questionnaire (CHEQ)[56]	24	No subtests	People with unilateral disability, e.g., obstetric brachial plexus, cerebral palsy	Provides children's and adolescents' experiences of hand use	6–18 years
14. ABILHANDS-Kids[57]	328	21 manual ability Items	Children with cerebral palsy (MACS levels I–V)	Measures manual ability (parent-reported)	6–15 years
15. Hand-Use-at-Home (HUH) questionnaire[58]	8	18 typical bimanual play and self-care activities	Children with neonatal brachial plexus palsy or unilateral Cerebral palsy	Assesses the amount of spontaneous use of the affected hand in in activities (parent-report)	3–10 years
16. Pediatric Motor Activity Log (PMAL)[59]	127	22 activities requiring the use of the affected arm and hand	Children with hemiplegic cerebral palsy	Parent-report questionnaire. Assess spontaneous use of affected upper-limb in everyday activities	6 months to 8 years

Ostensibly, a wide variety of children's hand function assessment instruments is available, but when charting these instruments in different categories and according to specific criteria, the opposite becomes evident. After certain instruments were excluded (as motivated above), Table I (page 24-25) was compiled and demonstrated that only two observational assessment instruments, seven pathology-specific, three pegboards and four questionnaires, were considered. Only one published clinical instrument covers several (although not all) hand function components, with a broad age range that is not pathology-specific. However, not one instrument standardised for the South African population is available. Therefore, a need for a contextually relevant paediatric hand function assessment instrument for occupational therapists is evident. However, before refining available instruments or developing a new instrument for children in South Africa, it is important to understand therapists' paediatric hand function assessment practices. Therefore, this study aimed to investigate occupational therapists' current paediatric hand function assessment practices and their preferences towards future practice.

METHODS

Study design

A quantitative, cross-sectional research approach was employed for this study[60].

Population and sampling

In this study, the population represented registered South African paediatric occupational therapists. During the study, 5 682 occupational therapists were registered with the Health Professions Council of South Africa (HPCSA). However, it was not evident who was retired, not practicing, or living in other countries. The HPCSA could also not disclose the exact number of occupational therapists practicing within the paediatric field. Therefore, convenience sampling was used to reach the population via email, social media (i.e., Facebook, Instagram and WhatsApp) and the Occupational Therapy Association of South Africa (OTASA) platform[61]. To reach even more occupational therapists, snowball sampling was also used[62, 63].

The inclusion was regulated based on the following criteria: (i) participants should be occupational therapists registered with the HPCSA; (ii) participants should have worked with children between the ages of 1 to 12 years directly or indirectly (through training of students or research in this field); (iii) participants should have practiced within the last five years; (iv) participants should have practiced in South Africa for more than two months; (v) participants should have assessed hand function in children; and (vi) participants should have access to the internet and email.

Measuring instruments

An online questionnaire developed from the literature and expert consultation was developed and posted on the EvaSys© survey system. Literature considered throughout the questionnaire development covered (i) available standardised and non-standardised paediatric hand function assessment instruments (c.f. Table I, page 24-25); (ii) instrument development theory; (iii) instrument evaluation theory; (iv) literature on psychometric properties, and (v) assessment approaches. The questionnaire consisted of closed and open-ended questions to allow participants to raise their opinions.

The first section of the questionnaire was directed at the demographic information of the participants and the second section at the paediatric client profile of the participants. The third section related to the current methods that participants used to assess hand function in children. The final section focused on the preferred assessment practices of participants and their preferences towards a potentially suitable hand function assessment tool to assess children in South Africa.

Pilot study

The questionnaire was piloted to determine face- and content validity. Aspects also considered were whether the EvaSys© survey link was accessible on different devices and overall technical efficiency[64,65]. Four occupational therapists from different practice sectors participated. Feedback was used to refine the questionnaire's format, wording and content. The results of the pilot study were not included in the final study since only a few small changes to some assessment instruments' names in the questionnaire were required.

Data collection procedure

The researchers used the EvaSys© survey system to distribute the questionnaire and collect data. Participants were able to access and complete the questionnaire online. The study advertisement and the specific EvaSys© survey link to the questionnaire were distributed via the OTASA electronic database and social media platforms. The link was available for three weeks and two reminder emails were distributed. To promote a higher response rate, an optional continuing professional development (CPD) activity was available for completion at the end of the questionnaire. The researchers scored the accredited CPD activity, and an electronic certificate providing three CPD units was distributed.

Validity was maintained by excluding ineligible participants, preventing selection bias and using consistent scoring procedures during data analysis. Reliability was ensured by maintaining the same questions throughout data collection; using an electronic survey to guarantee internal consistency; and maintaining confidentiality to ensure objectivity during data analysis.

Data analysis

The EvaSys© survey system automatically captured the responses and extracted the data to compile a Microsoft Excel spreadsheet. Descriptive statistics, namely frequencies and percentages for categorical data and medians and percentiles for numerical data, were calculated.

Ethical consideration

Approval for this study was obtained from the Health Sciences Research Ethics Committee (HSREC) of the University of the Free State in Bloemfontein, South Africa (reference number: UFS-HSD2020/0127/2104). OTASA granted written permission to use their platform. All the participants were provided with an information letter explaining the purpose of the study and were informed that completing the questionnaire implied voluntary agreement to participate. Participants could withdraw at any given time without being disadvantaged. Participation was not anonymous, but information of a personal nature was kept confidential.

RESULTS

A total of 203 questionnaires were completed, with 194 participants eligible for inclusion in this study. The calculated response rate for the 3 860 OTASA members was 3.8%, although a response rate of 5% was achieved, similar to other South African online survey studies[66].

Demographic profile

The participants' age ranged from 23 to 63 years, with a median of 29 years, of which most were female (n=191; 98.5%). Years of practice ranged from 0.25 to 40 years, with a median of 6 years. As shown in Table II (below), the highest level of education was a Bachelor's degree (n=151; 77.8%), while 32 (16.5%) participants had a Master's degree. Most participants provided direct occupational therapy services to children (n=155; 79.9%), and the majority worked in the private sector (n=132; 68.0%), followed by 58 (29.9%) participants who worked in the public sector. Regarding the client profile, most participants (n=184; 94.8%) assessed the age group 5–6 years with developmental delays (n=177; 91.2%) and neurological conditions (n=121; 62.4%). Additionally, children who suffered a head injury, brachial plexus injury, congenital condition/syndrome, or any post-injury condition (e.g., fractures and burns) were assessed.

Table II: Demographic profile of participants.

Variables		n (%)
Gender	Female	191 (98.4)
	Male	3 (1.6)
Highest level of education in occupational therapy	Diploma	1 (0.5)
	Bachelor's degree	151 (77.8)
	Honours degree	1 (0.5)
	Postgraduate diploma	8 (4.1)
	Master's degree	32 (16.5)
	Doctoral degree	1 (0.5)
Field of practice	Direct service to children	155 (79.9)
	Indirect service to children	5 (2.6)
	Both	31 (15.9)
	Neither	3 (1.6)
Practice sector*	Public sector	58 (29.9)
	Private sector	132 (68.0)
	Academic sector	21 (10.8)
	Community service	9 (4.6)
Practice setting*	Preschool/Early Childhood Development Care Centre	107 (55.2)
	Primary school	108 (55.7)
	Secondary school	15 (7.7)
	Tertiary institution	9 (4.6)
	Special needs school	64 (32.9)
	Hospital	52 (26.8)
	Community clinic	19 (9.8)
	Non-profit organisation	21 (10.8)
	Private practice	113 (58.2)
Paediatric client profile (age)*	1–2 years	91 (46.9)
	3–4 years	145 (74.7)
	5–6 years	184 (94.8)
	7–8 years	158 (81.4)
	9–10 years	116 (59.8)
	11-12 years	87 (44.8)
Paediatric client profile (reason for assessment)*	Hand function difficulty (without other pathologies)	90 (46.4)
	Developmental delays	177 (91.2)
	Mental disorders	97 (50.0)
	Physical condition	65 (33.5)
	Neurological conditions	121 (62.4)

*Participants could indicate more than one option

Current informal assessment methods used by participants to assess children's hand function

Regarding informal assessment methods used, all (n=194; 100%) participants used observation of tasks and/or activities, followed by collateral information (n=192; 99.0%) and checklists (n=134; 69.1%). The main source of collecting collateral information was via parent/caregiver consultations (n=183; 95.3%), as shown in Table III (below).

Table III: Current methods used – informal assessment.

Type of method	n (%)
Observations of tasks/activities	194 (100)
Scholastic task/activities#	185 (95.4)
Self-care task activities	132 (68)
Play tasks activities	186 (95.9)
Other*	9 (4.6)
Collateral information	192 (98.9)
Caregiver/parent interview#	183 (95.3)
Teacher interview	138 (71.9)
Checklist	134 (69.1)
Standardised checklists#	30 (22.4)
Non-standardised checklists	126 (94.0)

*Observation during other assessments (n=8), incidental actions (n=1).
#Participants could indicate more than one choice.

Current assessment instruments used by participants to assess children's hand function

Table IV (page 28) illustrates that most participants used assessment instruments (n=147; 75.8%). The standardised test most often used was the Beery-Buktenica Developmental Test of Visual Motor Integration (Beery VMI)67 (n=168; 86.6%), followed by the Early Childhood Developmental Criteria (ECDC)68 (n=41; 21,1%), Bruininks-Oseretsky Test of Motor Proficiency (BOTMP) [69] (n=31;16%) and Movement Assessment Battery for Children (Movement ABC) [69] (n=25; 12.9%). Thus, participants were more familiar with developmental tests than any other hand function specific instruments Participants were least familiar with the Melbourne Assessment of Unilateral Upper Limb Function (MUUL)[47] (177; 91.2%), followed by the Assisting Hand Assessment (AHA)[46] (158; 81.4%) and the Grasp and Reach Assessment of Brisbane (GRAB)40 (n=145; 74.8%).

It was noted that participants reported that they know of instruments, for example, the Peabody Developmental Motor Scales (PDM S)[71] (n=98;50.5%), the test of in-hand manipulation (n=85; 43.8%), and the Functional Strength Measure (FSM)18 (n=72; 37.1%), but did not often use it. Regarding the non-standardised tests, participants mostly used the Task-Based Bilateral Fine Motor Skill Assessment (TBA)[45] (n=50; 25.77%) followed by the Manual Ability Classification System (MACS)[49] (n=36; 18.6%). They were least familiar with the Besta Scale 50(n=190; 97.9%), Pizza Putty Tests[41] (n=176; 90.7%) and Michigan Hand Outcomes Questionnaire (MHQ)43 (n=167; 86.1%).

Participants indicated that they knew of the Children's Handwriting Evaluation Scale (n=49; 25.3%), the Ages and Stages Questionnaire (ASQ)72 (n=45; 23.2%) and (Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH)73 (n=45; 23.2%).

Table IV: Current methods used – hand function assessment instruments.

				n (%)
Assessment instruments				147 (75.8)
Standardised assessment instrument				10 (6.8)
Non-standardised assessment instrument				75 (51)
Both standardised and non-standardised assessment instruments				62 (42.2)
Assessment instruments	**Unfamiliar with**	**Familiar with**		
		Know of	**Used once**	**Used often**
	n (%)	**n (%)**	**n (%)**	**n (%)**
Standardised instruments				
Assisting Hand Assessment (AHA)	158 (81.4)	35 (18.0)	1 (0.5)	0 (0)
Beery-Buktenica Developmental Test of Visual Motor Integration (Beery VMI)	7 (3.6)	8 (4.1)	11 (5.7)	168 (86.6)
Box and Block Tests	130 (67)	53 (27.3)	8 (4.1)	3 (1.6)
Bruininks-Oseretsky Test of Motor Proficiency (BOTMP)	87 (44.9)	51 (26.3)	25 (12.9)	31 (15.9)
Early Childhood Developmental Criteria (ECDC)	80 (41.2)	52 (26.8)	21(10.8)	41 (21.1)
Functional Strength Measure (FSM)	80 (41.2)	72 (37.1)	17 (8.8)	25 (12.9)
Grasp and Reach Assessment of Brisbane (GRAB)	145 (74.87)	41 (21.1)	4 (2.1)	4 (2.1)
Jebsen Hand Function Test (JHFT)	144 (74.2)	34 (17.5)	12 (6.2)	4 (2.1)
Melbourne Assessment of Unilateral Upper Limb Function (MUUL)	177 (91.2)	16 (8.3)	1 (0.5)	0 (0)
Movement Assessment Battery for Children (Movement ABC)	64 (33.0)	60 (30.9)	45 (23.2)	25 (12.9)
Nine-Hole Peg Test	85 (43.8)	68 (35.1)	24 (12.4)	17 (8.8)
Peabody Developmental Motor Scales (PDMS)	57 (29.4)	98 (50.5)	25 (12.9)	14 (7.2)
Purdue Pegboard Test	108 (55.7)	46 (23.7)	23 (11.9)	17 (8.8)
Quality of Upper Extremity Test (QUEST)	137 (70.6)	51 (26.3)	4 (2.1)	2 (1.0)
Test of In-Hand Manipulation	84 (43.3)	85 (43.8)	11 (5.7)	14 (7.2)
Total responses	1543	770	232	352
Non-standardised instruments				
Ages and Stages Questionnaire (ASQ)	102 (52.6)	45 (23.2)	17 (8.8)	30 (15.5)
Assessment of Children's Hand Skills (ACHS)	150 (77.3)	30 (15.5)	5 (2.6)	9 (4.6)
Besta Scale	190 (97.9)	3 (1.6)	0 (0)	1 (0.5)
Children's Handwriting Evaluation Scale	100 (51.6)	49 (25.3)	21 (10.8)	24 (12.4)
Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH)	91 (46.9)	45 (23.2)	27 (13.9)	31 (16)
Manual Ability Classification System (MACS)	112 (57.7)	32 (16.5)	14 (7.2)	36 (18.6)
Michigan Hand Outcomes Questionnaire (MHQ)	167 (86.1)	19 (9.8)	7 (3.6)	1 (0.5)
Pizza Putty Test	176 (90.7)	12 (6.2)	2 (1.0)	4 (2.1)
Task-Based Bilateral Fine Motor Skill Assessment (TBA)	106 (54.6)	33 (17.0)	5 (2.0)	50 (25.8)
Total responses	1194	257	98	186

Qualities of assessment instruments frequently used by participants to assess hand function of children

Most participants (69.6%) indicated that they frequently used standardised assessment instruments to assess the hand function of children. The tests frequently used are as follows. The majority (n=100; 72.5%) of participants based their answers on the Beery VMI test (n=81; 60.0%), followed by BOTMP (n=16; 11.9%), the Movement ABC (n=12; 6.7%) and the DASH (n=8; 5.9%). Other tests used by the remaining 38 (27.5%) participants included the Nine-Hole Peg Test (n=4 (2.9%), Purdue Pegboard test (n=5; 13.2%), MACS (n=6; 13.2%), Jebsen Hand Function Test (n=2; 5.3%), and the ECDC (n=3; 7.9%).

Table V (page 28) shows that most participants (86.9%) did not consider the assessment instrument they used to comprehensively assess all components of hand function. Overall, participants considered the hand function assessment instruments that they used at the time of the study to have sufficient evidence of psychometric properties (n=93; 67.4%) and normative data on specific age groups (n=100; 72.5%), and also noted the availability of technical manuals for administration and scoring (n=124; 89.9%).

However, comments indicated that certain instruments were not regarded as valid and reliable for hand function specifically but more in terms of developmental tests (e.g., Beery VMI). Some instruments (n=77; 55.8%) did not include a standardised or prefabricated kit or material available to purchase. Additionally, some participants reported on the expensiveness of test material that often has to be procured from overseas. Other limitations experienced included the lack of in-depth hand function results, too lengthy administration times, difficult portability, and lack of cultural, age and language relevance.

Most participants (n=109; 78.9%) considered the instrument they used to be clinically useful to assess children in South Africa. However, they were aware that these assessment instruments had not been standardised on South African children and were thus not ideal to use.

Table V: Qualities of frequently used standardised hand function assessment instruments (n=135; 69.6%).*

	Yes	No
	n (%)	n (%)
Training received on the assessment instrument	108 (55.7)	86 (44.3)
Comprehensively assess all components of hand function	18 (13.0)	120 86.9)
Sufficient evidence of psychometric properties	93 (67.4)	45 (32.6)
Sufficient evidence of normative data on specific age groups	100 (72.5)	38 (27.5)
Technical manual for administration and scoring	124 (89.9)	14 (10.1)
Consist of a standardised/prefabricated *kit* or material available to purchase	61 (44.2)	77 (55.8)
Clinically useful to assess children in South Africa	109 (78.9)	29 (21.0)
Experience additional limitations within the assessment instrument most frequently used.	88 (63.8)	50 (36.2)

*Only participants who used a standardised hand function instrument completed this section and related it to the instrument/s they used.

Practical aspects of current and preferred hand function assessments

The median time participants spent on the administration of assessments was 30 minutes, whereas the preferred median was 21 minutes, as shown in Table VI (page 29). Both the current and preferred median scoring time was 15 minutes. Regarding the materials used by participants, most used toys, objects, and/or activities within their clinical setting (n=175; 90.2%), while 81 (41.8%) also used the assessment instruments' specified materials. One participant preferred to use tasks within the context of functional activities, such as buttoning a shirt or handling utensils. Another participant preferred using materials that would not have to be replaced or run out.

When presenting instructions to the child, most participants indicated using clear verbal instructions in the child's language (n=172; 88.7%) and demonstration and visual cues (n=176; 90.7%). However, less than half (n=93; 47.9%) indicated providing an opportunity for a practice run. Only 19 participants (9.8%) indicated using electronic devices (e.g., tablets) with video clips and/or pictures to present instructions.

Most participants (n=179; 92.3%) indicated recording their findings on informal clinical notes at the time of the study. Nevertheless, 110 participants (56.7%) preferred informal clinical notes. While only 99 (51.0%) used an established scoring sheet at the time of the study. 183 (94.3%) indicated they prefer established scoring sheets to record their assessment findings. Overall, approximately one third of the participants (n=67; 34.5%) preferred video recording the assessment to be scored afterwards .

Table VI: Current and preferred hand function assessment: practical aspects.*

		Current assessment	Preferred assessment
		Median (range)	Median (range)
Administration time (in minutes)		30 (3–270)	21 (5–60)
Scoring time (in minutes)		15 (0–120)	15 (1–60)
		n (%)	n (%)
Materials/ activities used	Hand functions assessment *kit* with various objects/activities	116 (59.8)	112 (57.7)
	Toys/objects/activities in clinical setting	175 (90.2)	130 (67.0)
	Don't have any specific toys/objects/ materials to assess hand function	9 (4.6)	–
Presenting instructions	Clear verbal instructions in child's language	172 (88.7)	151 (77.8)
	Demonstration and visual cues	176 (90.7)	187 (96.4)
	Opportunity for practice run	93 (47.9)	120 (61.9)
	Present instructions via an electronic device (with video clips/pictures)	19 (9.8)	–
Recording of findings	Informal clinical notes	179 (92.3)	110 (56.7)
	An established scoring sheet (from standardised instrument)	99 (51.0)	183 (94.3)
	Taking video clips/photographs to score later	73 (37.6)	67 (34.5)

*Participants were able to choose more than one option.

Current assessment practice and future assessment preference of different components of hand function assessment

As shown in Table VII (adjacent), over 80% of the participants indicated a strong preference for incorporating most aspects listed in Table VI (above) into any future assessment instrument. Least preferred but still of importance were components of palpitation (n=135; 69.6%), manual gesture (n=145; 74.7%) and body contact (n=155; 79.9%). All participants (n=194; 100%) indicated that a future instrument should include grasping, releasing and in-hand manipulation. Almost all the participants indicated that they currently assessed object-related aspects of hand function and would prefer these aspects to be included in a future assessment instrument. A small number of participants indicated that although they did not currently assess specific components of hand function (e.g., grip strength and muscle tone of the hands), they would prefer its inclusion in a future assessment instrument.

Table VII: Current and preferred hand function assessment – components of assessment.

	Current assessment practice		Future assessment preference	
	Do assess	Do not assess	Include	Do not include
	n (%)	n (%)	n (%)	n (%)
Components of hand function				
Muscle tone of the hands	164 (84.5)	30 (15.5)	182 (93.8)	12 (6.2)
Muscle strength of the hands	158 (81.4)	36 (18.6)	188 (96.9)	6 (3.1)
Grip strength	145 (74.7)	49 (25.3)	183 (94.3)	11 (5.7)
Sensation of the hands	126 (65)	68 (35.1)	182 (93.9)	12(6.2)
Range of motion of the hands	147 (75.8)	47 (24.2)	179 (92.3)	15 (7.7)
Appearance of the hands at rest[a]	152 (78.4)	42 (21.7)	170 (87.6)	24 (12.4)
Palpitation components[b]	87 (44.9)	107 (55.2)	135 (69.6)	59 (30.4)
Non-object-related aspects of hand function				
Manual gesture[c]	105 (54.1)	89 (45.9)	145 (74.7)	49 (25.3)
Body contact[d]	105 (54.1)	89 (45.9)	155 (79.9)	39 (20.1)
Object-related aspects of hand function				
Arm-hand use				
Turning	156 (80.4)	38 (19.6)	181 (93.3)	13 (6.7)
Carrying	137 (70.6)	57 (29.4)	168 (86.6)	26 (13.4)
Throwing	190 (97.9)	4 (2.1)	188 (96.9)	6 (3.1)
Catching	190 (97.9)	4 (2.1)	188 (96.9)	6 (3.1)
Manipulating	189 (97.4)	5 (5.6)	193 (99.5)	1 (0.5)
Adaptive skilled hand use				
Grasping	190 (97.9)	4 (2.1)	194 (100)	0 (0)
Holding	180 (92.8)	14 (7.2)	189 (97.4)	5 (2.6)
Releasing	181 (93.3)	13 (6.7)	194 (100)	0 (0)
In-hand manipulation	186 (95.9)	8 (4.1)	194 (100)	0 (0)
Isolated finger movement	175 (90.2)	19 (9.8)	190 (97.9)	4 (2.1)
Hand dominance	192 (99.0)	2 (1.0)	193 (99.5)	1 (0.5)
Bilateral hand uses:				
Transferring	170 (87.6)	24 (12.4)	185 (95.4)	9 (4.7)
Using both hands together at the same time	190 (97.9)	4 (2.1)	191 (98.5)	3 (1.6)
Using hands supportively	185 (95.4)	9 (4.6)	190 (98.0)	4 (2.1)
Eye-hand coordination	191 (98.5)	3 (1.6)	192 (99.0)	2 (1.0)
Other aspects related to hand function				
The quality of movement[e]	187 (96.4)	7 (3.6)	190 (97.9)	4 (2.1)
The speed of movement	167 (86.1)	27 (13.9)	186 (95.9)	8 (4.1)
Compensation methods used	186 (95.9)	8 (4.1)	190 (97.9)	4 (2.1)
Incidence of dropping objects	116 (59.8)	78 (40.2)	162 (83.5)	32 (16.5)

[a] Such as temperature, capillary refill and oedema.
[b] Such as muscle, joints and alignment.
[c] Hands are used as a means of communication, such as waving or clapping.
[d] Arm-hand actions that involve body contact, such as scratching or rubbing.
[e] Smoothness, accuracy and control of movement.

Contextual aspects of an assessment

Overall, participants considered the instruments that they used to be relevant for children's age (n=182; 93.8%), gender (n=182; 93.8%), cultural (n=148; 76.3%) and socio-economic background (n=137; 70.6%), and also acknowledged its importance in future instruments.

Preferences for a future hand function assessment instrument

Table VIII (page 30) summarises that most participants (n=134; 69.1%) preferred an instrument to be available in the public domain (open access) with specifications of the equipment/materials required for self-assembly, over a standardised format. A very small number of participants (n=3; 1.5%) commented that they would like a combination of both formats to make it affordable in all clinical settings.

The most preferred form of training was indicated to be online courses with video tutorials. Participants considered it important for future instruments to display evidence of all the properties listed in Table VIII (page 30). Participants preferred a future hand function assessment instrument to accommodate an age range of 2–12 years. A standardised assessment instrument with age-related norms was the most preferred characteristic of a future instrument (n=165; 85.1%).

Observation of tasks and activities was the recommended assessment method (n=185; 95.4%). Both component- and occupational-based assessment approaches were preferred by most participants (n=153; 78.9%).

A total of 163 participants (84.0%) stated they did not know of any standardised hand function assessment instrument for South African children. The few who indicated otherwise (n=10; 9.8%), proposed the ECDC as a hand function assessment instrument standardised on South African children. Almost all the participants (n=189; 97.4%) agreed that there is a need for a paediatric hand function assessment instrument designed for and standardised on South African children.

Table VIII: Preferences for a future hand function assessment instrument.*

Format of the instrument	**n (%)**	
Standardised, with the full *kit* (administration and scoring booklets, assessment material), available to order online or buy in a shop at an affordable cost	86 (44.3)	
In an open access / public domain with specifications of equipment / materials required for self-assembly	134 (69.1)	
Components to be included in the instrument	**n (%)**	
Assessment materials / tools / activities / equipment	176 (90.7)	
Administration instructions	174 (89.7)	
Scoring instruments	183 (94.3)	
Interpretation instructions	183 (94.3)	
Form of training	**n (%)**	
Open access 10-minute online training course (free)	84 (43.3)	
An online course with video tutorials on administration, interpretation and scoring (2–3 hour, CPD-accredited, with registration costs)	132 (68)	
Manual-based self-study	73 (37.6)	
Practical group CPD-accredited course to attend in person	58 (30.0)	
Properties of the instrument	**Yes n (%)**	**No n (%)**
Assess all components of hand function of children	180 (92.8)	14 (7.22)
Training in the administration, scoring and interpretation	172 (88.7)	22 (11.3)
Have proof of instrument development process	183 (94.3)	11 (5.67)
Have evidence of psychometric properties	190 (97.9)	11 (5.7)
Have evidence of standardisation / norm referenced data of specific age groups	193 (99.5)	1 (0.5)
Age range preference	**Median (min–max)**	
Youngest age	2 (less than one year up to 7 years)	
Oldest age	12 (3 years 6 months to 12 years)	
The purpose of the instrument	**n (%)**	
Descriptive instrument[a]	113 (58.3)	
An evaluative instrument[b]	148 (76.3)	
A predictive instrument[c]	51 (26.3)	
A standardised assessment instrument[d]	165 (85.1)	
An outcome measure	101 (52.1)	
Methods of assessment	**n (%)**	
Observation of task / activities	185 (95.4)	
Collateral information	123 (63.4)	
Checklists, screening forms, non-standardised instruments	143 (73.7)	
Standardised assessment instrument	137 (70.6)	
Approaches to assessment	**n (%)**	
Component-based assessment[e]	15 (7.7)	
Occupation-based assessment[f]	31 (16.0)	
Both	153 (78.9)	

[a]Providing useful information about the child's hand function.
[b]Identification of functional limitations and participation restrictions.
[c]Assisting to predict possible disability.
[d]Measure a child's abilities in relation to the norm for their age group or a criterion.
[e]The evaluation of a child's occupational performance components (to identify possible underlying factors that can potentially cause occupational performance difficulty).
[f]The evaluation of children's occupational performance on their meaningful occupations in relevant environments
*Participants were able to choose more than one option.

DISCUSSION

Current hand function assessment practices

The study revealed that in current practice, most participants used developmental or visual perception assessment instruments rather than hand function-specific instruments. The limited use of hand function-specific instruments might be attributed to a lack of knowledge, diminished satisfaction with and appreciation of available instruments and limited time[27,74]. Although some standardised developmental instruments used are not hand function-specific and those that are, do not comprehensively assess all components of hand function. However, developmental assessments such as the Beery VMI or ECDC do provide the opportunity to observe hand function components.

According to our findings, the standardised test most often used was the Beery VMI. Previous studies also reported the Beery VMI as one of the most popular tests used in paediatric practice in South Africa[75] and internationally[6,7]. Although the Beery VMI is not standardised for our population, evidence has revealed that South African children's performance on the Beery VMI compared well to the American normative sample[76]. But, the VMI can only be used to observe a child's hand function (i.e., pencil grip) of the VMI, and was not developed as a comprehensive hand function assessment.

All participants indicated using observation of tasks/activities as part of their assessments, which could be expected since it is considered one of occupational therapists' core skills[77], developed from their unique assessment outlook and subjective experience6. However, observation alone creates the risk of subjectivity[8,75]. Therefore, using it in conjunction with a standardised hand function assessment, if available, is preferable to obtain objective and evidence-based results[8,78].

Most participants agreed that the currently used instruments fail to comprehensively assess all components of hand function. Consequently, participants frequently found it necessary to supplement their assessment with informal observations. No single comprehensive assessment standardised on South African children that also provides psychometric evidence has been described before. Comprehensive evaluation is crucial to determine the child's ability to participate in daily occupations and to understand participation limitations that ensure evidence-based practice[2,9,10].

More participants reported that they were unfamiliar with most of the standardised and non-standardised tests than those familiar with them. This could be due to clinicians not routinely using standardised tests due to time constraints, difficulties in assessing young children and the complexity of the tests66. Similar findings have been reported by Visser et al.[25], who described that the measuring instruments currently used by occupational therapists in South Africa, were often either standardised on foreign populations, not affordable or unavailable for the specific outcome. These tests lack clinical utility, which could be described as the usefulness (appropriateness, accessibility, practicability and acceptability) of an assessment in clinical practice[12,79].

Participants mostly assessed the 5–6 year age group and developmental delays or neurological conditions were the most common reasons for assessment (Table I, page 24-25), aligning with findings by Brown et al.[6] and Feder et al.[7].

Although the prevalence of developmental delays in South African children has not been well documented, the worldwide prevalence is 2–5%[80]. The prescribed assessment materials to be used for the developmental age of the children create a discrepancy for children with physical and neurological disorders, and profound intellectual barriers (functional versus chronological age).This could indicate the need for a standardised test appropriate for the age group of 5–6 years, accommodating developmental delays and neurological conditions.

It became evident in this study that many of the participants want to use inclusive instruments but most instruments either do not contain a standardised or prefabricated kit or materials, are not available for purchase, are often too expensive, and are limited by therapists' practice setting and financial resources. Hence, these tests do not meet the requirements of clinical utility in terms of accessibility[79]. Moreover, according to instrument evaluation literature by Rudman and Hannah[13] and Law[12], assessment materials need to meet standardised specifications. In contrast with paper-based visual perception instruments (e.g., Beery VMI), hand function is a construct that implies the use of material/objects (in a prefabricated kit) to observe certain components of hand function.

When designing an assessment instrument, it is important to consider the child's context, which influences their activity choices[8,13]. Some participants in the private sector indicated that tests were usually culturally and socio-economically compatible with the population of children they assessed. However, participants commented that although some materials were neutral, e.g., crayons, they often adapted the materials and toys according to the child's age, gender, cultural and socio-economic background. It is important to incorporate terms that are compatible across different cultural groups[33].

Preferred hand function assessment practices

More than 80% of the participants demonstrated a high preference for most aspects presented in Table VII (page 29), namely object-related and non-object-related components, to be included in a future assessment instrument. Components of palpitation, manual gesture and body contact were least preferred but are still important to include in developing a future assessment instrument, as proposed in the literature[19]. Participants strongly preferred grasping, releasing and in-hand manipulation to be part of the components assessed in a future instrument. Bieber et al. recommended developing a new comprehensive tool that includes the different aspects of manual function[19].

Most participants preferred an affordable instrument, available in the public domain, with a standard format for equipment and materials. Availability of an assessment instrument can be limited by cost, language or format[13,27,74,79]. Participants preferred a standardised assessment instrument designed to measure or describe a child's abilities at one moment in time in relation to norms or criteria, corroborating the findings reported by Diamantis[74] and Janse van Rensburg et al.[75]

Most hand therapists agree that occupation-based assessment and intervention are ideal, although it is not always the most commonly used form of therapy due to time constraints[74,81]. A clinically applicable instrument is one that assesses both underlying components of hand function as well as the use of hands in activities[13, 81].

Participants reported currently spending more time administering a test than they would prefer. Scoring times remained consistent for both current and preferred practices. According to the literature, administration time and training are crucial factors that may affect occupational therapists' choice of assessment[6,74-75]. Occupational therapists in South Africa often face high caseloads, quick referral turnover and medical aid-related time limits. Consequently, time constraints are a common reason for therapists not to use an occupation-based approach to assessment[81].

Age appropriateness, relevance to all genders, cultures and socio-economic backgrounds were important, as supported by Rudman and Hannah[13], who recommended that therapists should select instruments appropriate for their clients' population and settings. These are therefore important factors to consider within the diverse South African population.

Consequently, there is a need for a test that provides in-depth hand function assessment results, has a short administration time, is easily transportable and is culture, age and language relevant and clinically useful.

Strengths and limitations of the study

In terms of strengths, this study made use of a comprehensively developed questionnaire through (i) performance of an in-depth literature search of all relevant assessment instruments (c.f. Table I, page 24-25); (ii) researchers attending an EvaSys© training session to ensure accuracy and user-friendliness of the questionnaire; and (iii) confirming face validity of the questionnaire by means of the pilot study.

Another strength of this study was the use of an online questionnaire accessible on different social media platforms through snowball sampling, which allowed more participants across South Africa to be reached. An optional CPD activity increased the response rate of the questionnaire. Although it was a quantitative study, the participants had the opportunity to add comments that enriched the data.

A limitation of this study was, firstly, the sample size, preventing the generalisability of the findings to all South African occupational therapists. Secondly, completing the questionnaire was time-consuming, which could have influenced the response rate negatively. Finally, the test-retest reliability of the questionnaire was not determined in a second-round questionnaire.

Recommendations

Based on the results and conclusions drawn from this study, the authors made the following recommendations with regard to future research: (i) a scoping review of the literature to provide a broad overview and critical evaluation of available paediatric hand function assessment instruments with evidence on the validity/reliability; and (ii) developing a new, or refining an existing, hand function assessment instrument according to a systematic instrument development process.

Recommendations for clinical practice include the following: (i) training in the use of the available instruments; (ii) critical evaluation of assessment instruments; and (iii) using standardised instruments to ensure objective results and evidence-based practice.

We recommend that more attention should be paid to under- and postgraduate training in the assessment and treatment of hand function.

CONCLUSION

This study was the first of its kind, documenting the unique voice of South African occupational therapists on their current and preferred assessment practices to evaluate children's hand function. Results highlighted that although a variety of instruments may be available when mapped out and compared, the lack of a standardised, comprehensive hand function assessment instrument with evidence of established psychometric properties is evident.

Hence, the preference for an assessment instrument standardised on South African children is irrefutable. Furthermore, practical direction for developing a future instrument or refinement of a potential assessment instrument is proposed. Recommendations for the continuation of research towards the development of a standardised assessment instrument are supported to guide intervention planning and in due time, improve children's engagement in all their daily activities.

Author contributions

Marieta Visser identified the research topic and supervised the study. Marieta Visser, Zoë Muller, Tessa Kellerman, Carien Oosthuizen, Chanelle Bornman and Mariette Nel formulated the research aims and objectives, and contributed to the conception and design of the study. Zoë Muller, Tessa Kellerman, Carien Oosthuizen and Chanelle Bornman collected the data. Mariette Visser analysed the data. Marieta Visser, Zoë Muller, Tessa Kellerman, Carien Oosthuizen. and Chanelle Bornman interpreted the data, and prepared the first draft of the manuscript. The authors finalised and approved the final version of the manuscript.

Conflicts of interest

The authors have no conflict of interest to declare.

Acknowledgements

All the occupational therapists who participated in the study, and Dr. Daleen Struwig, medical writer/editor, Faculty of Health Sciences, University of the Free State, for technical and editorial editing of the manuscript.

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[MAPPING REVIEW]

Wrestling with evidence-based practice: An evidence mapping review of publication trends in the South African Journal of Occupational Therapy

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KEYWORDS

evidence-informed practice, levels of evidence, research gaps, national research strategy, children and youth

HOW TO CITE THIS ARTICLE

Hendricks F, Buchanan H, Clark AR. *Wrestling with evidence-based practice: An evidence mapping review of publication trends in the South Africa Journal of Occupational Therapy.* South African Journal of Occupational Therapy. Vol 53 No3. December 2023
DOI: https://doi.org/10.17159/2310-3833/2023/vol53n3a5

ARTICLE HISTORY

Submitted: 24 October 2022
Reviewed: 15 February 2023
Revised: 15 June 2023
Accepted: 21 June 2023

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DATA AVAILABILITY

From the corresponding author

FUNDING

No funding was received for this study

ISSN On-line 2310-3833

ABSTRACT

Introduction: Occupational therapy research to support clinical decision-making must be responsive to local needs, illustrate our unique value to clients, communities and providers, and demonstrate efficacy for quality assurance and reimbursement. This article examines the publication trends in the South African Journal of Occupational Therapy (SAJOT) with the intention of contributing to dialogues about evidence-based practice.

Methods: A mapping review was undertaken of articles published in the SAJOT from January 2009 to December 2021. All articles excepting commentaries, book reviews and editorials were included. Articles were categorised by year of publication, title, author, research approach, study design, practice area, research affiliation, and nature of authorship. Quantitative research articles were classified according to the Australian National Health and Medical Research Council (NHMRC) levels of evidence.

Results: Of the 265 articles published in the 13-year period, slightly more took a quantitative approach (52.1%) compared with qualitative approaches (42.4%). Most quantitative studies were Level III-2 studies (31.3%). Children and Youth was the practice area with the highest number of articles (34.8%) and the strongest evidence base.

Conclusion: As occupational therapy continues to wrestle with EBP, further dialogue about a national occupational therapy research strategy to identify and harness enablers and explore and mitigate the barriers identified in this review, is recommended.

Implications for practice

- This research serves as a bridge between theoretical findings and practical applications, by providing data from research that can be put into action through the development of research agendas by institutions.
- By understanding what research has been done, professionals can make informed decisions that are backed by evidence-based findings. This not only enhances the quality of their work but also improves overall efficiency and effectiveness.
- The study helps practitioners identify areas where improvements or interventions are needed. They shed light on potential challenges and offer possible solutions that can be implemented to address specific issues or concerns within their respective fields.
- This data provides a platform for collaboration between researchers and practitioners across institutions in terms of common research agendas.

INTRODUCTION

The advent of evidence-based practice (EBP) precipitated a period during which the occupational therapy profession sought to expand the dominant paradigm of therapy based on expert opinion and practice experience, with practices supported by research evidence[1]. Reasons for adopting an evidence-based approach in occupational therapy have included blending theory and practice[2], demonstrating the benefits and effectiveness of occupational therapy[2-6], efficient services[7], the survival of the profession[6,8] and 'filling in knowledge gaps'[6]. Literature outside the occupational therapy profession has critiqued EBP for its:

- rooting in a scientocentric model[9]
- epistemological challenges and what is considered as knowledge within the hierarchy of evidence[10]
- restrictive nature (considering that decision-making requires more inclusive forms of evidence)[11]
- embedding of research evidence in power and racial injustice[12]
- role in widening disparities between evidence-based strategies and community resources for knowledge translation (thus exacerbating inequities)[13]
- exclusion of indigenous healing practices and failure to acknowledge disparate research funding to indigenous communities[14,15] and,
- lack of engagement with what constitutes evidence[16].

Whilst sharing these common issues, occupational therapy literature raises its own concerns. Firstly, systematic reviews carry the potential of individualised bias and inclusion criteria errors[17]. Secondly, several barriers have stunted the adoption of EBP, including lack of time, lack of availability and accessibility of research, and limited research skills[18]. Thirdly, historical, professional and institutional constraints exacerbate the theory-practice gap[19]. Fourthly, limited involvement in research[20], and lastly, ongoing conceptual and practical challenges despite substantial international educational efforts[21]. A recent systematic review examining the international position statements on the use of EBP in occupational therapy from five Westernised countries highlighted similar concerns[22]. Factors limiting the uptake of EBP included "limiting occupation focus, lack of studies, lack of time, low quality/relevant research, negative attitudes, and lack of training, skills, and motivation"[22:e10]. Notably, the Canadian statement raises concern that the strict adherence to EBP limits the focus on occupation for therapists committed to enabling occupation using a client-centred, occupation focused approach[23].

Hence, whilst health care professionals in general, and occupational therapists specifically, have wrestled with EBP, there have been suggestions to move towards the evolving concept of evidence informed practice (EIP)[24-26]. EIP is defined as the holistic integration of research evidence, practitioner expertise and the people experiencing the practice, with equal consideration of all three components (without preferencing evidence)[26, 27]. Although EBP has been similarly defined, evidence has dominated the other two considerations of practitioner expertise and clients. Whilst recognising the emergence of EIP as an area of theoretical and conceptual growth in seeking to address the limitations of EBP, the term EBP is still largely used in occupational therapy literature. This article thus uses the term EBP rather than EIP.

A shift towards evidence that is more strongly grounded in research requires substantial re-orientation not only in the practice of occupational therapy but also in education and research[28]. Based on Kuhn's[29] four stages in the development of a profession – pre-paradigm, dominant paradigm, period of crisis and a period of accepting a new paradigm – the profession has to navigate a period of crisis in moving from the previous dominant paradigm (expert-based practice) into the new paradigm of EBP. To explore how far we have come in transitioning to this new paradigm in South Africa, we undertook a mapping review to examine publication trends in the South African Journal of Occupational Therapy (SAJOT) over the past thirteen years (2009-2021) with the intention of evaluating our progress towards developing the evidence-base required to support occupational therapy practice in South Africa. We had three objectives: (1) to summarise the recent publication trends in SAJOT over the last thirteen years; (2) to analyse the research generated during this period by research approach and evidence level; and (3) to identify current research gaps.

LITERATURE REVIEW

Fleming-Castaldy and Gillen[28: 368] state that "the integration of science into a profession requires introspection, confrontation, and discourse."

Introspection leads us to think about the importance of research activity broadly. More specifically, introspection requires us to observe and examine our thoughts and feelings about EBP in relation to the values of the occupational therapy profession and its ethical foundations, and the profession's responsiveness and relevance in meeting mounting people and planet pressures.

EBP originated as evidence-based medicine (EBM) as early as 1991 but became popularised through Sackett who defined it as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients"[2:71]. EBP very quickly became adopted by other health professions including occupational therapy. The initial definition has evolved to encapsulate the process of weighing up the evidence (usually considered to be research evidence) together with professional knowledge and experience and client values, preferences and circumstances within a specific context in order to make the best possible decision about health care for a client[30]. This definition leads us to reconsider what is meant by 'evidence' through an epistemological lens on knowledge[31] and truth[32].

Central to this debate is the origin of EBP in medicine and its evolvement from EBM to EBP, with the former having a firm grounding in positivism which "assumes that phenomena are measurable using the deductive principles of the scientific method"[33:129]. In this context, evidence has traditionally been viewed as quantitative research, organised into a hierarchy according to the degree of bias inherent in their designs[34]. The roots of EBP are thus strongly embedded in logical empiricism which forms the foundation of experimental research[34] and values factual and objective information[32]. Juxtaposed with this is the alternative position of diversity in ways of knowing[31,32].

Although rooted in different philosophies these forms of naturalistic inquiry view knowledge as being founded on perceptions of experiences and understandings of the world which cannot be separated from the outside world[35]. Hence, the concept of providing care operates within a particular worldview that determines the type of evidence required and influences thinking about what is considered 'high-quality' evidence. Occupational therapy's unique focus on achieving health and participation through engagement in occupations[36] encompasses a broad interpretation of health that departs from a biomedically-oriented approach to one concerned with participation and social justice[37] Occupational therapy thus spans positivistic and naturalistic ways of knowing which requires diverse research designs[38] which necessitates quantitative and quantitative approaches to knowledge genera-rtion.

Confrontation, the second aspect of integrating science into the profession, necessitates active engagement with the established knowledge base underpinning practice. Hinojosa raised three concerns related to EBP in occupational therapy[17], viz. (a) Should occupational therapy adopt a hierarchy of evidence from medicine? (b) What are the consequences of assuming that randomised controlled trials provide the best, if not the only, evidence that establishes credibility? (c) Is internal validity more important than external validity when judging the value of a research study? An important consideration is the confrontation on how much of what is taught and researched in South Africa, is produced in South Africa, as part of broader occupational consciousness[39] dialogues about occupational therapy hegemony and context, the manifestations of which are described in the critiques of EBP at the outset of this paper. Furthermore, the EBP assumption that health care decisions are made at an individual level by the therapist with input from the client, may not be appropriate in an African society where the Ubuntu philosophy encompasses a culture of collectivism with decisions being made for the well-being of the family, community and individual[40,41].

Another confrontation calls for an examination of the tensions arising from a "disconnect between our commitment to currency and efficacy, and the press to include outdated and unsubstantiated information" in textbooks, and practices that are outdated yet still in use[28 36 4]. A practical example of such a confrontation relates to evidence presented in a systematic review which challenges the continued use of traditional approaches, such as Bobath in promoting sensori-motor control of limbs, activities of daily living and quality of life[42]. However, it is for precisely these reasons that EBP requires active dialogue.

The third aspect, **discourse**, requires interchange of ideas, knowledge and experience of the application of the new paradigm of EBP. An example is the relationship between evidence and ethics. Chabon[43] advocates that our use of EBP in conjunction with our Code of Ethics elevates us as professionals and encourages public trust in the profession . The standing of EBP is evident in the World Federation of Occupational Therapists (WFOT) Code of Ethics[44 1] which states that "Occupational therapists will .... apply their acquired knowledge and skills in their professional work, based on the best available evidence. "

"Notably, the term *evidence-based practice* is absent from the Occupational Therapy Association of South Africa (OTASA) Code of Ethics[45] (currently under revision) and the Ethical and Professional Rules of the Health Professions Council of South Africa (HPCSA)[46] although inferences are present in both as reflected in these statements:

> *"Occupational therapy personnel shall achieve and continuously maintain high standards of competence and be aware of current trends and legal issues or developments affecting their practice"[45:3]."A practitioner shall at all times keep his or her professional knowledge and skills up to date"[46:20].*

Discourse thus requires assertive educators that model reflection and critical dialogue on how to move forward beyond comfort zones of practice based on tradition[43]. Beyond educators, it also demands that clinicians actively engage their clients in ensuring their values and preferences are considered, their safety is promoted, and that they participate actively in decision-making and exercise their healthcare choices[7, 8, 28]. Locally, Hinojosa's[17] reflections recede against the broader social and historical impacts of apartheid on health in the context of South Africa.

Through the framework of introspection, confrontation, and discourse there is a need to bring the considerations of power, race, gender, and class and other dimensions into the conscious dialogues about EBP, in terms of inequality in the production and reproduction of knowledge and social relations in occupational therapy. However, current dialogues in occupational therapy and EBP do not sufficiently foreground the fundamental question about the epistemological underpinnings about what knowledge is, how it is produced and by whom, which this mapping review can provide glimpses into. Hence, can a discussion on progress towards becoming an evidence-based profession in South Africa be authentic without addressing issues of decoloniality and epistemology as root constructs, perhaps described in Kuhn's[29] words as an unresolved failure? Do we continue an evaluation into the growth of EBP in South Africa despite the 'unresolved failure' of sufficient robust epistemological engagements or do we proceed to evaluate our progress towards the implementation of EBP within practice, education, and research? Aware of these unresolved issues, we proceed to examine EBP specifically to establish what scholarly articles were published in the SAJOT, with a clear intent of contributing to discussions and debates about EBP. As the official journal of the OTASA, the SAJOT predominantly publishes research and academic articles produced by South African occupational therapists. It therefore provides an ideal forum for monitoring paradigm shifts within the profession.

METHODS

A mapping review was conducted to plot publication trends in the SAJOT. Mapping provides a systematic approach to understanding the 'map' of a profession, theory, research question, or practice and is useful for identifying trends on a particular topic[47].

A mapping review focuses on "categorising, classifying, characterising patterns, trends or themes in evidence production or publication"[48:14]. The objectives of the review were to: (1) summarise the publication trends in the SAJOT over a 13-year period; (2) analyse the research during this period according to evidence level; and (3) identify research gaps. Ethical clearance was not obtained as this is not a requirement for a mapping review.

The search strategy was conducted manually from the SAJOT website and double checked on Scielo.org.za which holds an online repository of SAJOT issues. All articles published in the SAJOT from January 2009 (volume 39, issue 1) to December 2021 inclusive (volume 51, issue 3) were retrieved and screened for eligibility. All researched articles were included but commentaries, book reviews and editorials were excluded. As the journal only became digitised in late 2010 (volume 40, issue 3), the authors hand-searched articles published prior to this date. The journal website content search function was used to identify potentially relevant articles from volume 40 issue 3 (2010) to volume 51, issue 3 (2021).

The full-text articles were read to extract the following data from each included article: a) year of publication; b) research approach; c) research design; d) practice area; e) author affiliation; and, f) presence of interdisciplinary authorship. The research approach was classified as quantitative, qualitative or mixed methods, and the research design was captured as it was reported, for example 'cross-sectional', 'quasi-experimental', 'descriptive', 'analytical'. Articles that did not describe the study design were labelled as 'not reported' and those based on literature reviews were labelled 'not applicable'. To analyse publications on contribution to EBP (objective 2), articles reporting quantitative research designs were classified according to the hierarchy of evidence described by the Australian National Health and Medical Research Council (NHMRC)[49].

The NHMRC hierarchy was developed in response to the bias towards intervention studies in existing evidence hierarchies[49]. This hierarchy appreciates that responses to the different types of clinical questions, such as those related to intervention, assessment, prognosis, and aetiology, require different research designs, and thus different evidence hierarchies. In doing so, the importance of the appropriate research design to answer the specific research question is elevated. Hence, our decision to select it as the tool to categorise evidence levels to examine the trajectory of locally produced research.

The NHMRC hierarchy indicates the best study design for the particular question. It is organised according to EBP question type (intervention, diagnosis, prognosis, aetiology and screening intervention), and categorises articles as: Level I (systematic review of level II studies), Level II (randomized controlled trials), Level III-1 (pseudorandomised controlled trials including other experimental or prospective observational studies), Level III-2 (comparative studies with concurrent controls), Level III-3 (retrospective studies) and Level IV (case reports, position statements, etc). Level IV was broadened to include opinion papers and non-systematic literature reviews. Qualitative studies and mixed methods studies were noted as such and were not assigned to a research hierarchy.

We used the OTASA fields of practice in use at the time of the study as a guide for categorising practice areas. Fields of practice were collapsed where necessary, for example adult neurology and adult physical were grouped together and renamed adult physical rehabilitation. Additional categories, such as occupational therapy education, and management and leadership, were created as the need arose. Naming of some field of practice categories were changed to align with terminology that was in use at the time of data collection.

All three co-authors coded the research approach, research design and level of evidence. Coding discrepancies were resolved through discussion to achieve consensus. Data were captured in a Microsoft Excel spreadsheet, codes assigned to all non-numerical data, and cleaned for analysis. Once the final data sets were assigned agreed-upon codes, the Microsoft Excel 'COUNTIFS' formula was used to calculate frequencies and percentages. Descriptive statistics were used to summarise the data and patterns across the years to identify trends (objective 1) and gaps (objective 3), and to describe the evidence by research approach and evidence level (objective 2).

RESULTS

In total, 265 articles met the inclusion criteria and were included in the analysis of publication trends in the SAJOT.

General publication trends

Number of articles per year

Table I (below) shows the number of research articles published in the SAJOT per year from 2009 to 2021 (n=265). The most active publication year (31 articles) was 2016 followed by 2014 (28 articles), 2015 and 2021 (26 articles each).

Table I. Number of articles per year (2009-2021)

Year	Total Articles
2009	12
2010	12
2011	25
2012	15
2013	14
2014	28
2015	26
2016	31
2017	20
2018	20
2019	14
2020	22
2021	26
Total articles (2009-2021)	**265**

Research approach

Mixed method approaches were least used (n=12, 4.7%), whilst 52.9% of articles were quantitative (n=136) and 42.4% were qualitative (n=109) (Table II, page 40). Articles that did not report the research approach or were not research-based were excluded from this analysis (n=8; 3.0% of the total).

Table II. Research approach used in included articles (n=257) *

Approach	No.	%
Quantitative	136	52.9
Qualitative	109	42.4
Mixed	12	4.7
Total	**257**	**100**

* Excluding articles that did not report the research approach or were not research-based

Practice Area

Table III (below) shows the number of articles published in each practice area in descending order. Articles that did not relate to practice, for example methodological, epistemological, and ethics articles (n=21; 7.9% of the total), were not included in the analysis. Children and Youth were highest (34.8%) whilst Productive Ageing was lowest (0.4%).

Table III. Number of articles in each practice area (n=244)

Practice Area	No.	%
Children and Youth	85	34.8
OT Education	45	18.4
Adult Physical Rehabilitation	32	13.1
Work Practice	27	11.1
Mental Health	26	10.7
Community	13	5.3
Management & Leadership	5	2.0
Health and Wellness	5	2.0
Driving and Community Mobility	5	2.0
Productive Ageing	1	0.4
Total	**244**	**100**

Research affiliation

Table IV (below) shows research affiliations for articles authored exclusively from one university (n=136). The University of the Witwatersrand was highest at 31.6%. Just over half (51.3%) of all articles were authored at single universities without co-author collaborations from other disciplines or other universities. Two articles (0.8% of the total sample) were authored by individuals in private practice and are not included in Table IV (below).

Table IV. Number of articles with author affiliations without external partners (n=136)

Author Research Affiliation	No.	%
University of the Witwatersrand	43	31.6
University of Free State	29	21.3
University of Cape Town	17	12.5
University of Western Cape	14	10.3
University of KwaZulu Natal	14	10.3
University of Stellenbosch	11	8.1
University of Pretoria	5	3.7
Sefako Makgatho Health Sciences University (SMU)	3	2.2
Total	**136**	**100**

Table V (below) shows that 127 articles (47.9% of the total sample) had co-authors from multiple locations like local tertiary institutions with local universities, private practices, public institutions, international universities, and international organisations. Mixed co-authorship between private practice, public institutions and international settings was highest at 44.1% (n=56).

Table V. Number of articles with other author affiliations (n=127)

Research Affiliation	No.	%
Mixed (Private Practice, Public, International)	56	44.1
University & Private Practice	28	22.0
University & International	24	18.9
Partnered Local Universities	19	15.0
Total	**127**	**100**

Interdisciplinary co-authorship

Compared to 168 (63.4%) articles with occupational therapy-only authorships, 85 articles (33.0%) had interdisciplinary co-authorship, such as occupational therapy with disciplines such as physiotherapy, biostatistics, and public health. Twelve articles (4.5%) were not authored by occupational therapists.

Evidence-based practice publication trends

This section addresses the second research objective on publication trends in the SAJOT over the last thirteen years (2009 to 2021) by summarising the research approach and study design (as reported in the articles). Figure 1 (below) shows the types of research designs found in the data set in the form of a word cloud. The higher the frequency of appearance, the larger the font size. Descriptive studies were most common followed by pretest-posttest studies.

Figure 1. Study design word cloud

Table VI (below) presents the number of articles for each practice area according to research approach (quantitative, qualitative or mixed methods). Articles that were conceptual in nature and did not report research were categorised 'not applicable'. The majority of studies were quantitative (n=136, 52.9%) but qualitative approaches were almost as high (n=109, 42.4%). Quantitative articles were further categorised by NHMRC evidence level[49]. Most quantitative articles were classified as level III-2 studies (n=83, 31.3%). Children and Youth was the practice area with the highest number of articles produced as well as the widest spread of evidence. The strongest level of evidence in this practice area was level I, but the level of evidence most prominently represented was level III-2 (n=36 articles).

Table VI. Frequencies and proportions for research approach by practice area (n=265)

	Quantitative NHMRC evidence level#						Qual	MM	N/A	Total
Practice Area	I No. (%)	II No. (%)	III-1 No. (%)	III-2 No. (%)	III-3 No. (%)	IV No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Children & Youth	1 (0.4)	2 (0.8)	6 (2.3)	36 (13.6)	7 (2.6)	7 (2.6)	21 (7.9)	3 (1.1)	2 (0.8)	85 (32.1)
OT Education	0 (0.0)	0 (0.0)	1 (0.4)	15 (5.7)	2 (0.8)	3 (1.1)	20 (7.6)	4 (1.5)	0 (0.0)	45 (17.0)
Adult Physical Rehabilitation	0 (0.0)	1 (0.4)	2 (0.8)	14 (5.3)	0 (0.0)	3 (1.1)	11 (4.2)	1 (0.4)	0 (0.0)	32 (12.1)
Work Practice	0 (0.0)	2 (0.8)	2 (0.8)	5 (1.9)	1 (0.4)	1 (0.4)	15 (5.7)	0 (0.0)	1 (0.4)	27 (10.2)
Mental Health	0 (0.0)	0 (0.0)	1 (0.4)	6 (2.3)	1 (0.4)	2 (0.8)	15 (5.7)	1 (0.4)	0 (0.0)	26 (9.8)
Other	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.8)	2 (0.8)	3 (1.1)	10 (3.8)	0 (0.0)	4 (1.5)	21 (7.9)
Community	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.4)	0 (0.0)	1 (0.4)	10 (3.8)	1 (0.4)	0 (0.0)	13 (4.9)
Management & Leadership	0 (0.0)	0 (0.0)	0 (0.0)	3 (1.1)	0 (0.0)	0 (0.0)	1 (1.1)	1 (1.1)	0 (0.0)	5 (1.9)
Health & Wellness	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.8)	0 (0.0)	2 (0.8)	0 (0.0)	1 (0.4)	5 (1.9)
Driving & Community Mobility	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.4)	0 (0.0)	0 (0.0)	3 (1.1)	1 (0.4)	0 (0.0)	5 (1.9)
Productive Ageing	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.4)	0 (0.0)	0 (0.0)	1 (0.4)
*Total n=265	1 (0.4)	5 (1.9)	12 (4.5)	83 (31.3)	15 (5.7)	20 (7.6)	109 (41.1)	12 (4.5)	8 (3.02)	265 (100)

MM=mixed methods; NA=not applicable; Qual=qualitative. *>100 due to rounding

Level of evidence:

Level I: "... systematic reviews of the appropriate level II studies in each case"'[49:13].

Level II: "The most appropriate study design to answer each type of clinical question (intervention, diagnostic accuracy, aetiology or prognosis) ..."[49:13].

Levels III and IV: "Study designs that are progressively less robust for answering each type of question ..."[49:13].

Gaps in the research

The distribution of research articles across practice areas is dominated by five main areas: Children and Youth, Occupational Therapy Education, Adult Physical Rehabilitation, Work Practice and Mental Health, and could be supportive of EBP. Table VI (adjacent) provides valuable insights into practice areas where research is noticeably lacking: management and leadership, health and wellness, driving and community mobility and productive ageing. Few studies reported level I (0.4%), II (1.9%) and III-1 (4.5%) designs.

DISCUSSION

This mapping review of research articles published in the SAJOT over a 13-year period examined the patterns in research output with the intention of contributing to dialogues about EBP. The inconsistency in the number of articles published in each issue may be due to several factors. Peaks in the data over the 13-year period could be due to professional conferences which may have encouraged more submissions. The OTASA hosted national conferences in 2012, 2014 and 2016 and co-hosted the World Federation of Occupational Therapists international congress in 2018 may have encouraged authors to work towards submitting articles in preparation for their presentations, resulting in the observed peaks in 2011, 2014, and 2016. During the review period, university research programmes were under pressure due to interrupted schedules resulting from student movement protests such as the Rhodes Must Fall[50] and Fees Must Fall[51] movements, which may have impacted research output capacity due to shortened academic calendars. The COVID-19 public health crisis may have been a further reason for the decline in publications, as educators were under pressure to move to online modes of teaching which was extremely time-consuming and likely affected research productivity. However, the publication figures for 2020 and 2021 do not reflect this.

With regard to the research approach used, qualitative and quantitative approaches were reasonably on par with each other, but mixed methods approaches were less often utilised, possibly due to the resource demands of conducting such studies and the complexity of synthesising the findings. The relatively large number of articles with authors from multiple locations and co-authorship across disciplines and institutions could be used to leverage resources. Given the modest research output seen in the SAJOT, leveraging research partnerships through interdisciplinary and multi-partner collaborations could potentially increase the number of articles published in the SAJOT per year. An opportunity to increase research output could be to develop communities of practice between clinicians and academics similar to the collaborations between the University of the Western Cape and clinicians.

This mapping review shows the variety of study designs that were used over the 13-year period. The type of study design relates to the research question which raises questions about how decisions are made on which questions to investigate, in terms of push or pull demands, i.e. leading the field by asking new questions, or leading the field through responsive research. Guided by Fleming-Castaldy and Gillen's[28] suggestions of introspection, confrontation, and discourse, EBP requires that our understanding of occupation arises

from, and is deeply connected to, what is observed in daily practice, integrating both push and pull demands in the research questions being asked. Of note were the relatively similar number of quantitative and qualitative studies that were published and the noticeable lack of level I and level II studies. This could indicate a predominance of student research, that academics are publishing higher level studies in other journals, or that this type of research is not being conducted. Soeker and Olumide[52] similarly reported a paucity of level I studies in their content analysis of the OTASA research database. The gaps in level I and II research are a threat to the profession in terms of the evidence required by the National Department of Health (NDOH) for National Health Insurance[53]. Collective action is thus needed to explore ways of producing the levels of evidence which the NDOH is calling for.

The current study identified a strong research focus on Children and Youth which had the highest number of articles and widest spread of evidence. Other relatively productive research areas were occupational therapy education, adult physical rehabilitation, work practice and mental health. An analysis of the OTASA research database of published and unpublished South African research produced from 2017 to 2019 similarly identified education and training and mental health as the most common research areas[52]. While this research production is encouraging, we need to explore how and where this research is being implemented. We also need to consider why research is low in some practice areas. Possible explanations for the limited spread of articles across some practice areas could be the low number of occupational therapists specialising in those fields, difficulty securing research funding and limited time and capacity to conduct research.

A viable recommendation towards building a more coherent and comprehensive body of evidence is the development of a national occupational therapy research strategy and agenda that focuses the research output of universities with national strategic priorities. To this end, the relatively recent launch of an OTASA database of South African occupational therapy research will enable mapping of the research that has been done, identifying gaps, and determining research priorities. This OTASA Research Committee initiative seeks to address the fragmentation and poor dissemination of South African occupational therapy research[54]. Du Toit[55] advocated that to strengthen research dissemination and support the growth and recognition of the profession the OTASA should develop a research plan, in collaboration with universities, for producing and disseminating research that is relevant and appropriate for the South African practice context. Progress has been made in this regard through a recent survey of OTASA members which identified three research priority areas: "effectiveness of occupational therapy intervention, evidence-based occupational therapy practice and the development of valid and reliable occupational therapy measurement tools"[52:6]. Researchers should seriously consider how they can contribute to broadening and strengthening the evidence-base for our profession by focusing on these identified research priorities[53].

At a systemic level, factors that continue to hamper the implementation of EBP include lack of access to appropriate research information[56], limited resources and poor infrastructure in public health services, gaps in published research for the health conditions, context and type of practice in South Africa[52,53] and a weak EBP culture[56]. Proposals arising from a national occupational therapy survey included the need for training to equip occupational therapists to implement EBP and increased availability and access to resources for research[56].

Training has to occur at multiple levels – in formalised undergraduate and postgraduate programmes and as part of continuing professional development (CPD). To ensure that the country produces graduates that are adequately equipped to become evidence-based practitioners, university programmes need to instil thinking that both challenges and changes existing practices as advocated by Fleming-Castaldy and Gillen[28]. In line with the WFOT Minimum Standards for the Education of Occupational Therapists, educational curricula should incorporate content to equip students with the knowledge, skills and attitudes for EBP[56]. CPD activities could form part of a nation-wide programme aimed at equipping practitioners with the tools required for EBP and to provide updates on the latest evidence in particular fields of practice. Online tutorials could be a practical way of offering further training opportunities for participants to work through practical case examples designed to help them navigate through the thought processes related to EBP[56].

Limitations

The authors acknowledge that the number of publications included in this review is not necessarily a full indication of research activity in South Africa. As the mapping review was limited to publications in the SAJOT it cannot be assumed to represent a complete view as research published in other journals has not been accounted for.

CONCLUSION AND RECOMMENDATIONS

As South African occupational therapists wrestle with dialogues about EBP, establishing a longitudinal view of the state of our evidence base is important for perspective making. In lieu of both the benefits and limitations of a paradigm shift in practice towards EBP, as alluded to by Kuhn's[30] stages in the development of a profession, this mapping review provides significant clues, and perhaps challenges, about where we are, and where we may need to go.

On a micro-level, this mapping review offers insights that there may be missed opportunities in client-centeredness and subsequent client-provider conversations about evidence options due to the limited range of evidence produced. On a macro-level, in addition to contributing to larger dialogues about EBP, the review may be used to identify evidence gaps to set agendas for future research, evaluate grant applications according to the need for further research in a particular practice area, and to inform policy. It may also be useful for motivating for research funding to produce higher levels of evidence. Lastly, the review could be used as a discussion document to inform operational and strategic research priorities at local and national levels.

Author/s contributions

Fatima Hendricks conceptualised the original article and contributed to all subsequent data collection, analyses and revisions, and approved the final version of the article. Helen Buchanan guided the re-conceptualisation of the original draft and contributed to all subsequent data collection, analyses and revisions, and approved the final version of the article. Asia Clark assisted with the data extraction and analyses and approved the final version of the article.

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RESEARCH ARTICLE

The lived experiences of South African occupational therapists regarding the impact of COVID-19 pandemic on their wellness

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KEYWORDS

health professionals, employee wellness, online wellness/resilience programmes, professional engagement, healthcare workers

HOW TO CITE THIS ARTICLE

van Niekerk K, Balbadhur R, Casteleijn D, D'Oliviera J, Msimango H, Uys K. *The lived experiences of South African occupational therapists regarding the impact of COVID-19 on their wellness.* South African Journal of Occupational Therapy. 2023; 53(3):
DOI: https://doi.org/10.17159/2310-3833/2023/vol53n3a6

ARTICLE HISTORY

Submitted: 17 August 2022
Reviewed: 6 June 2023
Revised: 10 July 2023
Accepted: 13 July 2023

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DATA AVAILABILITY

From the corresponding author

FUNDING

This research was funded by a grant awarded by the University of Leeds.

ISSN On-line 2310-3833

ABSTRACT

Introduction: The Covid-19 pandemic impacted the wellness of health professionals around the world. In order to ensure that healthcare systems are sustainably able to provide services during times of emergency, the health and wellness of health professionals should be safeguarded. The researchers were interested in exploring the impact of the first wave of the pandemic on the holistic wellness of South African occupational therapists and to identify strategies therapists employed to facilitate their own wellness.

Method: The study followed a qualitative research design with phenomenological characteristics. Two asynchronous (text-based) online focus groups were conducted, each with eight participants. Participants providing occupational therapy services in different fields of practice and in different contexts were purposefully selected. Participants in both groups were asked a series of five questions in an online forum over a period of six days. Two researchers facilitated interaction within the groups to encourage in depth discussions.

Results and Discussion: The data were analysed by means of deductive thematic analysis, whereby the dimensions of holistic wellness were used to guide analysis. The results illustrate the pervasive influence the COVID-19 pandemic had on the wellness of South African occupational therapists.

Conclusion: Lessons learnt are discussed to facilitate the preparedness of South African occupational therapists for future pandemics.

Implications for practice

- Occupational therapists should endeavour to prioritise their own wellness to the best of their abilities.
- Occupational therapists should utilise familiar strategies to facilitate their own wellness during future highly stressful times, such as during future pandemics or states of emergency.
- Occupational therapists may be excellently positioned to facilitate the fostering of wellness of other HPs in the professional team.

INTRODUCTION

'Wellness' is viewed as an umbrella term that encapsulates all dimensions of a person's life[1]. These dimensions as summarised by Miller & Foster[1] include physical; emotional/psychological; social; intellectual; spiritual; occupational; environmental; economic; cultural and climate wellness.

The WHO indicates that wellness includes not only the absence of illness, but that it refers to a state of overall wellbeing[2]. The wellness of health professionals (HPs) is widely acknowledged as a necessity to service provision, as their state of wellness may directly affect their ability to provide quality service to clients3. Health professionals who are experiencing emotional exhaustion and burnout may have diminished professional engagement4. Medical errors may contribute to medical costs and client safety and satisfaction have been shown to increase when the wellness of HPs are ensured[3].

Literature review

The first wave of the COVID-19 pandemic impacted on the wellness of HPs around the world [5,6]. Studies have focussed predominantly on the impact of the pandemic on the emotional and physical wellness of HPs. Various studies have highlighted the increased incidence of symptoms of, for example, anxiety, depression, workplace burnout, psychological trauma and sleep problems in HPs during COVID-19[5–8].

Various stressors impacted negatively on the wellness of HPs during the COVID-19 pandemic. Many HPs experienced an unusually high risk of being infected during the COVID-19 pandemic. This aligns with studies on previous viral outbreaks indicating that both frontline and non-frontline healthcare workers experienced an increased risk of infection[9,10]. In terms of emotional stressors, HPs may have experienced emotional contagion[11] where the negative emotions of clients could influence the emotions of the health professional (HP). Health professionals were prone to compassion fatigue[7], as their clients faced new and diverse challenges. Changes in methods of service delivery (e.g. telehealth) was common[12] during the pandemic. Uncertainty regarding the appropriateness and effectiveness of new and/or untried methods may contribute to feelings of self-doubt in HPs and may impact their confidence and could lead to burnout[6]. In addition to these stressors, HPs were faced with several ethical dilemmas and potential moral injury, that has been described as distress that arises from actions (or the absence of action) that violates a person's moral/ethical code[7,13].

It has been suggested that the impact of these stressors on HPs in low and middle income countries (such as South Africa) are particularly significant[6,14] due to added socio-economic pressures. Health professionals in these contexts provide services within systems that were over-burdened even prior to the pandemic. Appropriate management of the stressors experienced by HPs during pandemics is required to ensure that the wellness of HPs does not suffer the consequences. Safeguarding the health and wellness of HPs is vital in order to ensure that healthcare systems are sustainably able to provide services to the population[9]. With the added burden that the COVID-19 pandemic has placed on healthcare services, this is more important than ever.

Occupational therapists, who are part of the health professions team, provide services in various contexts in South Africa. These include services within the public and private healthcare systems, providing acute and long-term intervention. During the countrywide lockdown for the first wave of COVID-19 in South Africa, occupational therapy services were not deemed essential by the government[14]. Therefore, occupational therapy services were initially brought to a standstill when the movement of the population was restricted. After the first few weeks, services were gradually reintroduced.

It was within this context that the researchers were interested in exploring the lived experiences of the South African occupational therapists regarding the impact of COVID-19, with all the resulting infection control measures, on their holistic wellness[1]. Although the majority of international literature focuses on the impact of the pandemic on the emotional and physical wellness of HPs, the authors were interested in broader aspects related to wellness, as indicated by Miller and Foster[1], as well as understanding whether the participants experienced COVID-19 as having a purely negative impact on their wellness.

This study was part of a larger project aimed at exploring the overall impact of COVID-19 on occupational therapy clinicians in South Africa. The broader project is reported elsewhere[14,15]. Thus, this article reports specifically on the lived experiences of occupational therapy clinicians in South Africa regarding the impact of the first wave of COVID-19 in 2020 on their wellness.

METHODOLOGY

Study Design

This study followed a qualitative research design with phenomenological characteristics. This design allowed for the understanding of the lived experiences of the participants[16] during the first wave of the COVID -19 pandemic and consequently its impact on their wellness. Two asynchronous (text based) online focus groups were conducted in order to explore the lived experiences of South African occupational therapists during the first wave of the COVID-19 pandemic.

Sampling

Postgraduate students and clinical supervisors from two universities in Gauteng, South Africa, were invited to participate in the study via email. The inclusion criteria for participants were 1) occupational therapists in private, public, education or non-governmental practice in South Africa and 2) being able to participate via the online platform.

Stratified purposive sampling was employed to ensure representation from different sectors e.g., public, and private health care in the fields of mental health, vocational rehabilitation, physical, and neuro rehabilitation with adults and the elderly. Occupational therapy services with children were represented by therapists employed in public and private sectors. A sample size of 16 participants was obtained, with eight participants per focus group. Participants were allocated by the researchers to one of the two focus groups to ensure maximum variation in experiences and representation of the different sectors within each focus group.

Participants were each allocated a code. The code consists of several digits that represent the setting where the participants provide services. This includes the following: 1) Digit one and two represent the participant number, 2) digit three represents the gender of the participant (male of female), 3) digit four and five show the field of practice (Pa: paediatrics; Sb: school-based; Ph: physical and/or neurological conditions; Dh: district hospital; Lp: long term psychiatry; Ap: acute psychiatry; Vr: vocational rehabilitation and Mx: a mix of conditions), 4) digit six and seven indicate whether the participant provides services in private (Pr) or public (Pu) settings. For additional demographic details of participants see Table I (below).

Table I: Demographic details of participants (N=16)

Participant demographics	n	Percentage of total
Involved in frontline service delivery since lockdown due to COVID-19		
Yes	10	62.50%
No	6	37.50%
Gender of participant		
Male	2	12.50%
Female	14	87.50%
Age of participants in years		
20 - 29	4	25.00%
30 - 39	8	50.00%
40 - 49	3	18.75%
50 - 59	1	6.25%
Province of South Africa where service is provided		
Free State	1	6.25%
Gauteng	13	81.25%
Mpumalanga	1	6.25%
Northern Cape	1	6.25%
Field of Occupational Therapy		
Physical	6	37.50%
Psychiatry	6	37.50%
Paediatrics	3	18.75%
Not specified	1	6.25%
Current employment sector		
Department of Health	5	31.25%
Department of Education	2	12.50%
Private practice	9	56.25%

Data collection

Two asynchronous (text-based) online focus groups were conducted over six days. Data collection took place during June 2020. The two groups were conducted concurrently, and each group had its own facilitator. The facilitators were part of the research team that planned the study and were both experienced in collecting qualitative data. The Blackboard learning management system was used to host the focus groups and participants were provided secure access to the system through use of a unique password.

Several advantages of online focus groups over in-person focus groups have been identified. Participants have geographical independence and can access the focus groups from any location. This was an important consideration, as the data collection occurred when the movements of South African citizens were restricted due to COVID-19 regulations. Asynchronous (text-based) online focus groups have been reported to improve the experience for focus group participants[17]. It has been reported that participants in asynchronous online focus groups may feel more comfortable to provide diverse opinions due to the perceived anonymity of the online format[18]. It has also been mentioned as beneficial that participants can reflect and answer in their own time [19] and in the comfort of their home[17,20].

The Blackboard learning management system, where the focus groups were hosted, was available to the researchers and thus an affordable data collection tool. As participants type their own responses, transcriptions of the raw data were accurate (as participants type themselves) and available in real-time, which saved time and reduced costs. Disadvantages may have been technical difficulties such as an unstable internet connection, data costs and electricity interruptions. None of these were mentioned as challenges by any participants and were therefore not considered barriers in this study.

The facilitators of the groups posted one primary question every day for five days. The sixth day of the focus group was used for concluding remarks. The daily questions have been included in Table II (below).

Table II: Focus group questions

Day	Focus group question
1	How has COVID-19 affected your practice as an occupational therapist?
2	What made things more difficult or more challenging in terms of your occupational therapy practice?
3	What made things easier for you in terms of your occupational therapy practice?
4	Considering your mental health: Describe any changes you have experienced.
5	How has the lockdown affected your ability to provide compassion and care to your clients?

Participants shared their experiences on the impact of COVID-19 on their clinical practice and themselves. Two basic actions of phenomenology were used by the facilitators, namely bracketing and intuition[21]. The facilitators of the focus groups laid aside their preconceived ideas about the possible impacts of COVID-19 on occupational therapy practices. Their intuition followed when the facilitators probed for more examples of the participants' experiences to develop an awareness of the impact of COVID-19 on their wellness. The participants were continuously encouraged to respond to their fellow participants. As the focus groups continued over several days, the facilitators were able to continuously compare the data and were able to query responses from participants to obtain rich data for analysis.

Data analysis

The responses from participants were extracted from Blackboard and collated for analysis. The transcriptions were imported into Atlas.ti for thematic analysis and coding of responses.

The steps of thematic analysis as described by Braun and Clark[22] were followed namely 1) familiarization with data by reading through the transcripts 2) Initial codes generated 3) codes sorted into themes and subthemes 4) refinement and review of themes and subthemes 5) themes and subthemes labelled in relation to the study question 6) findings reported through narrative descriptions supported by direct quotes. Deductive analysis was guided by the dimensions of wellness as described by Miller and Foster[1]. Three authors were continuously involved in the data analysis process and concluded on themes.

Trustworthiness

In order to facilitate trustworthiness of the analysis, several strategies were employed[3]. Firstly, the three authors involved in the thematic analysis had prolonged engagement with the data to facilitate credibility. Peer debriefing was utilised by discussing the analysis with authors that were not primarily involved in the analysis. To facilitate transferability, the authors aimed at providing an in-depth description of the context in which the data were collected. This enables the reader to comprehend the transferability of the results to a different context. Dependability in this study is demonstrated by the detailed description of the research process that was followed. This was done to strengthen the conformability of the study, as suggested by Lincoln and Guba[24].

Ethical clearance

The Research Ethics Committee of the Faculty of Health Sciences of the University of Pretoria gave permission for the study (clearance number: 436-2020). All ethical principles as specified by the Declaration of Helsinki[25] were followed. The potential benefit of conducting the study outweighed the perceived risk to participants. Participants provided informed consent to participate in the study. Confidentiality of the participants was maintained by using coded names during data analysis and reporting of the findings. All participants were informed that they could withdraw at any time.

FINDINGS

The dimensions of wellness as described by Miller and Foster[1] were utilised as themes for the analysis. Analysis indicated that 8 of the 10 dimensions of wellness were represented in the data. These include 1) emotional; 2) environmental, 3) intellectual, 4) occupational, 5) physical, 6) economic, 7) social and 8) spiritual wellness. Wellness in terms of culture and climate were not referred to by the participants. Although the participants described the negative influence of COVID-19 on their wellness, the positive impact of the pandemic was also highlighted.

Emotional wellness focuses mainly on a person's attitudes and beliefs about themselves and about their life, including their sense of purpose. It includes someone's ability to develop a positive and realistic self-concept[1]. Participants expressed fear, stress, and anxiety in response to the COVID-19 pandemic. Many feared contacting the virus but at the same time, transmitting it to family members, clients and significant others. Th e pandemic protocols as well as regulations were also experienced as overwhelming. Furthermore, constant changes due to the pandemic were expressed by one participant as being on a *"rollercoaster"* (06FApPr) which often left her feeling anxious. One participant mentioned that when a client passes away or an employee tests positive, she tends to go into *"auto pilot mode"* (15FPhPr) and ensures that administrative aspects of practice are addressed. Participants noted that increased levels of stress and anxiety were further aggravated as they were restricted from engaging in their usual leisure pursuits.

Amidst the negative impact on emotional wellness, several participants referred to their own resilience, for example one participant noted: *"I feel I am quite resilient and adaptable..."* **(04FVrPr)**. Another participant described how her compassion towards self and others as well as her commitment to therapy was enhanced. *"I would like to venture and say this time has made me more compassionate and committed"* **(06FApPr).** Furthermore, they were hopeful that they would overcome this challenging time.

Environmental wellness as described by Miller and Foster "includes the individual's relationship with nature and community resources, i.e. involvement in a recycling or community clean-up effort, as well as the importance of safety of food and water supply and the impact of infectious diseases, violence, ultraviolet radiation, air and water pollution, and second-hand tobacco smoke"[1:6]. Furthermore, the balance between home and work life is included as an aspect of environmental wellness. This was impacted during COVID-19 restrictions as individuals were required to do tasks that they usually engaged in - such as work tasks - in a different environment, in this case the home environment. Participants mentioned their concern of contracting the virus and being responsible for passing it on to clients at their place of work or to family at home.

> *"I am also immensely worried of contracting it and being responsible for bringing it into the hospital I work at as many of our clients have comorbidities - I would hate to be the reason a client becomes ill."* **(06FApPr)**

> *"I could possibly one day bring the virus back home with me. I find myself constantly worried about that aspect."***(05FDhPu)**

Sanitisation procedures as well as sterilisation before and after contact therapy sessions were also experienced as challenging.

> *"Emotionally the patients and therapists are struggling as a lot of extra focus is placed on hygiene and cleaning before and after sessions."* **(07FPhPr)**

These feelings were compounded by concerns about the availability of PPE and the impact on the safety of clients and staff.

> *"We have had concerns about the availability of PPE in order to keep patients safe and staff safe too."* **(16FPhPu)**

The initial hard lockdown COVID-19 restrictions limited the participants' access to green spaces.

> *"I am currently unable to engage in most of my leisure activities due to all the restrictions put in place. It definitely has affected my ability to manage stress and just to relax after hours and over the weekend."* **(02MLpPu)**

Additionally, maintaining home and work life balance was expressed as a challenge. A participant highlighted that changes in routine and additional child care responsibilities exacerbated this difficulty.

"I think what is having a huge impact on my energy and/or motivation levels, is to try and keep the atmosphere calm at home, despite all the scary news and changes in routine." **(08FPaPr)**

Many also explored online platforms as opportunities for service delivery and social interaction.

Intellectual wellness is the "perception of, and motivation for, an individual's optimal level of stimulating intellectual activity by the continual acquisition, use, sharing, and application of knowledge in a creative and critical fashion. This is for both personal growth and the betterment of society"[1:6] .

Several participants highlighted that the pandemic created many challenges that they had to overcome by thinking differently. Two participants spoke of what they called a *"learning curve"* where they suddenly had to gain and master skills to be able to continue to provide services. Telehealth and the technological skills required to deploy this efficiently provided an intellectual challenge that several participants experienced.

Although participants mentioned that opportunities for traditional skill and knowledge acquisition were reduced due to restrictions, many referred to how the pandemic provided ample opportunity for growth. These opportunities included the shift and skill acquisition required to adapt to, for example telehealth. One participant reported that she found herself *"having to think outside the box"* (01FSbPu). Although the participants spoke of the challenges posed, they also detailed the positive aspects that the pandemic offered. One participant described it as a "good experience" to learn to use a new platform like telehealth and described herself as "finding creative ways of doings things differently" (04FVRPr).

"I think a positive thing for myself is that I engaged in online learning and made use of extra time doing courses; especially during level 5 lock down as I was not at work during this time." **(03FVrPr)**

Participants described utilising their knowledge of occupational therapy theory to understand the behaviour of clients and described implementing occupational therapy theory in their own lives by implementing the strategies that they would typically teach clients.

"It really helped to 'sit myself down' and think of the tools I am teaching my clients and how I need to implement them practically in my own life." **(06FApPr)**

Furthermore, participants described how their insight into and understanding of the context and needs of clients increased.

"The lockdown has caused insight into what the families I work with might be experiencing, which, in a way, created a deeper understanding of their needs." **(08FPaPr)**

"I now have a far better understanding (I hope) of what my clients are feeling like" **(06FApPr)**

Whilst one can hear the challenges experienced by the participants in terms of intellectual wellness, a strong sense of overcoming those challenges through adaptation and resilience was also present.

"I was surprised at my own capacity and ability to adapt to unknown circumstances. I would be uncomfortable or unsure for a while but before I know it, I have formed a new routine, and am quite content with it" **(10MApPr)**

Occupational wellness, as described by Miller and Foster refers to "the level of satisfaction and enrichment gained from one's work, whether paid or unpaid, and the extent one's occupation allows for the expression of one's values. Occupational wellness includes the contribution of one's unique skills, talents and services to the community and the level to which the individual views their work as rewarding and meaningful." [1:6]

Participants described various challenges they experienced with regards to their role as occupational therapists. Participants expressed that occupational therapy was not recognised or supported within the health care system. As occupational therapy was not deemed an essential service, service delivery was disrupted.

"The nitty-gritty of navigating our role as health care professionals proved quite challenging when your role is not fully supported and recognized in the system." **(05FDhPu)**

"I have also had some experience of not per se our role not being recognised, but rather OT being deemed less important." **(06FApPr)**

Furthermore, they found it challenging to maintain the level of care they provided pre-COVID-19 and expressed their uncertainty as to what best practice under these conditions was. Additionally, having to adapt their facilitation style due to the use of telehealth or to accommodate restrictions to face-to-face encounters as well as how they use activities was reported as challenging.

"Telehealth has been quite a daunting experience - for me firstly to master the technology, secondly to gather and grasp all the legalities and ethical considerations around using an online platform for therapy and lastly adjusting my facilitation style to ensure am still using activities as a therapeutic medium whilst ensuring it remains an engaging/satisfying experience for the client..." **(06FApPr)**

Participants referred to the limited resources available in a developing country such as South Africa as having a negative impact on their ability to continue to offer care and therefore experience occupational wellness.

"The limited resources makes it harder to do all we wished we could do and the context our patients are from vary, so it all depends on the patients what we are able to do..." **(16FPhPu)**

Participants described how much time the pandemic took from their day, reducing the hours they were able to experience satisfaction in their roles:

"The time that COVID consumes is alarming, not only the protocols that need to be followed, but also the time that it takes to explain and comfort and convince clients and staff" **(12FSbPu)**

The pandemic with the imposed restrictions also had an impact on the balance that participants experienced between work and their other occupations or commitments. One participant described her struggle to home school her own school going children while working and keeping her house clean:

"[I] had to home-school my own two children at home, staying up to date and dealing with their emotions (and my own). Especially during the time when our cleaning lady could not come..." **(08FPaPr)**

The participants described the consequences of the imbalance between work and other commitments as an increase in stress and anxiety:

"Stress and anxiety levels have definitely increased as we are no longer able to follow a routine we are used to. It feels currently like I am leading a very unbalanced lifestyle as I am unable to engage in activities that use to help me to manage my stress levels." **(02MLpPu)**

The positive impact on occupational wellness experienced by participants include a participant who described herself as more compassionate and committed to clients. Others mentioned that they could adapt within their role as occupational therapist. They felt that their ability to show resilience had made this a rewarding time.

Physical wellness is "particularly relevant where cardiovascular fitness, flexibility, and strength are concerned. Actions to improve physical wellness include maintaining a healthy exercise regime and diet and monitoring internal and external physical signs of the body's response to events, including stress"[1:5].

Several participants indicated the negative impact of the pandemic on their physical wellness including not sleeping well, leading to exhaustion. However, participants described how they addressed this by paying better attention to their routines, sleeping enough, eating well and exercising.

"What really helped a lot when we could go hiking again, to get out of the house, and be active, and get some vitamin D and fresh air..." **(08FPaPr)**

It was also reported that participants found that therapists experienced less physical illness in that they did not contract regular flu due to the infection protection measures.

"Due to new health regulations (like regular handwashing, mask-wearing, social distancing etc.) the therapists are overall healthier. In previous years, colds and flu were highly prevalent during April-July months. Thus far, no therapist has contracted the flu or a cold this year." **(10MApPr)**

Economic wellness has been defined as containing several components. These include (among others) financial stability, financial security, financial control and financial autonomy [26]. Moreover, it comprises the ability of individuals to consistently meet their basic needs (including food, housing, utilities etc.), and have control over their day-to-day finances. In addition to this, it encompasses the ability to make economic choices and feel a sense of satisfaction and personal fulfilment with one's finances.

Participants noted that it was costing them more money to offer therapy due to the costs associated with PPE and infection protection control protocols while they were able to reach less clients. Many also noted that they were seeing a reduced number of clients which resulted in a reduction in income.

"It's costing more money, time and other resources to offer therapy yet we are reaching less clients and in the process we are becoming both physically and mentally drained" **(06FApPr)**

Social wellness includes the "interaction of the individual with others, the community, and nature" [1:6]. Participants commented that they struggled with isolation and that they initially found it difficult to interact while wearing masks. Although the limitations of the virtual environment were highlighted, several participants mentioned the value of online support from colleagues and professional organisations. It was also discussed that workplace teams bonded as all shared common concerns, and a sense of universality emerged.

"We got closer as an MDT [multi disciplinary team] - we all shared the same concerns, helped out where we could, and forgot about old baggage and issues" **(15FPhPr)**

Spiritual wellness encompasses "purpose and meaning in life; the self in relation to others, the community, nature, the universe, and some higher power"1:6. Furthermore, it refers to an inner resource that may give someone a feeling of strength and may lead to finding significance in their life. Two of the participants described a feeling of loss of purpose in life.

"One of the major stumbling blocks for me was the feeling of a loss of purpose, I couldn't do what I love and [what I] feel makes a difference." **(12FSbPu)**

"I have had the feeling of lack of purpose and boredom, due to the reduced numbers of therapy clients and lack of contact." **(13FPaPr)**

Participants attempted to remedy this by adopting practices such as journaling, meditation, prayer and mindfulness. Virtual mindfulness groups amongst work teams were also used as a vehicle to facilitate spiritual wellness. Additionally, expressing gratitude daily for that which participants can be thankful for, facilitated spiritual wellness.

"I believe that my faith trumps my fears and that's how my days are conquered." **(05FDhPu)**

DISCUSSION

From the data, one can appreciate that the first wave of COVID-19 had a pervasive influence on the wellness of the participants in this study. The data illustrates that participants

were affected in terms of their emotional, environmental, intellectual, occupational, physical, economic, social and spiritual wellness. The pandemic's toll on HPs' emotional, occupational and physical wellness aligns with international data [5,6,9,27]. Interestingly, participants framed their experiences not only as negative, but also highlighted the positive impact of the pandemic on their wellness. The occupational therapists demonstrated resilience and they overcame many of the unexpected challenges.

The essence of occupational therapy theory and training appeared to facilitate adaptation and resilience in the occupational therapists' own lives. A similar finding was reported by Tse et al[28] where Australian occupational therapists also experienced that their own coping with COVID-19 restrictions was directed by their theoretical approach to adaptation. Participants were able to identify the threats to wellness that they were experiencing and could implement strategies to overcome these. This reflects occupational therapists' focus on facilitating occupational balance[29], not only in the lives of their clients, but also in their own lives. Obtaining balance has been described as one of the best ways for HPs to practice self-care[30].

Participants did not mention any unfamiliar or novel strategies to facilitate wellness conceptualised specifically during COVID-19. Rather, occupational therapists focussed on implementing familiar strategies (such as meditation, establishing healthy routines etc.) that they would typically encourage clients to use, in their own lives. The practice of mindfulness is one such strategy that has been shown to have a mediating effect on the wellbeing of HPs[31]. A reduction in stress levels and increased self-reported mental health have been reported post mindfulness intervention[32]. It has been suggested that healthcare organisations introduce mindfulness practices at places of employment to encourage HPs to utilise this strategy[33]. Journaling has been described as a beneficial tool to facilitate reflection in HPs. Osteneck[34] describes journaling as serving several purposes, including documenting personal accounts, as well as a meditative tool for connecting with the inner self. Use of journals may be one way to facilitate awareness of difficulties experienced in balancing all aspects of life.

In facilitating their own physical wellness, participants described venturing outdoors. This practice is supported by literature that indicates that greenery supports mental health[35–37]. Furthermore, exercise is widely recognised as a strategy to facilitate wellness and has been highlighted during the COVID-19 pandemic[38,39]. Ensuring that one gets enough sleep and maintaining a healthy diet are vital strategies to ensure wellness. These strategies have been supported by literature highlighting the importance of maintaining a healthy lifestyle during COVID-19 [40,41]. Aspects related to exercise and nutrition have been identified as important starting points for intervention[42] when HPs experience signs of exhaustion, as supported by participants in this study.

In terms of occupational wellness, participants expressed the benefits of workplaces facilitating cohesion among HPs during highly stressful times to combat risks to occupational wellness. Establishing a positive and supportive workplace culture is required[7] to ensure that HPs are adequately supported. The issue pertaining to the inclusion of occupational therapy as part of essential services should be addressed[14] to provide occupational therapists with confirmation of the importance of the services that they provide.

Implications

Attending to their own mental health is an ethical obligation[43] of HPs. This is essential, as HPs are aware that with diminished wellness, they may offer their clients less than optimal care. Therefore, occupational therapy practitioners should ensure that they do all within their ability to ensure their own wellness. With their focus on facilitating occupational balance, occupational therapists should utilise familiar strategies to facilitate their own wellness, during future highly stressful times, such as during future pandemics or states of emergency.

Due to their focus on facilitating wellness during intervention with clients, occupational therapists may be excellently positioned to facilitate the fostering of wellness of other HPs in the professional team. Online wellness/resilience programmes [44,45] may be a novel way of facilitating resilience and improving wellness – particularly when infection control measures are in place.

Limitations

The findings of this study cannot be generalised. Although the State of Emergency in South Africa was only lifted in 2022, the data reported here were collected during June 2020. Therefore, the potential long-term implication of the COVID-19 pandemic on the wellness of occupational therapists in South Africa is not reflected by the data.

CONCLUSION

The results of this study are relevant to the practice of occupational therapy in that it illustrates the strength of occupational therapists to firstly, become aware of challenges and secondly, to address challenges to their own wellness. Although COVID-19 was experienced as a stressor impacting negatively on the wellness of South African occupational therapists, the participants demonstrated their skill in facilitating occupational balance in their lives in order to promote their own wellness. This skill of cultivating balance in life may be utilised by the larger HP community to foster wellness in a highly stressful sector.

Acknowledgement

The authors would like to extend our sincerest gratitude to all the participants for their insightful, valuable and in-depth contributions made towards this study.

Author contributions

Kitty Uys and Daleen Casteleijn were responsible for the study design. Data collection was performed by Karin van Niekerk and Daleen Casteleijn. Data analysis and interpretation was performed by Karin van Niekerk, Raashmi Balbadur and Jenna D' Oliviera.

The manuscript was drafted by Karin van Niekerk, Raashmi Balbadur, Jenna D'Oliviera, Daleen Casteleijn and Henry Msimango. The manuscript was edited by Raashmi Balbadur, Karin van Niekerk and Kitty Uys. The submission and references were finalised by Karin van Niekerk. Funding was obtained by Kitty Uys.

Conflicts of interest and bias declaration

The researchers declare no conflicts of interest. The views expressed in the article are the authors' own and not an official position of the University of Pretoria.

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RESEARCH ARTICLE

Cross-cultural adaptation of the administration instructions of the Developmental Test of Visual Perception (3rd Edition) for isiZulu-speaking children

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KEYWORDS

authentic assessment practice, functional equivalence, cultural equivalence, conceptual equivalence, linguistic translation, cross-cultural adaptations, assessment instrument

HOW TO CITE THIS ARTICLE

Naude S, Bekker BM, Uys CJE. *Cross-cultural adaptation of the administration instructions of the Developmental Test of Visual Perception (3rd Edition) for isiZulu-speaking children.* South African Journal of Occupational Therapy. Vol. 53 No 3. December 2023.
DOI: https://doi.org/10.17159/2310-3833/2023/vol53n3a7

ARTICLE HISTORY

Submitted: 21 June 2022
Reviewed: 17 December 2022
Revised: 21 July 2023
Accepted: 25 July 2023

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DATA AVAILABILITY

From the corresponding author

FUNDING

The authors have received no funding for this research.

ISSN On-line 2310-3833

ABSTRACT

Introduction: Visual perceptual skills are vital for developing academic skills and contribute to language development and socio-cultural participation. The Developmental Test of Visual Perception 3rd Edition evaluates visual perceptual skills but is only available in English. IsiZulu is the most spoken language in South Africa (24,4%), with English being the fourth. Therefore, the English version of the Developmental Test of Visual Perception 3rd Edition cannot be described as a universally authentic assessment instrument in this context.

Methodology: This study aimed to translate and cross-culturally adapt the Developmental Test of Visual Perception 3rd Edition administration instructions into isiZulu using a five-stage qualitatively driven multimethod sequential design. Qualitative feedback on the functional, cultural and conceptual equivalence was obtained at various intervals.

Results: This study demonstrated a methodology for translating and cross-culturally adapting the administration instructions of the Developmental Test of Visual Perception 3rd Edition into isiZulu to advance the authenticity of the assessment within the South African context. The isiZulu version was found to be functionally, culturally and conceptually equivalent.

Conclusions: This research has demonstrated a framework upon which the cross-cultural adaptations of other assessment instruments and other languages in South Africa can be based.

Implications for practice

- The rigorous methodology demonstrated in this research can be used as a framework to guide other studies in the translation and cross-cultural adaptation of other assessment instruments and into other languages.
- This study demonstrated that multiple contributors from various backgrounds are necessary to ensure equivalence during the process of translation and cross-cultural adaptation. However, an emphasis is placed on the value of including occupational therapists with clinical experience when translating and cross-culturally adapting assessment instruments intended to be used within the field of occupational therapy.
- Through the rigorous method used to translate and cross-cultural adapt the DTVP-3, this study enhanced its authenticity as an assessment instrument within the South African context. Having isiZulu administration instructions available could provide equal opportunity to children who may not be as proficient in English as in isiZulu.
- Once a distribution agreement has been reached with ProEd Inc., the original publisher and licence holder, the isiZulu administration instructions of the DTVP-3 will be made available for use in South Africa with isiZulu-speaking children.

INTRODUCTION AND LITERATURE REVIEW

This article presents the rigorous method used to translate and cross-culturally adapt the Developmental Test of Visual Perception Third Edition (DTVP-3) administration instructions into isiZulu while maintaining its functional, cultural and conceptual equivalence. This cross-cultural adaptation was done in advocacy for improved authentic assessment practices in evaluating visual perceptual skills among isiZulu-speaking children in South Africa.

Visual Perception

Schneck defines visual perception as the process incorporating the reception and cognition of stimuli perceived by the visual system[1]. The components of visual perception are essential for the processing and interpreting of information gained through the visual system. Therefore, it constitutes the ability to derive functional meaning from the visual world[1,2]. Visual-motor functions and visual perception support a child's ability to engage in meaningful educational occupations such as reading, writing and other school-related tasks[3,4]. Visual perceptual development has also been linked to developing functional skills such as attention, social interaction and motor development in childhood[5].

The evaluation of visual perceptual skills and how they impact occupational engagement falls within the scope of occupational therapy intervention[3]. The American Occupational Therapy Association outlines the occupational therapy process as consisting of evaluation, intervention and targeting intervention outcomes within the client's functional context[3]. Therefore, it is imperative that occupational therapists have authentic assessment instruments to accurately evaluate skills and subskills to identify deficiencies and inform efficient intervention and effectively target outcomes[1,3]. Many of the characteristics of authentic assessment, such as evaluating occupational performance within appropriate contexts and taking into account the impact of the environment on occupational functioning, is well established within the profession of occupational therapy[3,6].

Authentic Assessment

Authentic assessment is an alternative to traditional evaluation procedures and was born within the context of early childhood intervention (ECI)[7]. It advocates for using developmentally appropriate evaluation methods within an environment that emulates the functional setting within which the child would naturally perform the skills under investigation[8]. Conventional testing is argued to introduce limits in terms of content, procedures, process and evidence, which may lead to mismeasurement of a child's abilities in an unnatural context and deny their rights to beneficial expectations and opportunities[8-11]. Such mismeasurement misrepresents the child and instead of highlighting competence within uniqueness, may over-emphasize the child's limitations[8,10,11]. Bagnato et al. have emphasized eight major standards for developmentally appropriate and authentic assessment instruments and procedures based on over 25 years of collaborative documents compiled by many major national professional organizations[8]. These standards are acceptability, authenticity, collaboration, evidence, multi factors, sensitivity, universality and utility.

Each standard can be described using quality indicators which highlight aspects important for ensuring that the standards are upheld. These standards can be considered an ideal for which ECI assessment instruments and occupational therapy assessment practices should strive. This study has focused on specific quality indicators that fall under the standards of acceptability, evidence, universality and utility. These quality indicators are social appropriateness, diversity representation, equitable design, intervention content and performance monitoring. When applied to the DTVP-3, these quality indicators are enhanced through translation and cross-cultural adaptation as shown in Table I (below)

Table I: The enhancement of the DTVP-3 as applied to the standards for authentic assessment9

		Quality Indicator	*Translation and Cross-Cultural Adaptation of the DTVP-3*
Standards for authentic assessment	Acceptability	Social appropriateness	By translating and cross-culturally adapting the DTVP-3, its social appropriateness within the South African context is improved. In doing so, it can be presented in a manner more acceptable to isiZulu-speaking children, parents and other caregivers, namely in their native language.
	Evidence	Diversity representation	Although this study did not include large-scale reliability and validity testing of the translated instructions, it can be seen as a first step toward building a body of literature that encourages even greater diversity in the population for which the DTVP-3 is tailored.
	Universality	Equitable design	By translating and cross-culturally adapting the DTVP-3, the population of children who are provided equal opportunity to demonstrate skill through this assessment instrument in South Africa is broadened.
	Utility	Intervention content	Translation of the DTVP-3 intends to remove the unnecessary language barrier that isiZulu-speaking children could experience when being assessed with the current version of the DTVP-3, which will lead to more accurate results and more precisely inform the content of the occupational therapy intervention plan.
	Utility	Performance monitoring	As the authenticity of the DTVP-3 within the South African context is improved through its translation and cross-cultural adaptation, it becomes even more valuable in monitoring the isiZulu-speaking child's response to intervention.

The Developmental Test of Visual Perception

The DTVP was one of the first visual perceptual tests to be developed based on statistically established norms[8]. It has gained popularity since the second edition was released[8]. The third and latest edition (the DTVP-3) is widely used by occupational therapists to evaluate visual perceptual skills.

The DTVP-3 consists of five subtests evaluating eye-hand coordination, copying, figure-ground, visual closure and form constancy[12]. It can be administered to inform intervention strategies and measure the effectiveness of an intervention[12]. This link between the assessment instrument and the therapeutic outcomes is a characteristic of authentic assessment practices[13].

The majority of the children seen by occupational therapists have already been identified as a potentially compromised population before obstacles to their occupational engagement could be further compounded by language barriers. In previous studies, the administration of the DTVP within the South African context was consistently conducted in English, except for one study, which did not elaborate on the method used to translate it into Afrikaans[14]. However, according to the 2022 census, the most represented first-spoken languages in the South African

population were isiZulu (24,4%), isiXhosa (16,3%), Afrikaans (10,6%) and English (8,7%)[15]. The most represented first-spoken language in the province of Gauteng in 2022 was also isiZulu (23.1%)[15]. Hence, a significant representation of children evaluated using the DTVP-3 do not have access to it in their home language. Therefore, it cannot be considered an authentic assessment instrument for these children[8,16].

Translation

Direct or linguistic translation of assessment instruments has been utilized in various contexts. A method of linguistic translation is crowdsourcing the translation through online open translation tools. However, one study experienced difficulties in quality assurance of the translation and establishing its suitability for different contexts[17]. In another study, Guo investigated the viability of using a machine translator, such as Google Translate, but found various challenges and shortfalls rendering this method insufficient when used in isolation[18]. Another method is reflected in a published case study by Jones et al[19]. While translating elements of the ABA intervention programme from English to Welsh, Jones et al. found it necessary to establish new terminology for key concepts[19]. Methods they used to devise new terminology included adaptation (allowing old words to gain new meaning), derivation and neologisms[19]. As part of this case study, it was also experienced that direct translation by professional translators tended to be inadequate in maintaining grammatical fluency. The technically correct translations also failed to capture the intent of the original text[19].

Many authors have stressed that mere linguistic translation is insufficient to modify an assessment instrument for use with a different population group[20-27]. Instead, an instrument must be cross-culturally adapted to ensure equivalence and avoid potential sources of bias[20-22,28]. Peña emphasizes that merely meeting the requirements of equivalence is insufficient for an instrument to be cross-culturally adapted. It must also meet the requirements of functional, cultural and metric equivalence[22].

Linguistic equivalence can be facilitated through the backward translation method of translating from the source language to the target language, followed by back-translation from the target language back to the source language by a translator unfamiliar with the original text. Then the original text and back-translated text are compared for discrepancies and consolidated[22]. Another method to ensure linguistic equivalence is through review by a native speaker of the target language[22].

Functional equivalence ensures that the same response or behaviour will be elicited in the target language as was intended in the source language[29]. One of two methods is often employed to facilitate functional equivalence[22].One method is decentring, whereby wording in the target language may shift away from the original wording to prioritize linguistic familiarity[22,30]. Another method is adopting a dual focus in which the instrument is developed in both languages simultaneously[22].

Cultural equivalence emphasizes the degree to which different cultural and linguistic groups interpret and respond to the perceived meaning conveyed by the instrument items[22,28].Cultural equivalence is closely related to functional equivalence[22]. **Conceptual** (or metric) **equivalence** is an evaluation of whether the difficulty of an item is comparable in both the source and target languages by taking into account the frequency with which it occurs in that languag . According to Pena, using parallel vocabulary measures, which focus on word frequency comparisons between the source and target languages, may encourage metric equivalence during translation[22].

It is clear that instruments used cross-culturally need to b equivalent on many levels to provide an equal opportunity to demonstrate skill[22,24,31]. Many authors reiterate that a translation should meet the basic standards set for all measures in that it must be reliable, valid, legal, and cost-effective, as well as meet the requirements for equivalence beyond mere linguistic translation[20,22-25,27,28,31,32].

Various methods of cross-cultural adaptation have been recommended throughout literature[20,21,23-25,27,32,26]. Sousa and Rojjanasrirat have suggested a method for translation based on their review of methodological studies, focusing on the cross-cultural adaptation of instruments and scales within the context of health care research[20]. This method is based on seminal work by Guillemin, Bombardier and Beaton[20,33,36]. They recommend the following steps as a guideline:

Step 1: Translation of the original assessment instrument into the target language (forward translation) by at least two independent translators[20,24,25,2728,35]. These translators produce the target language translations one (TL1) and two (TL2) respectively. The translators should have the target language (TL) their mother language and have experience in the culture and colloquialisms of the TL[20].

Step 2: Comparison of TL1 and TL2 by a third bilingual, bicultural independent translator and a committee approach to resolving any discrepancies[20,36]. The committee consists of the two initial translators, the third independent translator and the researcher[20]. This committee reaches an agreement to produce the preliminary, initial translated version (P1-TL)[20,27].

Step 3: Blind, backward translation of the P1-TL back to the original language (SL) by two other independent translators[20,35,36]. The mother language of the translators involved in this step should be the SL. However, they should be fluent in both the SL and the TL[20]. It is essential that the translators involved in the back-translation not be familiar with the original assessment instrument to avoid previous exposure from influencing the back-translation, thereby ensuring a blind back-translation[20,24]. They will produce two backward translated versions (B-TL1 and B-TL2)[20].

Step 4: A multidisciplinary committee compares B-TL1 and B-TL2 to the SL[20,35]. This committee should consist of the researcher, all four translators involved in steps 1 and 3, a healthcare worker familiar with the original assessment instrument and at least one monolingual person whose mother language is the TL[20]. This committee then resolves any ambiguities or discrepancies between the SL, B0TL1 and B-TL2 to produce the pre-final version in the target language (P-FTL)[20].

Step 5: Pre-test the P-FTL among participants whose language is the target language[20,21,24,25]. These participants whould be representative of the target population for which the translation is intended, and the use of a dichotomous scale (clear or unclear), is recommented[20]. Table II (page 57) summarizes the multiple translation versions and their respective abbreviations.

Table II: Translation versions and abbreviations

Abbreviation	*Version*
SL	Source language / Original language
TL	Target language / Target language translation (Forward translation)
PI-TL	Preliminary initial version in the target language
B-TL	Backward translation
P-FTL	Pre-final target language translation

It is clear from the literature that cross-cultural translation of an assessment instrument requires a systematic and methodological approach for equivalence to be maintained[20,22,24,28]. Receiving administration instructions in a language other than the child's first language could have a detrimental effect on the child's opportunity for equal performance and does not align with the standards of authentic assessment[22,24]. Placing a child in such a situation could lead to mismeasurement and misrepresentation of the child's abilities[8]. Since isiZulu is the most represented spoken language in South Africa; there is a significant need for cross-cultural adaptation of the administration instructions of the DTVP-3 to isiZulu. This article reports on the rigorous process necessary to translate and cross-culturally adapt the administration instructions of the DTVP-3 into isiZulu.

METHODOLOGY

This study aimed to cross-culturally adapt the instructions of the DTVP-3 using a combination of the methods suggested in literature; as well as examining the functional, cultural and conceptual equivalence after translation into isiZulu to improve the authenticity of the DTVP-3 as an assessment instrument within the South African context[8,20,22,28]. The study's objectives were as follows: *Objective 1:* To translate the administration instructions of the DTVP-3 into isiZulu linguistically[22]. *Objective 2:* To examine whether the isiZulu translation represents a cross-cultural adaptation which satisfies the standard for ensuring functional[22], cultural[22], and conceptual[20] equivalence. *Objective 3:* To conduct a pre-test study to provide preliminary feedback on whether the adaptation is comprehensible for the isiZulu-speaking child in the Tshwane (Gauteng Province, South Africa) area. This qualitatively driven multimethod sequential study followed the ethical principles of human research and received approval from the Faculty of Health Sciences Research Ethics Committee (Ethics Approval: 459/2020)[37]. Figure 1 (page 58) presents the five stages of the design and is based on work by Guillemin et al., Sousa et al., Wang et al., and Beaton et al[20,21,24,28]. Each stage implements one or more of the research objectives. Therefore, the study design has been described in reference to the objectives.

Objective 1: To translate the administration instructions of the DTVP-3 into isiZulu linguistically

Stage I: Forward Translation: The original version was linguistically translated from the source language (SL), English, into the target language (TL), isiZulu, using three independent translators. Translator 1 was a native isiZulu-speaking occupational therapist trained in the administration of the DTVP-3. Translator 2 was a bilingual isiZulu-speaking layperson unfamiliar with the DVTP-3 but familiar with colloquialisms, slang and contextual interpretations of the target language. Translator 3 was a bilingual and bicultural third party trained in teaching languages to children. Translators 1, 2 and 3 produced target language translation 1 (TL1), target language translation 2 (TL2) and target language translation 3 (TL3), respectively.

Stage II: Synthesis and Agreement by Committee-1: Next, TL1, TL2 and TL3 were compared by committee-1, who discussed and resolved any discrepancies between the three translations to synthesize the preliminary initial translated version in the target language (PI-TL). Committee-1 consisted of translator 1, translator 2, translator 3 and the researcher.

Stage III: Blind Back-Translation: During stage III, the PI-TL was translated back into the SL by two other independent translators. Translator 4 was a healthcare professional unfamiliar with the DTVP-3. Translator 5 was a bilingual and bicultural layperson. Translators 4 and 5 produced back-translation 1 (BT1) and back-translation 2 (BT2), respectively. Both back-translators were unfamiliar with the original assessment instrument to preclude previous exposure to the original SL administration instructions from influencing the backward translation.

Objective 2: To examine whether the isiZulu translation represents a cross-cultural adaptation which satisfies the standard for ensuring functional, cultural, and conceptual equivalence.

Stage IV: Synthesis and Agreement by Committee-2: At this stage, committee-2 compared the SL, PI-TL, BT1 and BT2 versions. The committee discussed and resolved discrepancies to synthesize the pre-final version in the target language (P-FTL). Committee-2 consisted of translator 1 (TL1 translator), translator 2 (TL2 translator), translator 3 (TL3 translator), translator 4 (BT1 translator), translator 5 (BT2 translator), the researcher, and an independent isiZulu-speaking third party. This independent third party was a native isiZulu-speaking professional trained in administering the original assessment instrument. By including a native isiZulu speaker who was also a trained professional, the quality of the P-FTL was enhanced. This third party contributed relevant clinical experience in administering the assessment instrument with isiZulu-speaking children.

Following the conclusion of stage IV, the committee-2 discourse was analysed for themes of functional, cultural and conceptual equivalence. This analysis was verified by an external rater through a random sampling of 42%.

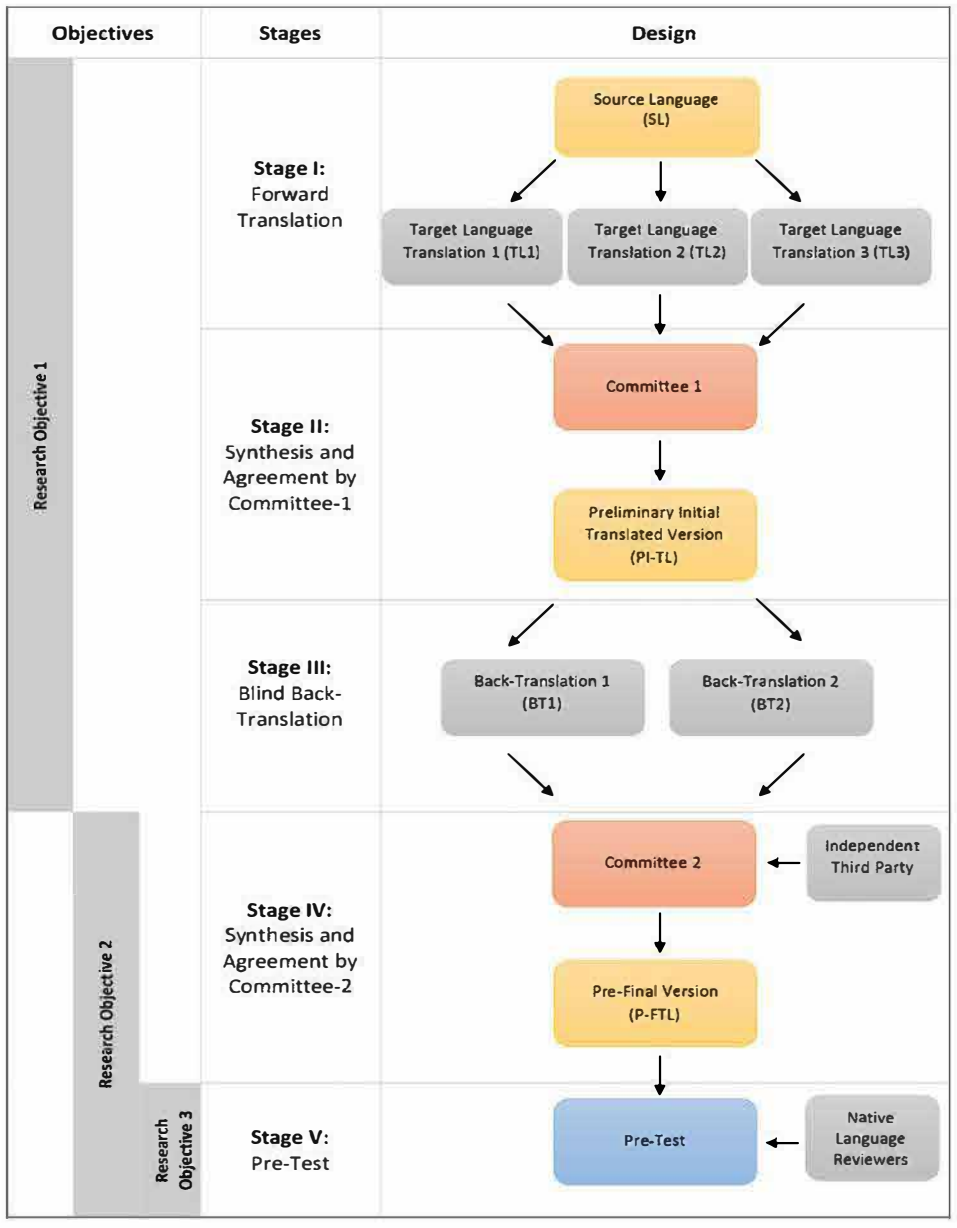

Figure 1: Study design based on works by Guillemin et al., Beaton et al., Sousa et al., and Wang et al[21, 22, 25, 29].

Objectives 2&3:To conduct a pre-test study to provide preliminary feedback on whether the adaptation is comprehensible for the isiZulu-speaking child in the Tshwane (Gauteng Province, South Africa) area

Stage V: Pre-test: During the pre-test stage, the newly translated and adapted isiZulu version of the administration instructions was used by isiZulu-speaking occupational therapists to administer the DTVP-3 to isiZulu-speaking children. The administering therapists first attended a virtual refresher on the administration procedures and received the isiZulu administration instructions on identical cue cards. These measures were undertaken to minimise administrator variability.

After each administration, the child provided qualitative descriptive feedback regarding his/her experience using a feedback questionnaire. The administering therapist assisted each child in recording his/her response to the questionnaire.Each participating occupational therapist also provided feedback on the functional, cultural and conceptual equivalence of the isiZulu administration instructions by completing an equivalence feedback questionnaire (adapted from Hambleton and Zenisky's Translation and Adaptation Review Form)[31,32]. The questions of the equivalence feedback form were analysed for themes of functional, cultural and conceptual equivalence.

As part of stage V, two native language reviewers also provided feedback on the equivalence of the isiZulu translation through the equivalence feedback questionnaire[22]. The two native isiZulu speakers were occupational therapists with experience in administering the DTVP-3 who had not been involved in stages I to IV.

Population

During stages I to IV, the target population consisted of professionals and laypersons fluent in isiZulu based in KwaZulu-Natal Province, Free State Province, North West Province and Gauteng Province, South Africa. The stage V pre-test represented three population groups. The first target population for stage V was isiZulu-speaking children between the ages of seven years two months and ten years seven months attending primary schools in Tshwane, Gauteng Province, South Africa. The second population of stage V was isiZulu-speaking administering therapists. These were occupational therapists practising in Tshwane, Gauteng, South Africa. The therapists were not known to the children prior to the study. The third population of stage V was native language reviewers based in KwaZulu-Natal Province, South Africa.

Sampling method and sample size

The stages I to IV participants were recruited using purposive snowball sampling from the researcher's and supervisors' network of professional acquaintances and colleagues. Translators 1 to 5 and the independent third party were recruited to meet specific criteria as shown in Table III (page 59)

The stage V administering therapists and native language reviewers were recruited using purposive snowball sampling through acquaintances, colleagues, fellow postgraduate students, and school-based occupational therapists' professional networks. It should be noted that stage V represents a pre-test (not a pilot study); therefore, a small sample size was used to gain initial feedback from the target population before a pilot study is conducted[20].The second target population of stage V was children from primary schools in the vicinity of the administering occupational therapists. The sample of children was recruited by contacting local schools. After permission from the Gauteng Department of Education (GDE) and the principals of each primary school was obtained, information was made available to the parents. This information explained the details of the study and invited their children to participate voluntarily. The third population of stage V was the native language reviewers, who were recruited using purposive snowball sampling of acquaintances, colleagues, fellow postgraduate students, and school-based occupational therapists' professional network.

Data Collection and Analysis

The data collected in stage I (TL1, TL2 and TL3) was tabulated and underwent a content comparison. Discrepancies between the versions were noted for discussion in stage II by committee-1.

The discrepancies and agreements reached by the committee-1 members were detailed and tabulated, as demonstrated by Pasin et al[38]. The data collected during stage III (BT1 and BT2) were combined in table form and underwent a content comparison with the SL. Discrepancies between the versions were noted for discussion by committee-2, who compared the original SL, PI-TL, BL1 and BL2. The discussion points of committee-2 were recorded, and the researcher noted whether they related to functional, cultural and conceptual equivalence. A random sample (42%) of the recording and observations regarding equivalence made was verified by an external rater.

The data collected from stage V also underwent content analysis. The responses to the child feedback questionnaire (completed by the isiZulu-speaking children) and equivalence feedback questionnaire (completed by the administering therapists and native language reviewers) were summarized as recommended by the ITC Guidelines for Test Translation and Adaptation[32].

Table III: Sampling method, size and criteria

	Sample	Criteria
Stage I - II	Translator 1 (n=1)	*Inclusion*: ➢ First language isiZulu ➢ Bilingual and bicultural ➢ Healthcare professional familiar with the DTVP-3
	Translator 2 (n=1)	*Inclusion*: ➢ First language isiZulu ➢ Bilingual and bicultural ➢ Familiar with colloquialisms, slang and contextual interpretations of the target language (isiZulu)
	Translator 3 (n=1)	*Inclusion*: ➢ Bilingual ➢ Bicultural
Stage III-IV	Translator 4 (n=1)	*Inclusion*: ➢ First language English ➢ Bilingual and bicultural ➢ Healthcare professional unfamiliar with the English DTVP-3 administration instructions
	Translator 5 (n=1)	*Inclusion*: ➢ First language English ➢ Bilingual and bicultural ➢ Familiar with colloquialisms, slang and contextual interpretations of the source language (English)
	Independent third party (n=1)	*Inclusion*: ➢ First language isiZulu ➢ Not previously involved in stages I to IV
Stage V	Administering therapists (n=3)	*Inclusion*: ➢ Qualified occupational therapist holding current registration with the Health Professions Council of South Africa. ➢ Self-professed fluency in reading, speaking and understanding isiZulu. ➢ Currently practising within the field of paediatrics, with at least one year of postgraduate experience in regular use of the DTVP-3 in clinical practice. *Exclusion*: ➢ Therapists who participated during the Stage I-IV translation of the instructions. ➢ Therapists unable to attend the refresher and briefing session.
	Children (n=10)	*Inclusion*: ➢ Children between the ages of 7 years 0 months and 12 years 11 months. ➢ Children fluent in isiZulu, isiZulu being the first language of one or both parents/guardians. ➢ Children located in Tshwane, Gauteng, South Africa during data collection. *Exclusion*: ➢ Children assessed by an occupational therapist within the past six months.
	Native language reviewers	*Inclusion*: ➢ First language isiZulu ➢ Experience in administering the DTVP-3 ➢ Not otherwise involved in stages I to V

RESULTS

Stages I - IV

This study proceeded through five rigorous stages of translation and cross-cultural adaptation. Table IV (page 59) describes the demographics of the participants in stages I to IV. As shown in this table, the participants represented various locations in the provinces of KwaZulu-Natal, Free State, North West and Gauteng, contributing a variety of vernaculars which broadened the translation beyond the dialect of a single province.

Table IV: Participant population description of stages I to IV

Participant	*Contribution*	*Stage*	*Location*	*Occupation*
Translator 1	TL1 Committee-1 and -2	Stages I, II, III and IV	KwaZulu-Natal Province, South Africa	Occupational therapist
Translator 2	TL2 Committee-1 and -2	Stages I, II, III and IV	Free State Province, South Africa	Language teacher in the private sector formerly affiliated with the African Language Institute
Translator 3	TL3 Committee-1 and -2	Stages I, II, III and IV	North West Province, South Africa	Language teacher in the primary education sector
Translator 4	BT1 Committee-2	Stages III and IV	KwaZulu-Natal Province, South Africa	Speech therapy student
Translator 5	BT2 Committee-2	Stages III and IV	KwaZulu-Natal Province, South Africa	Administration officer
Independent Third Party	Committee-2	Stage IV	KwaZulu-Natal Province, South Africa	Occupational therapist

As part of stage I, the translators completed the forward translation of the DTVP-3 administration instructions to produce the three isiZulu versions (TL1, TL2 and TL3). Google Translate, and the researcher's basic familiarity with elementary isiZulu, were used to prepare the comparison of SL, TL1, TL2 and TL3 by numbering the corresponding sentences. This numbering was done to ease the comparison of translated versions and facilitate verbal referencing of specific sentences during stage II.

The stage II committee-1 meeting took place on a virtual platform. The members of committee-1 were translator 1, translator 2, translator 3 and the researcher. During this committee, the members compared TL1, TL2 and TL3. They collaborated to adapt or correct discrepancies between the translations, reaching an agreement on the version that would become PI-TL. The administration instructions consisted of 46 numbered sentences, each discussed individually by committee-1.

Committee-1 collaborated to alter or combine TL1, TL2 and TL3 in 61% of the sentences. In 4% of the sentences, either TL2 or TL3 were agreed upon as the PI-TL without alteration. In 35% of the sentences, TL1 was agreed upon by all members as the PI-TL without alteration. These unaltered sentences from TL1 were judged as the most appropriate and easily understandable wording. TL1 appeared to consist of shorter, more concise sentences.

This numbering was done to ease the comparison of translated versions and facilitate verbal referencing of specific sentences during stage II.

The stage II committee-1 meeting took place on a virtual platform. The members of committee-1 were translator 1, translator 2, translator 3 and the researcher. During this committee, the members compared TL1, TL2 and TL3. They collaborated to adapt or correct discrepancies between the translations, reaching an agreement on the version that would become PI-TL. The administration instructions consisted of 46 numbered sentences, each discussed individually by committee-1. Committee-1 collaborated to alter or combine TL1, TL2 and TL3 in 61% of the sentences. In 4% of the sentences, either TL2 or TL3 were agreed upon as the PI-TL without alteration. In 35% of the sentences, TL1 was agreed upon by all members as the PI-TL without alteration. These unaltered sentences from TL1 were judged as the most appropriate and easily understandable wording. TL1 appeared to consist of shorter, more concise sentences. Since the occupational therapist produced TL1, it could be argued that experience in working with the target audience (namely young children) and relevant experience in administering the DTVP-3 was a significant asset during the translation process.

During stage III, translators 4 (BT1) and 5 (BT2) blind back-translated the PI-TL from isiZulu into English. Translator 4 and translator 5 were specially selected to have no prior familiarity with the SL. The majority (74%) of the 46 sentences revealed no discrepancy between the SL, BT1 and BT2. Therefore, most sentences were accurately translated during stages I and II. Of the 46 sentences, 26% (n=12) revealed some discrepancies.

The stage IV committee-2 meeting was conducted virtually where the members compared the SL, PI-TL, BT1 and BT2, deliberated on the discrepancies and reached an agreement to produce the P-FTL. The members of committee-2 were translator 1, translator 2, translator 3, translator 4, translator 5, an independent third party and the researcher. T

Table V (page 60) shows an analysis of the discourse during committee-2. Committee-2 judged PI-TL as the most accurate version in 33% of the sentences with discrepancies. In these instances, PI-TL was accepted as the P-FTL without alteration. Of the sentences which contained discrepancies, 67% were discussed by the committee-2 members who collaborated and produced P-FTL while considering various factors of equivalence (i.e. functional, cultural and conceptual equivalence). The equivalences described in Table V were not mutually exclusive, and some sentences enjoyed consideration of multiple sub-characteristics.

When considering the 12 sentences which revealed discrepancies, cultural equivalence was the main discussion point for 42% of the 12 sentences. An example of a sentence considering cultural equivalence is sentence number 9: "See the dog? You are going to draw a line from the dog to this bone over here." During the committee-2 discussion, the members agreed that "from… to…", as it occurs in sentence number 9, is not a culturally appropriate manner of giving instructions in isiZulu. Instead, the members agreed that P-FTL should read: "*Buka inja. Dweba ulayini uyaku [sic] kwithambo* (Look at the dog. Draw a line to the bone)."

Table V: Results of stage IV

Sub-characteristic	Sentence numbers	n	% out of 12
A discrepancy existed between SL, BT1 and BT2 but committee-2 retained PI-TL without alteration.	3, 4, 6, 9	4	33%
Committee-2 collaborated to correct or produce P-FTL.	2, 13, 18, 27, 30, 32, 43, 44	8	67%
Functional equivalence considered	18, 44	2	17%
Cultural equivalence considered	2, 3, 9, 30, 32	5	42%
Conceptual equivalence considered	2, 3, 4, 30, 32, 43	6	50%

Another example of cultural equivalence occurred in sentences number 2, 7 and 9, where committee-2 chose *"dweba"* (draw) instead of *"uzodweba"* (you will draw) to remain faithful to the culturally familiar way of giving instructions. In four sentences (3, 18, 30 and 32), committee-2 concluded that appropriate pointing to the target picture is vital for ensuring cultural equivalence. The necessity for pointing is also due to the way instructions are given in isiZulu, which differs from English.

Functional equivalence was the focus of 17% of the discussion surrounding the 12 sentences with discrepancies. An example of this occurred in sentence 44: "…there may be more than one shape like the one at the top." Decentring was necessary to ensure that the instructions elicit the same response from the child. The PI-TL was not clear that the child had to look for more than one answer. However, committee-2's P-FTL version ensured the child would understand to look for multiple responses. Similar confusion was revealed in sentence 18: "The car can go around the racetrack in either direction." Initially, this sentence was mistranslated as *"Imoto ingahamba noma yikuphi.* (The car can go anywhere)", which the child could misinterpret as drawing anywhere on the page instead of within the targeted stimulus. After much deliberation, committee-2 improved on the functional equivalence to ensure that the desired response (drawing a line within the targeted stimulus) would be elicited.

Conceptual equivalence was the focus of discussion in 50% of these sentences. In the P-FTL, conceptual equivalence was obtained through words such as *"ulayini"* (used in sentences 2, 3, 7, 9, 10, 13, 14, 17 and 19) instead of *"umugqa"*. *Umugqa* is the proper isiZulu word for "line"; however, it was decided that it may not be equally familiar to young children. Similarly, the word *"ipeni"* (sentences 4, 6, 8, 15 and 19) was chosen for pencil since it was considered by committee-2 to be more familiar to a young child than the proper isiZulu word for *"pencil"*. Conceptual equivalence proved challenging in sentences number 30 and 32, which read "…which of these shapes down here are part of the drawing at the top of the page." The isiZulu word for "part of " or *"ingxenye"* ("part") was considered by the committee-2 members as unlikely to be in a young child's vocabulary. In sentences number 30 and 32, the committee agreed that with appropriate pointing by the administering therapist, ingxenye should be omitted. Similarly, sentence 43 also includes "…they may be part of a drawing", which presented the same challenge. However, in this case, decentring was required to maintain equivalence. Committee-2 agreed that *"inhlangane neminye imidwebo"* ("combined with other drawings") would be the most suitable alternative in this case.

To ensure rigour, an external rater corroborated the equivalence analysis. Out of the 12 sentences with discrepancies, a random selection of 42% was designated for verification. The randomised sentence numbers and the committee-2 meeting recording were provided to the external rater for blind verification. The results of the external rater report confirmed that the equivalences observed during the analysis were present points of discussion during the committee-2 discourse.

Stage V

The sample of participants in stage V consisted of administering therapists (n=3), native language reviewers (n=2) and isiZulu-speaking children (n=10). All the administering therapists involved in the stage V pre-test were trained occupational therapists and fluent speakers of isiZulu. Similarly, both native language reviewers who contributed to stage V were native isiZulu speakers and trained occupational therapists. Refer to Table VI (below) for the contributions, settings and professions of the administering therapists (n=3) and native language reviewers (n=2).

The sample of isiZulu-speaking children (n=10) who participated in stage V ranged from seven years two months old to ten years seven months old. All the children were located in Gauteng Province, South Africa. Nine of the ten children were attending mainstream schools and one was from a school for learners with special educational needs. Table VII (adjacent) shows the demographic representation of the isiZulu-speaking children. Assent was obtained from each child before the assessment was administered. The administering therapists then administered the DTVP-3 to the isiZulu-speaking children (n=10) using the isiZulu instructions. Following the assessment, the children verbally responded to the Child Feedback Questionnaire. The Child Feedback Questionnaire was developed for this study and consisted of three dichotomous questions relating to the children's experience of the isiZulu administration instructions. The average responses for the three questions were 9.3 out of 10 positive responses. Therefore, the majority of the responses from the isiZulu-speaking children indicated that they could understand the isiZulu administration instructions.

After administering the DTVP-3, the therapists (n=3) completed the equivalence feedback questionnaire. This questionnaire was also completed by native language reviewers (n=2), who had read through the isiZulu administration instructions. Responses to 80% of the questionnaire items indicated unanimous agreement that the translation was successfully translated and cross-culturally adapted while maintaining functional, cultural and conceptual equivalence. Responses to questionnaire items consisted of either minor rewording suggestions or variations that had already been discussed during the committee stages. Overall, all five occupational therapists (administering therapists and native language reviewers) indicated that the DTVP-3 was successfully translated and cross-culturally adapted. One of the questionnaire item responses recommended an addition that does not occur in the SL but would improve upon the practicality of administering the instrument. The suggestion was to add the phrase *"Ngikombise* [sic] *futhi* (Show me again)." Also, in response to a question regarding metaphors, idioms and colloquialisms, one participant suggested alternate wording for the visual closure subtest instructions. The suggestion is a simplified paraphrasing of the SL instructions and therefore employs a great degree of decentring. The P-FTL more accurately mirrors the SL version, but the suggested simpler version represents a more culturally appropriate manner of speaking. This suggestion should be considered when the translation is prepared for a pilot study (not included in the scope of this research).

One native language reviewer suggested a significant alteration to how subtest five is presented to the child. This recommendation was noted but not incorporated into the P-FTL since it significantly deviated in structure and length from the SL version. In the researcher's clinical opinion, this could compromise the psychometric properties of the subtest. In the comments section of the questionnaire, four of the five occupational therapists commented that the SL and P-FTL are equivalent. Native language reviewer 1 described the translated version as concise and easy to administer.

Table VI: Demographics of stage V administering therapists and native language reviewers

Participant	*Contribution*	*Stage*	*Setting*	*Profession*
Administering Therapist 1	Administered the Translated DTVP3 Completed the Equivalence Feedback Questionnaire	Stage V	Gauteng Province, South Africa	Occupational therapist
Administering Therapist 2	Administered the Translated DTVP3 Completed the Equivalence Feedback Questionnaire	Stage V	Gauteng Province, South Africa	Occupational therapist
Administering Therapist 3	Administered the Translated DTVP3 Completed the Equivalence Feedback Questionnaire	Stage V	Gauteng Province, South Africa	Occupational therapist
Native language reviewer 1	Expert review Completed the Equivalence Feedback Questionnaire	Stage V	KwaZulu-Natal Province, South Africa	Occupational therapist
Native language reviewer 2	Expert review Completed the Equivalence Feedback Questionnaire	Stage V	KwaZulu-Natal Province, South Africa	Occupational therapist

Table VII: Demographics of stage V isiZulu-speaking children

Characteristics		*n*
Gender	Male	7
	Female	3
Age	7 years old	1
	8 years old	3
	9 years old	4
	10 years old	2
Total		10

. She also emphasized that even in cases where no direct translation was possible, the meaning remained the same. Administering therapist 1 described the P-FTL version as being *"perfect"*.

DISCUSSION/IMPLICATIONS OF RESEARCH

This study demonstrated a rigorous method for translating and cross-culturally adapting an assessment instrument such as the DTVP-3 to advance the authenticity of the assessment within the South African context. To the researcher's knowledge, this is the first time this method has been applied to test administration instructions in a South African setting. The main finding of this study is that the methodology produced the pre-final isiZulu administration instructions that were revealed to be functionally, culturally and conceptually equivalent to the original version of the OTVP-3. Ther strength of the methodology is that it consisted of five stages, and included two communities with various contributors from diverse backgrounds and professions. Various successes and challenges were experienced throughout the study, providing a road map for future researchers. This study discusses these successes and challenges.

As integrated into the methodology, the committee approach proved vital to the cross-cultural adaptation of the DTVP-3 into isiZulu. From the beginning of the study, emphasis was placed on translation with the target audience in mind. Simple, developmentally appropriate language was prioritized over pure vocabulary and formal grammar. As a result, conceptual equivalence was the predominant consideration in the discourse of both committee-1 and committee-2. This emphasis on age-appropriate language was also confirmed by the responses of the two administering therapists and two native isiZulu-speaking occupational therapists. All four therapists judged the P-FTL as similar in meaning, difficulty, commonality, structure, length, familiarity and complexity (according to their responses on the Equivalence Feedback Questionnaire) and therefore equivalent. Another advantage of the translation methodology used for this study is the addition of the third translator (TL3 translator) in the stage I forward translation. This translator had experience teaching children languages, which contributed much value to the translation and the committee-1 discourse.

Various practical considerations worked well during the stage I to IV committees. Google Translate, and the researcher's basic familiarity with elementary isiZulu, were used to prepare the comparison of SL, TL1, TL2 and TL3 by numbering the corresponding sentences. This numbering was done to ease the comparison of translated versions and facilitate verbal referencing of specific sentences during the committee discussions. Stages I to IV committee meetings were conducted virtually on a well-known virtual meeting platform. Conducting the meeting on-line broadened the geographical reach of the study so that participants from other provinces could be included and also allowed for more scheduling flexibility.

It proved to be very important that all the committee members be familiar with the administration procedure of the DTVP-3 in order to apply the translation to the context. The translators were initially provided with examples of the subtests, but some confusion remained regarding whether the children would have to read the instructions themselves. It was explained that the instructions would be given verbally by a therapist trained in the DTVP-3. This understanding of the context and administration procedure influenced both committees' discourse, especially committee-1.

South Africa's eleven official languages often blend where cultures harmonize together. As a result, many isiZulu dialects have developed. Although the translation proved to be equivalent, the differences in the dialects were apparent during both committees and the feedback received from the therapists involved during stage V. Some dialect differences, such as the use of *"ingxenye"* (part), ended up being discussed repeatedly.

One aspect that also contributed much value to the translation was the inclusion of multiple occupational therapists in stages I to IV. During the stage I forward translation, the occupational therapist who produced TL1 was able to draw on his training and experience with the DTVP-3 to benefit the translation. As a result, TL1 was concise and accepted as the equivalent version for almost half (n=22) of the sentences chosen by committee-1. For the stage IV committee-2 discussion, the independent third party was also a trained occupational therapist. During the committee-2 collaboration, both occupational therapists contributed their experience and assisted in making the translation more applicable to real-life administration, thereby enhancing its equivalence. In the context of this translation, the inclusion of an additional occupational therapist may have added more value to committee-2 than the monolingual third party suggested by some previous studies[20].

Through the rigorous method used to translate and cross-cultural adapt the DTVP-3, this study also enhanced its authenticity as an assessment instrument within the context of South Africa. It can be said that the newly translated isiZulu instructions have improved the DTVP-3's social appropriateness within this context. Social appropriateness is a quality indicator of authentic assessment. It can be expected that both professionals and parents would find the DTVP-3 a more socially appropriate assessment instrument for isiZulu-speaking school-going children when presented in their native language. Another indicator of authentic assessment procedures is an equitable design enabling equal opportunity to demonstrate skills. Having the administration instructions of the DTVP-3 available to isiZulu-speaking children in their native language provides equal opportunity to children who may not be as proficient in English as in isiZulu. The DTVP-3's utility is founded on its capacity to inform intervention goals and facilitate performance monitoring when treating isiZulu-speaking children with visual perceptual and visual-motor integration difficulties seeking therapeutic intervention. Therefore, its utility as an indicator of authentic assessment can now be considered more appropriate.

The methodology followed during this study was not dependent on the researcher's fluency in the target language. The implication is that an assessment instrument's translation and cross-cultural adaptation can be carried out without being limited by a researcher's language skills. This methodology has already incorporated various mechanisms to ensure that it transcends the language skills of any one participant.

Limitations of the study

Although this qualitatively driven multimethod sequential study presented a thorough and rigorous methodology, it is merely preliminary. Some limitations must be considered. The researcher acknowledges that this study included a limited, non-representative sample of administering therapists (n=3) and children (n=10). This study intended to progress only to the pre-test stage. Therefore, a pilot study was not included in the scope of this research. Should this study have included a larger sample of administering therapists and children or have progressed to a pilot study, other threats to equivalence might have been revealed. Another limitation of this study is the limited inclusion of participants from the provinces of Gauteng, Free State, Mpumalanga and KwaZulu-Natal. The populations of the Northern Cape, Western Cape, Limpopo, North-West and Eastern Cape provinces were not represented.

The isiZulu administration instructions are currently limited to use by therapists fluent in isiZulu. This is another motivation for further research applying the methodology to more assessment instruments in more languages.

Future studies should consider including the original developer/publisher of the assessment instrument in the committee discussions. If the developer could be a contributor to the committee-2 review, the feedback could inform an adaptation of the English version for the South African context.

CONCLUSION

This study describes a rigorous methodology for translating and cross-culturally adapting the administration instructions of an assessment instrument, such as the DTVP-3, into isiZulu to advance the authenticity of the assessment within the South African context. The methodology progressed through five stages: 1) forward translation, 2) synthesis and agreement by committee one, 3) blind back-translation, 4) synthesis and agreement by committee two and 5) pre-testing. The methodology was shown to successfully ensure the functional, cultural and conceptual equivalence of the isiZulu version. The difficulties and successes experienced throughout the process are also reported. This research is intended to be a framework upon which the cross-cultural adaptations of other assessment instruments and other languages in South Africa can be based.

Author contributions

All listed authors contributed to the study design, data analysis, references and final review. Sumarié Naude was responsible for the data procurement and writing of the first draft. All authors contributed to and agreed with the of the final, revised manuscript.

Acknowledgements

The authors wish to acknowledge the participants who contributed their time and knowledge to this research. Particularly, the occupational therapists and other professionals who applied their clinical experience and cultural knowledge and without whom this research would not have been possible.

Conflicts of interest

The authors have no conflicts of interest to declare.

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RESEARCH ARTICLE

Entrepreneurial knowledge and skills transmitted from parents to their children: An occupational legacy strategy for family-owned businesses

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KEYWORDS

economic occupations, transgenerational transmission, intergenerational success, social security, entrepreneurial occupations, family tradition

HOW TO CITE THIS ARTICLE

Mthembu TG, Christiansen N, Kriel S, Marone C, Mason J, Zwane, S. *Entrepreneurial knowledge and skills transmitted from parents to their children: An occupational legacy strategy for family-owned businesses.* South African Journal of Occupational Therapy. Vol 53 No 3 December 2023 DOI
https://doi.org/10.17159/2310-3833/2023/vol53n3a8

ARTICLE HISTORY

Submitted: 14 February 2023
Reviewed: 20 May 2023
Revised: 27 June 2023
Accepted: 6 July 2023

EDITOR

Blanche Pretorius
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DATA AVAILABILITY

From the corresponding author

FUNDING

No funding was received for this research.

ISSN On-line 2310-3833

ABSTRACT

Background: Transmission of entrepreneurial legacies in family-owned businesses has received increased attention. There is still uncertainty, however, whether families pass down the knowledge and skills onto their children.
Aim: This study explored how families transmit entrepreneurial knowledge and skills as part of occupational legacy to their children.
Methods: This narrative qualitative research was conducted with five families who owned business in the Western Cape and Mpumalanga Provinces. Twelve participants were selected through purposive sampling. Semi-structured interviews were conducted with the participants using a face-face approach and telephone calls were audio-recorded, transcribed verbatim then thematically analysed in a credible manner.
Findings: Four themes captured the qualitative evidence of how the families transmit entrepreneurial knowledge and skills to the children consists of Theme 1: Parental family traditions; Theme 2: Inherited entrepreneurial knowledge and skills; Theme 3: Experiences of the entrepreneurial occupations; and Theme 4: We need to let go and let them carry on.
Conclusion: Overall, this study indicates that through enacted togetherness, transitions and adaptations allowed families to engage in entrepreneurial occupations that facilitated inculcation of knowledge and skills needed for family-owned businesses. The social implication of this study is that families transmitted the legacy of social security of their communities.

Implications for practice

This study suggests that occupational therapists should consider the needs of older generations who are prone to imposter syndrome due to handing over their family-owned businesses to the younger generations. Greater efforts are needed to ensure that older and younger generations have mental and emotional capacity to deal with the psychological and environmental factors that can influence transmission of entrepreneurial legacies. Therefore, occupational therapists may design intervention strategies to facilitate transition, resilience, productivity and wellness.

INTRODUCTION AND LITERATURE REVIEW

Transmission of entrepreneurial legacies in family-owned businesses (FOBs) has received increased attention across a number of disciplines including occupational therapy profession. Entrepreneurship is a "process of transformation of opportunities using existing resources and it involves identifying an opportunity, making a product, growing the venture, taking risks and producing rewards for the entrepreneur and stakeholders"[1,2]. It is one of the relevant and critical work that fosters economic occupations that contributes to meaning, identity, income, wages, economic growth, interaction and development in FOBs[2].

FOBs accounted for approximately 70% of the gross domestic product (GDP) globally, which originates from the entrepreneurial occupations and they create two-thirds of employment opportunities[3]. Transition and continuity of the FOBs from the past to present and future transmission of legacies are needed[4-7]. Members of the same family from different generations govern and engage in the entrepreneurial occupations that are passed down onto the children and grandchildren, as part of occupational legacy strategy[4,5]. Thus, occupational legacy must be approached with some caution because passing the same occupations to younger generations could illuminate the dark sides of occupation, such as "poverty trap, low wage and precarious work generating a vicious cycle of poverty"[4:169,8].

In a post-apartheid South African context, unemployment is a grave form of economic injustice estimated to be 34,5%, while among youth is 63,9% for those aged 15 – 24 and for those aged 25 – 34 years is 42,1%, which appears as a problematic situation that perpetuates social and economic inequalities in families experiencing financial and food insecurity[9,10]. Less than half (42%) of African FOBs indicated that they need to create employment opportunities for other family members to ameliorate the unemployment rate11. In FOBs, entrepreneurial legacies are passed on from one generation to other generations to eradicate poverty, create wealth for the economies of the societies and encourage growth and employment opportunities[6,12-14]. In contrast to the perceived benefits, barriers such as limited "access to capital and managerial talent", lack of skills, training, intergenerational succession, and experiences influence the transmission of entrepreneurial legacies[15:155,16]. Senior generations tend to have problems in passing over their family businesses to the next generations because they need to protect their status, meaning, power and other rewards as well as emotional attachments[17]. Yet, there is a paucity of research on how senior generations pass on legacies related to entrepreneurial knowledge and skills needed by the next generations to manage the family businesses.

Economic occupations

A significant paradigm shift has been noted in occupational therapy profession towards community-based and emerging practice opportunities that incorporate economic occupations in social entrepreneurships[18,19]. Street vending and self-employment of people with disabilities are economic occupations that contribute to wellbeing, economic freedom and security[19-22]. This paradigm shift reinforces goal 8 (Decent work and economic growth) of the Agenda 2030 Sustainable Development Goal, which targets growth of small- and medium sized enterprises, supporting productive and entrepreneurial activities[23]. Family legacy is perceived as an enabler that facilitated women to engage in the economic occupation of street trading, which assisted in generating income for their families[20]. Despite the importance of street trading as an economic occupation, there remains a gap of evidence on how parents transmit entrepreneurial legacies of street vending to their children as part of occupational legacy[12,24,25]. Our study takes its departure from the research indicating that family legacy passed on by the parents to their children fosters survival skills[4,20]. It is envisaged that the study will contribute to community-based and emerging practice opportunities then occupational therapists may consider occupational legacy as a strategy that facilitates intergenerational entrepreneurial occupations and family transition process.

Transgenerational transmission

The transgenerational theoretical framework underpins how families transmit entrepreneurial knowledge and skills to the younger generations. Transgenerational theory focuses on the transmission of rules that facilitate communication of acquired practices, behaviours and beliefs between generations[26]. It emphasises that parents with entrepreneurial roles influence their children's "choice of occupation, educational aspirations, attitudes towards money and politics"[26:350]. In the family environment, transgenerational legacy comprises both positive and negative aspects[27]. Consequently, FOBs should consider the feelings of solidarity, commitment and co-responsibility to enable participation in the transmission of entrepreneurial legacies and loyalty among the generations[27]. Three significant modes of transmission: knowledge passed from the older generations to the younger ones[27]; knowledge passed on from the younger generations to the older ones[27]; knowledge transmission involves peaceful or conflicting coexistence, which deals with dialogues about boundaries between the past and present to prepare for future success[27].

Intergenerational success

Intergenerational succession plan is an "explicit process by which management control is transferred from one family member to another"[28:233]. In FOBs, senior generations relinquish ownership and control roles to become consultants and retirees, while the younger generations take the successors role to reduce the business challenges, risk of liquidation and negative consequences for the family relations[12,17,24].

The challenges of FOBs' continuity include emotional regulation, power struggles, sibling rivalry, family values, family conflicts, autocratic paternalistic cultures, nepotism, rigidity in innovation, succession and resistance to change[13:10].Buckman et al's[29] six-stage holistic succession model entails the founder's readiness and willingness to pass on the baton to the successor to take over the control of the FOB. In stage 1 of knowledge codification, the founders ensure that their entrepreneurial orientation is guided by the lessons learnt, which are used in the transmission of legacies. It has been highlighted that the transmission of entrepreneurial legacies in FOBs could be in the form of genetic, material, historic, symbolic heirlooms and values[30]. The successors are not involved in the management responsibilities; however, they are provided with occupational opportunities during school holidays and weekends.

In the second stage of successor selection, the founders identify the gaps in skills and provide the successor of the FOB with holiday work to foster the capabilities needed for managerial and technical competency, cultural knowledge and skills to their offspring[31]. The third stage of strategic training involves mentoring, coaching and experiential learning outside FOB.

However, the successor could be guided to explore formal education and informal training in the field of entrepreneurship, which strengthens entrepreneurial self-efficacy. The fourth stage succession bridging deals with the communication and readiness of the founders to transfer powers and share written plans with the successors to take responsibilities in a shared leadership. In passing down FOBs, families engage in a complex transition process, which results in potentially hard decisions and opportunities to explore family and legacy goals[5]. The fifth stage of strategic transition, the founders become consultants to guide the successors to take full responsibilities to manage and make decisions in the FOBs[27,32]. In the last stage of post succession performance, the founders are not involved but the successors engage in entrepreneurial activities, conflict management with the founders, family members, customers, employees and advisory board for successors' transition process[33].

Occupational science perspective

The Theory of Transition undergirds the understanding of the transmission of entrepreneurial legacies. This theory was developed in a rigorous process described in Crider et al.'s[7] integrative review, which resulted in seven strands describing how healthy populations experience transition: 1) qualities of transition, 2) the experience of transition, 3) roles and transition, 4) environment and transition, 5) occupation and transition, 6) factors that facilitate transition and 7) factors that make transitions difficult[7:307]. These strands are adopted to enhance our insight into parents' and children's transition through their engagement in the occupation of transmitting legacies related to entrepreneurial knowledge and skills. In using the Theory of Transition, the strands provide evidence of how the parents' and children's self-esteem and motivation improve their participation in entrepreneurial activities. In the area of work, the strands support economic occupations related to traditional and cultural activities that enhance the livelihood of the masses; which is still lacking in occupational therapy[19].

Regarding goal 11 *(Sustainable cities and communities)*, the Agenda 2030 of Sustainable Development Goals highlights that there is a need for strengthening efforts to protect and safeguard the world's cultural and natural heritage[23]. Passing entrepreneurial knowledge and skills related to the economic occupations such as weaving, sewing income generation projects, farming/agriculture as well as cleaning and gardening business enhance families' well-being, cultural identity, empowerment, social support, and economic survival[4,19,34,35]. The exposure of the younger generations to these economic occupations reinforces competency and a sense of continuity so that they are able to appreciate the skills that their parents passed on to them[35,36]. Through being part of the FOBs, the children and other family members are provided with opportunities for occupational transition, which supports "sharing expertise, ideas and interests and learning from each other"[35:70]. Thus, transmission of legacies related to entrepreneurial knowledge and skills within families influence on occupational identity, individual's roles, values and personal goals as well as concepts of choice, productivity and social dimensions[37,38].

However, there is a rarity of discussions about the transmission of entrepreneurial legacies and economic occupations for income generation, as part of the area of work. Therefore, an understanding of and insight into how the families pass on entrepreneurial knowledge and skills in a family-owned business might provide occupational scientists with opportunities to contribute to economic occupations. Thus, the study aimed to explore how families transmit entrepreneurial knowledge and skills as part of occupational legacy to their children.

METHODS

Study design

A narrative qualitative research design was employed to gain an insight into the social and occupational phenomenon of transmitting legacies of entrepreneurial knowledge and skills. The narrative qualitative research has been used to bridge the gap between positivism and social constructivism paradigms to learn about the culture, historical experiences, identity, human experiences, and lifestyle of the participants[39,40]. In the narrative study, the interactions about the past, present and future of the FOBs provided a rich and in-depth information and meanings attached to the phenomenon[39].

Family-owned Businesses Profile

FOBs in the Western Cape Province: The Venter family focuses on vegetable and fruits farming, while their daughter is a Protea-farmer on the farm passed on by the father. The Koopman family focuses on electrical services with both parents and successors involved in the sector. In the Marais family, the father started retail services; currently, the only son is in charge of everything. In Mpumalanga Province: The Meyer family deals with farming ranging from forestry, maize, cattle, game, chicken, dairy and even cabbage as well as Bed and Breakfast. The families and their descendants who appeared to be eligible for continuity of the business are willing to learn the entrepreneurial knowledge and skills from the enterprise. The Sibiya family deals with construction, room rental and small tuckshop, while the son owns a catering company.

Population and sampling

The population of this study include families who own businesses in the Western Cape and Mpumalanga Provinces. Purposive sampling method with maximum variation was used to select participants who met the inclusion criteria: being family members from the FOBs identified as parents and adult child; diversity in business profile; different races (black, white and people of colour); all genders and ages; and able to converse in English, Afrikaans, siSwati and German.Five families were approached and recruited through different routes, such as emails, telephone and personal communication. A total of 12 participants consists of eight males and four females between 22 – 91 years of age with a mean and standard deviation of 54.83±20,74. Table I (below) presents the participants demographic information.

Table I: Demographic profile of the study participants (n=12)

Family	Participants*	Age	Race	Occupation	Family Structure
Venter Family	Mr. Venter	81	White	Retired Farmer	Married. 4 children
	Mrs Venter	79	White	Retired primary school teacher	Married. 4 children
	Daughter	52	White	Protea farmer	Married. 4 children – 2 daughters, 2 boys
Sibiya Family	Mrs Sibiya	60	Black	Small business entrepreneur/ teacher	Married. 4 children - 3 boys, 1 daughter
	Son	30	Black	Small business entrepreneur/Student development advisor	Single
Koopman Family	Mr. Koopman	58	Coloured	Handyman	Married. Complex family
	Son	37	Coloured	Handyman	Single
Marais Family	Mr. Marais	91	White	Retired salesman	Married. 5 children – 2 daughters, 1 son and 2 deceased sons
	Son	50	White	Salesman	Divorced. 3 children – 2 daughters, 1 son
Meyer Family	Mr. Meyer	51	White	Farmer	Married. 2 children – 1 son and 1 daughter
	Mrs Meyer	47	White	Bed and Breakfast owner	Married. 2 children – 1 son and 1 daughter
	Son	22	White	Student	Single. No children.

*Pseudonyms

Data collection and analysis

Semi-structured interviews were conducted between July and September 2019, through a face-to-face approach and telephone calls for a duration of 25-90 minutes, with the participants without interference of non-participants.

Participants were asked to provide their demographic information. An interview guide (see Table II, adjacent) was developed and the questions were formed based on the reviewed literature focusing on family-owned businesses, entrepreneurship, legacies and succession plans.

The semi-structured interviews were audio-recorded and transcribed verbatim in preparation for analysis. Data redundancy was reached when there was no new information forthcoming from the twelve participants.

Table II: Semi-structured interview guide for parents and adult child

Parents	Adult child
1. What is your understanding of occupation? Please elaborate and share your examples of occupation 2. If you were unable to engage in your occupations, how would that make you feel? 3. Can you elaborate your understanding of legacy? It is important for people to leave something behind that they will be remembered with. Looking at your business and family, please elaborate and your examples. 4. If you combine occupation and legacy, what does that mean to you? 5. Did your parents influence your career choice or other entrepreneurship activities? Please explain 6. What is your understanding of entrepreneurship? Could you provide examples where you have applied this within your family? 7. What skills would you like to pass on to your family that would contribute to the aspect of entrepreneurship? 8. What knowledge would you like to pass on to your family that would contribute to the aspect of entrepreneurship? 9. How have you in the past thought about the value that lies within passing your entrepreneurship skills and knowledge to your children? 10. What value is there in passing entrepreneurship skills and knowledge that you have acquired throughout your life to your children? 11. What are the skills and knowledge you have within your business that you try to pass on to your children? 12. How do you pass on or share these entrepreneurship skills and knowledge to your children? 13. Why is it important to you to pass on these skills and knowledge that you have to your children? Please elaborate.	1. Is there something that you have learnt from your parents that relates to their jobs? Please elaborate and provide examples. 2. Would you follow your parent's example in terms of your career in the future? If yes, please elaborate why. If not please elaborate why not. 3. What do you like most when your parents teach you things? Please elaborate. 4. Do you think it is important to learn skills and knowledge from your parents? If yes, please explain why. If not, please explain why not. 5. What value do you find in these skills and knowledge you have learnt from your parents? 6. How do you think the skills and knowledge your parents pass on to you influence who you are? 7. What are the occupations/activities that you participate in, but do not enjoy? 8. Do you participate in these occupations/activities because your parents do so? Please elaborate and provide examples.

A six-step narrative thematic analysis process was used[41]. The transcripts were read several times for familiarisation with the data in preparation for generating initial codes. As a result, the authors generated codes in a consistent manner. This led to the third step whereby the similar codes were merged into categories, which was guided by the discussions between authors after they reached consensus. The themes were not identified in advance from the data; the authors searched, defined and named the themes through the process of continuous discussions to reach consensus. Subsequently, the authors employed consolidated criteria for reporting and writing up the qualitative research (COREQ)[42].

Trustworthiness

Credibility was enhanced by using peer reviews with knowledgeable researchers in qualitative research, and the authors presented and discussed the findings until consensus was reached. A triangulation of investigators enhanced the credibility of the study by employing an interview guide for consistency with the participants. Participants validated the findings, as part of member checking. Transferability was enhanced by providing a thick description of the research settings, methods, participants and analysis. Dependability was enhanced through an audit trail to keep track of the study.

Ethical considerations

Ethical approval was sought from the Humanities and Social Sciences Research Ethics Committee at the University of the Western Cape and ethical clearance HS19/6/56 was granted. All the participants consented to be part of the study after the authors provided information about the purpose of the study. Participants had an opportunity to withdraw from the study without any repercussions. Pseudonyms were used as a strategy of anonymity to protect personal information and confidentiality of the participants.

FINDINGS

Four themes with categories and subcategories were identified during the iterative process of data analysis (Table III, page 69).

Table III: Themes, categories and subcategories

Themes	Categories	Subcategories
Parental family traditions	Legacy of family practices	• Family cohesion • Religious beliefs • Giving back to the community • Essence of social values
	Dividing families' inheritance	• Children's participation in business • Gender equity • Capabilities of the children
Inherited entrepreneurial knowledge and skills	Management skills needed for family business	• Power delegation • Financial management • Resources and assets management
	Early exposure to family business	• Active experimentation
Experiences of the entrepreneurial occupations	Experiences of positive transmission	• Methods of transmission • A sense of appreciation • Survival v/s identity • Safety nets • The joy work brings
	Dark sides of transmission	• Parental pressures
"We need to let go and let them to carry on"	Intergenerational succession plans	• Passed on the baton • Gradual release of responsibilities

Theme One: Parental family traditions

The first theme deals with the parental family traditions that emerged from the families with businesses, which comprised several legacies related to family practices and dividing families' inheritance. Firstly, the legacy of family cohesion was shared among three different families who own businesses, which supported family functioning and entrepreneurial spirit.

"It is very important that the children should love their mother and father; and love the kind of business where the mother and father work". **(Mr. Marais)**

"We are trying as a family to help each other, let us be united, all of us; we all need each other in good and bad times".
(Son of Sibiya's family)

Secondly, the participants in their parental voice shared that they have passed down the legacy of spiritual-religious beliefs, diversity, and autonomy on the children to sustain their lives and businesses.

"They [Children] know God, he knows everything and in God we ask everything that we need and we are surviving because of God". **(Mrs Sibiya)**

"I want my kids to ask more questions and they should not judge anyone, not even Muslim". **(Son of Marais' family)**

Thirdly, parents passed down onto their children the legacy of giving back to the community to contribute to environmental, social and corporate governance (ESG).

"We wish that the entire community could improve and not just ourselves". **(Mrs Sibiya)**

"This family business does something for other people (community members) more than other businesses do for the people in need". **(Mr. Marias)**

"People in the informal settlements have depression because they do not have a choice and they worry about hunger. In this town, there is no organisation where you go to, where our business has not given something... it is just gift-vouchers but it is constant."
(Son of Marais' family)

Fourthly, parents passed down the legacy of social values, such as respect for human dignity, punctuality, commitment, work ethic and task oriented onto their children, which supported the family practices and enabled solidarity amongst families.

"...respecting everyone around you, as you would like to be respected is what we tried to teach them". **(Mr Meyer)**

"My children learned to work and to respect the people who work in the farm, the labourers also accepted the children".
(Mrs Venter)

"My dad always got up early; he believed if it is light outside then you should start working. He also went to bed early in the evenings, so he was always punctual and yes, very diligent with his work. He set a good example of commitment with his work and he is very task oriented". **(Daughter of Venter's family)**

Regarding the families' inheritance, parents used their discretion to divide the inheritance amongst the children based on the active participation in the operations of the business and gender equity was significant not to favour only the sons but also the daughters.

"On the farm, we have now made a difference because my son is now in management, not because it is discrimination, but he gets 60% of the farm and my daughter 40%". **(Mr. Venter)**

"My daughter has the same right that he (my son) does. It is all the things that we need to think about and look at how we can accommodate them". **(Mr. Meyer)**

"Depends on my dad and them, if they draw up their testament... the farm where we live now, the farm apparently goes to mysister and she inherits the farm. The thing is we have to be satisfied with what we inherit and live with it". **(Son of Meyer's family)**

Parents shared that inheritances will be divided and passed down onto the children based on their capabilities so that they will be able to use the resources.

"I will look at them (children) and divide them based on their weaknesses and strengths...The one who has the lowest intelligence will get the rental rooms. I will also divide the cars. Whoever gets a car, would have got a car, whoever gets a tractor, would have got something". **(Mrs Sibiya)**

Theme Two: Inherited the entrepreneurial knowledge and skills

The second theme deals with the participants' perceptions of entrepreneurial knowledge and skills passed down onto the children, which included management skills needed for the family business and early exposure to business. Regarding the management skills needed, parents adopted a shared leadership style that facilitated power delegation to their children so that they could learn how to manage the FOBs, as a transition strategy for the successors of the corporate.

"If they (community members) come to me and ask. I say they have to ask my son. I sent them to him (son)". **(Mr. Koopman)**

"They know that is why they (community members) always come to ask me. They no longer come to fetch my father; he is getting old now". **(Son of Koopman's family)**

For instance, parents delegated their children with social work qualifications to focus on the employees' health, quality of life and wellness.

"I did social work. When we came to the farm, my dad said I should also take care of ... the workers with troubles". **(Daughter of Venter's family)**

Parents passed down the legacy of financial management skills onto the children at an earlier age so that they could learn the daily functions and operations, such as quotations, deposits, savings, and a general sense of how to manage money in the FOBs.

"They (parents) have managed their finances when they started getting money; I would say it really helped me in terms of understanding money...So that I will be able to manage my own money. They gave us all the opportunities to be involved in the family business. In terms of knowing exactly how much, how to check in the money and how they (the workers) have worked...When my parents are not at home, we are able to prepare the salaries for the employees". **(Son of Sibiya's family)**

"I helped him (son) by explaining what to do when doing business. Another person did not want to pay him. I always try to tell him that he must take a deposit. He must insist on a deposit. So that if they (clients) are scammed, then he knows, you have a portion". **(Mr. Koopman)**

The legacy of being a handyman was passed on from the parents to their children and grandchildren, which promoted intergenerational transmission and succession. In the Koopman's family, the son indicated available tools were heirlooms that sustained their business. The tools were used and grandchildren learned how to use and manage them.

"I use his (Father) tools. I still have some of his old stuff. I do not have any new ones (tools). I have always used the old ones. I also teach my children with those tools such as screwdrivers and drills. A big reason why the work is done is because the tools are already here. Any tools out there I use from him. These are the stuff that I got, I mean, it was there". **(Son of Koopman's family)**

An early exposure provided occupational opportunities for the parents to pass down technical skills needed for technical occupations, such as welding, pipefitting, oven making, and cold rooms onto the children for active experimentation, which steered them to the entrepreneurial directions.

"Yes, just exposure to the business from a young age". **(Son of Sibiya's family)**

"I watched my dad work when I was a child... I sometimes handed him the tools most of the time and I just kept an eye on it... what he does with each tool, if he told me; do this and that, then I did. Later, I started to work with my hands. I learned everything, now I am a Jack-Of-All-Trades. Now I teach my own child what and how to do it. I taught him (son) how to weld the pipes and I learned that from my dad. I first taught him how to put the pipes together. We do the oven, then I teach him all those things. Firstly, I would do it, and then he does it. Actually, we do everything together. He also learns from his grandfather. Not just by exposure. He sat down with me and explained to me, that is how he did this and that. He did it to his fullest potential". **(Son f Koopman's family)**

Son of the Meyer's family reported:

"He always offered me the opportunity to go along with him (Father), and to participate in everything that he was doing. He gave me the opportunity to do things on the farm by myself, which is how I discovered my love for the farm, and I have wanted to do it since I was a small child. With farming, just everything that is on the farm, I learnt from my dad. From planting trees, to cattle, to maize, from the beginning to the end". **(Son of Meyer family)**

Mrs Meyer echoed her son:

"Our legacy is that we can give them something. Otherwise you could say, here I will give you the money, go and buy yourself a farm if you want to. Now he gets something that has already been built, something he carries on, and he can build on". **(Mrs Meyer)**

Participants indicated that their family businesses provided occupational opportunities for community capacity building with technical skills.

"I help and teach other people (workers), not just my children. I show people how to work with electricity, saws, or grinding. I teach them. It is good work for them too... it is something for their future as they move forward. **(Son of Koopman family)**

Theme Three: Experiences of the entrepreneurial occupations

The third theme captures the participants' experiences of entrepreneurial occupations within FOBs, which illuminated positive and dark sides. Participants shared importance of family relationships, which added value on the positive experiences of engaging in entrepreneurial occupations.

"I feel that I have plenty of stuff, buildings, new store and shares. Now, it is about relationships with my children. I am going and I hope we will be able to remain good friends for a long time. It is not important to me for them to come to the business... I think I have a much more open perspective; I make my children think. I talk to them about the books". **(Son of Marais' family)**

Innovation is one of the skills that was evident amongst the participants who transferred the knowledge of growing different types of flowers to their children.

"I try to give them (children) the knowledge I have about the flowers, I tell my children it is this and this type of protea".
(Daughter of Venter's family)

Participants shared deep feelings of gratitude and great admiration about the sacrifices and efforts that their parents made for their successes. They further indicated that they drew their inspiration from their parents who inculcated entrepreneurial knowledge, which contributed to the continuity of the legacies.

"You also need to appreciate what they have already done for you and where they come from in business, and everything they have gone through to get the farm to where it is now. The things that they have taught me, are more valuable, and are more meaningful to me...I just realised how much I have actually already learnt about farming from my dad, with the things he has always told me and all those things; yes, it is more valuable than my university education". **(Son of Meyer's family)**

"I learnt many things from him (Father). Not just about electricity but tiles, plumbing work, so I learned all of this from him. I had to ask my dad again, how to connect it. Then he shows me again... the red one goes here or the pink wire goes there... he taught me". **(Son of Koopman's family)**

Parents occupationally adapted when they had no business opportunities and they ventured in other areas to expand their services and markets, as part of diversification and safety nets. Through engaging in the alternative occupations, they were able to fulfil their well-being needs.

"The problem with the work that I do, the money is not always there. So, I have to do a lot of different things. Look, when I cannot do electricity work, I just do whatever work is available. As for example; the ceilings. I will say jack-of-all-trades. This is what I really do when there is no work". **(Mr Koopman)**

"There is no work these days. I was largely boosted by the finances that I accumulated from tractors and selling clothes. I was able to pay for my children's tuition with that money. I raised my children with that money that I received from selling old clothes". **(Mrs Sibiya)**

Based on the South African economic status, participants shared that they had to use their talents as safety nets to explore other business opportunities for financial security.

"In this South Africa economic status, a person does not really need to rely on their salary as a source of income, but should use their talents to make money. Currently, I am in the accommodation sector as well as catering".
(Son of Sibiya's family)

Engaging in entrepreneurship activities rejuvenated the entrepreneurial spirit amongst the parents and children, which resulted in a sense of joy. Participants enunciated that as entrepreneurs they have an internal drive that pushes them to succeed in their FOBs.

"It is very fun for me; I am involved all the time, but I can do something else if I like too". **(Daughter of Venter's family)**

"I'm enjoying the space where I'm in, the activities and the duties that I am doing currently. I'm doing something that I'm really passionate about. ... it's something that I have the skills for, and it's not really influenced by what my parents are doing".
(Son of Sibiya's family)

Two of the participants (Mr Koopman and Mr Meyer) echoed the daughter of the Venter and son of the Sibiya-families regarding the importance of enjoyment in all the activities that they engaged in, as part of the family business and other jobs.

"I say one thing when you go into any business - you have to enjoy it". **(Mr Koopman)**

"You need to have your head right, regardless what job you may have, that you are happy and that you do it to the best of your ability". **(Mr Meyer)**

Participants shared that bricklaying is one of the entrepreneurial occupations that illuminated the dark sides of precarious activities and parental pressures.

"My dad was a bricklayer. He wanted us to do it but no one ever did. It was too dangerous. He told us all one day; one of us has to become a mason because it does not help that the materials and tools are here and be wasted. One day he told us that there has to be someone who follows his example". **(Mr. Koopman)**

"When he (Son) was leaving university, I said, listen, if you do not get the right job now, then you work with us (family business)".
(Mr. Marais)

From the Sibiya- and Venter- families, it was evident that parental pressures did not restrict the children's business decisions about introducing contemporary ideas in the FOBs. Parents' flexibility and openness instilled in their children a sense of agency and autonomy to engage in diverse activities.

"We were given the liberty to make decisions, when it comes to expanding and growing the family business...they (parents) gave us that liberty they said 'you guys can also be able to do the things that we do if we are not around'... My parents also instilled from a tender age, that value of choosing what you would want to be and directing your life as an individual".
(Son of Sibiya's family)

"There was no pressure, nobody ever expected us to go to the farm. I was able to study anything I wanted to".
(Daughter of Venter's family)

Theme Four: "We need to let go and let them carry on"

The last theme deals with the parents' perceptions of willingness to relinquish their roles and hand over the family business to their children to become successors for continuity. The title of this theme emerged from the story of Mr. Meyer who expressed "The biggest legacy that is ahead of us now, is that we need to let go and let them carry on". This theme also highlights parents' readiness to pass down the baton of leadership, management, and decision-making responsibilities of their FOBs onto their children.

"They (children) still invite me so that I will always know what is happening with the finances, but I do not involve myself anymore". **(Mr Venter)**

"My eldest son is unemployed, he is here at home, and I told him that I am leaving him to be a manager of the tractors".
(Mrs Sibiya)

Parents had opportunities to provide advice as consultants to guide their children when they needed assistance with operations of the business. They shared leadership to facilitate taking new roles, and resiliency in the FOBs.

"If I am stuck, I come and get him to come help me with something. I tell him, we need to do this now; I get it from him".
(Son of Koopman's family).

"They (children) took over and I, the father, stepped back completely. We then told my wife she could retire. I stepped back so I helped where I thought was needed". **(Mr. Marais)**

Parents gradually released the business responsibilities to their children and they created opportunities for active experimentation to apply entrepreneurial knowledge and skills transferred to them into practice. This enabled the children to learn from their mistakes and master the newly acquired skills and knowledge of how to operate in a family business. The parents employed strategies such as observation of how the work is done, practically do the work with them and gradually decrease the assistance required.

"I would leave him to continue; then I would leave him alone. Then I come home or I go to another client. Then I let him continue. Then I go to him and I say, 'Don't close it, I need to see first. When I come back and I look at it then I might say, that one is wrong, or that one is right, do something like that....' Then I let him go again". **(Mr. Koopman)**

"All the time you keep the kids updated. You cannot just leave someone ... You must have pointed out all the mistakes you see happening now. . . You talk to them; and I think it helps a lot if you give people feedback. . . Every month, I see the state of the business, how it progresses, and the turnover". **(Mr Marais)**

Imposter syndrome is the condition that involves feeling anxious, self-doubt, and negative self-views among people with high performance who tend to experience uncertainty about their abilities[43]. Therefore, imposter syndrome was inevitable amongst the participants who released their responsibilities of the FOBs to the children. Nevertheless, the participants used adaptive strategies, such as continuous knowledge sharing, a sense of calmness and communicating their concerns.

"There are times that I feel as if I am not good enough anymore. I cannot scold him that much anymore... I do not get angry, I just explain to him then he tells me, 'no, you have to stop shouting.' Then I tell him, 'No it's not the point. You have to learn harder; when you reach a certain point then you have to listen".
(Mr Koopman)

DISCUSSION AND IMPLICATIONS

The current research aimed to contribute towards the qualitative evidence base on the transmission of legacies related to entrepreneurial knowledge and skills situated in family-owned businesses in a post-apartheid South African context. The four themes are discussed based on enacted togetherness[44], strands of the Theory of Transition[7], and occupational adaptation[45].

Enacted togetherness in family-owned businesses

The findings of the current study indicate that engagement in delegated entrepreneurial occupations provided the parents and children with opportunities for meaning-making through their connectedness and interdependence, which is consistent with enacted togetherness, sense of belongingness and well-being[27,44,46,47]. It was evident that the socio-cultural context of the FOBs enabled the parents to engage in the altruistic occupations of passing down entrepreneurial legacies onto their children and community members, which supported connecting and contributing to others[46-49]. These occupations improved the well-being and lives of the families, employees and communities through giving back nutrition, entrepreneurial knowledge and skills to sustain the society contributing to environmental, social and corporate governance (ESG)[50].

The findings in our study show that the parents did not only preserve the FOBs' legacies of values related to respect for every human, equality, relationships and social capital but also the standard of living, faith, religious beliefs and economic growth[27,51]. The parents as role models passed down legacies of capabilities of '*Know-how*', such as entrepreneurial and technical skills onto their children, which strengthened their problem-solving and occupational potential[52,53]. These findings show that the children developed capacities "to do what is required and what they have the opportunity to do, to become whom they have potential to be" as future entrepreneurs were transformed[53:137]. The findings of the present study are consistent with other studies that valued parents' validation as an enabler for development of children's occupational identities[54]. Through enacted togetherness, the children engaged in a transition process of "inheriting from parents; being directed by parents; and being mentored by elders"[54:99]. Knowledge gained about transmitted entrepreneurial legacies can assist occupational therapists to invest in collective and collaborative occupations that enacted togetherness and belonging, to honour the past and present while preparing for the future. Occupational therapists should consider collaborative participation in intergenerational occupations, such as farming, woodwork, pipe fitting, gardening, mentoring and others to foster occupational identities, meaning and purpose, hope among the parents, grandparents, children and grandchildren[36,48]. Thus, occupational therapists should be guided by a we-consciousness when they put a premium on serving the community, lifting others, and finding joy in empowering others[55].

In sustaining the FOBs' operations and functions, the parents passed down shared leadership and responsibilities onto their children so that they can take control over the entrepreneurial activities, as part of autonomous-supportive parenting. Our study indicates that the children also inherited inalienable heirlooms such as tools, land for farming, and tractors as part of objects that enabled their engagement in entrepreneurial occupations, which corroborates with previous studies[50,51,56]. The heirlooms were imbued with domestic history and achievement, which affirmed the family identities and continuity[56]. The findings of the present study indicate that the parents trusted their children to be the guardians of the heirlooms for future generations to transition.

Transitions through engagement entrepreneurial occupations

Understanding the link between roles as part of occupational patterns and occupations enhances occupational therapists' knowledge about factors that facilitate and constrain transition during engagement in entrepreneurial occupations[7]. The fourth theme *(We need to let go and let them carry on)* indicated parents' readiness to engage in the transition process as they accepted the reality that their children should continue with the FOBs. Availability of both social support and resources enabled on-the-job training that facilitated skills building so that the parents are convinced the children had successful transition[7,36]. The findings in the second theme *(Inherited the entrepreneurial knowledge and skills)* corroborate with Crider et al.[7] who concur that knowledge facilitates effective transitions to new roles, like in our study the parents became retired owners and consultants while their children adopted being successors. A possible explanation for the successful transition is that the parents and children had clear expectations about the tasks and goals of transmitting the leadership and responsibilities of the FOBs. Another possible explanation for smooth transition is that the parents and children invested in intergenerational relationships, which facilitated their adjustment and role development through earlier exposure in entrepreneurial occupations.

Transition may disrupt participation in occupations[7]; however, the findings of the present study indicate that parents at some points were frustrated by how their children responded to constructive feedback. The findings further revealed that there was a major change in selecting and organising entrepreneurial activities, leadership and responsibilities of the FOBs, which enabled occupational adaptation and resilience. Through children's performance evaluation, parents were convinced that the future of the FOBs was bright because they were all committed to strive for stabilisation, which enabled their transition and adaptation[57]. It could be argued that the positive results were due to the fact that the parents were confident that their entrepreneurial legacy lives on because they shared leadership with the children who inherited the FOBs[58]. Passing down FOBs onto the children can be disruptive and difficult for the older generations. It can therefore be suggested that occupational therapists should engage in collective efforts to overcome injustices that may influence the transmission of entrepreneurial legacies and facilitate occupational adaptation.

Occupational adaptation in family-owned businesses

Imposter syndrome is inevitable amongst new entrepreneurs; which necessitates occupational adaptation and transitions in the operations of the FOBs. Nonetheless, our study found that the children experienced a sense of adaptiveness because they went through the transition process of rejuvenation and they embraced their legacy of entrepreneurship[59]. Older generations not only needed to urgently adapt and accept but also allow their offspring to turn over a new leaf to facilitate rebirth transition, which promotes new ideas and goals of entrepreneurial projects[59]. The results of this study show that interactions between the participants and the socio-economic context facilitated their adaptation. In congruent with Jaskiewicz et al.'s[59] explanation of exaptation transition, it is a process whereby children repurpose existing ventures by pursuing new entrepreneurial activities based on the new market demands, which might be linked or different from the original business.

This is evident among the parents and their children who used strategic agility to explore new entrepreneurial opportunities to ameliorate disappointing occupational challenges by adopting diversification[59]. The third theme *(Experiences of the entrepreneurial occupation)* highlighted that economic occupations, such as selling clothes, accommodation, catering, and ceiling fitting were safety nets of the businesses.

Participation in these economic occupations instilled hope amongst the participants so that they fulfil their wellbeing needs of occupational resilience and survival, which assisted in the future projections and flow of the FOBs[20]. Accordingly, our findings reverberate entrepreneurial intention, as the participants' conscious state of mind encouraged their aspirations to establish a new enterprise while building on an existing one[6].

The children occupationally adapted as they had opportunities to engage in new entrepreneurial occupations together with their parents[58]. Through the process of exaptation transition, the parents adopted a hand off approach as a coping and adaptive strategy, which assisted in stepping back and retiring from the FOBs[7,58,59]. In accordance with the present results, previous studies have demonstrated that through the process of occupational adaptation people develop a sense of competence, self-efficacy and identity in occupational participation[35,60,61]. In making the world a better place for everyone, occupational therapists should collaborate with FOBs in communities to design and develop intergenerational entrepreneurship programmes. This may enable collective efforts to promote healthy cities and communities where younger generations engage in entrepreneurial occupations to address social determinants of their everyday lives such poverty, hunger, unemployment and food insecurity[23,36,47]. The present study raises the possibility that there are perceived benefits of engaging in transmission of entrepreneurial legacy projects include occupational adaptation, skills development, transition, resilience and safeguard heritage. Digitalisation is an adaptive strategy that FOBs used to network and market their products in social media; nevertheless, our study failed to highlight how parents passed onto the children the digital skills like other entrepreneurs[11,50].

Limitations

Purposive sampling was used with maximum variation with inclusion criteria of adult children from the FOBs; however, only one female child participated. This might mean that future research should consider recruitment of female children to explore their experiences of legacies of "operational and emotional family support, as control, decision making and management" in FOBs[14:431]. A lack of female children's narratives in the sample adds further caution regarding the generalisability of these findings.

CONCLUSION

By advancing an understanding of the transmission of the entrepreneurial knowledge and skills amongst family-owned businesses as an altruistic occupation contributes to occupational legacy and economic occupations. Incorporating transgenerational and occupational lenses, parents engaged in connecting and contributing occupations to facilitate transitions of the children to successors of the FOBs while parents to retirees.

Although the findings should be interpreted with caution, this study has several strengths of passing down the legacy of parental family traditions and entrepreneurial knowledge. Another strength of the present study was the legacy of entrepreneurial skills (i.e., leadership, financial, technical, communication) passed down for the operations of the FOBs. This study offers some insight into entrepreneurial occupations that enable the parents and their children and grandchildren to achieve occupational identities, competence and adaptation. Thus, occupational therapists are challenged by the results to collaborate with the FOBs in the communities so that they consider entrepreneurial occupations as a medium to facilitate collective efforts to give back, lift others and satisfy wellbeing needs.

Author contributions

Thuli Mthembu supervised the research and reviewed the intellectual content of the project. All listed authors engaged in the conceptualisation of the research, literature review, research methodology, findings and structuring, prepared the content and wrote the manuscript for publication.

Conflicts of interest

The authors declare that they have no competing interests related to financial or personal relationships that might inappropriately influence them in writing this article.

Acknowledgements

The authors would like to thank the participants who consented to share about their family-owned businesses

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RESEARCH ARTICLE

Exploring the autism diagnostic odyssey in the Greater Accra Region of Ghana

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KEYWORDS

autism spectrum disorder, participatory research, nominal group technique, barriers and facilitators, early diagnosis and intervention

HOW TO CITE THIS ARTICLE

Akrofi JNS, Brew YN, Carreon, ED, Cornelius IY, Angell AM. *Exploring the autism diagnostic odyssey in the Greater Accra Region of Ghana.* South African Journal of Occupational Therapy. Vol 53 No 3 December 2023. DOI: https://doi.org/10.17159/2310-3833/2023/vol53n3a9

ARTICLE HISTORY

Submitted: 26 October 2022
Reviewed: 23 June 2023
Revised: 23 August 2023
Accepted: 27 August 2023

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DATA AVAILABILITY

From the corresponding author

FUNDING

This study was funded by the University of Southern California, Mrs. T. H. Chan Division of Occupational Science and Occupational Therapy and the USC Chan DREAmS Lab

ISSN On-line 2310-3833

ABSTRACT

Introduction: Despite the increasing global prevalence of autism spectrum disorders (ASD), there is limited information about ASD in Africa. Existing research on ASD in Africa shows that autistic children are diagnosed relatively late or not at all. The purpose of this study was to understand the barriers to an autism diagnosis and to engage key stakeholders to action plan steps to reduce the barriers.
Methods: We conducted a participatory, mixed methods study using semi-structured interviews, a survey, photo elicitation, and focus groups with 11 participants (four parents and seven health professionals) in the Greater Accra region of Ghana.
Findings: Neuro-paediatricians in our study reported that it takes, on average, two to six visits over two weeks to two years or more to diagnose a child. Our thematic qualitative analysis yielded three overarching themes, with barriers and facilitators for each: 1) Systemic, 2) Community, and 3) Parent/Family factors that influence the diagnostic process. The action plan of our stakeholder focus group prioritizes community education to dispel myths and encourage autism acceptance within the Ghanaian community.
Conclusion: Knowledge about the diagnostic odyssey can help facilitate early diagnosis and intervention.

Implications for practice

This research study confirmed known challenges to the autism diagnostic process. It contributed nuanced insights into the role of culture, the importance of education, and the need for community involvement in improving the diagnostic process, early occupational therapy intervention, and autism acceptance within the community.

INTRODUCTION AND LITERATURE REVIEW

Background

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which is widely used in making diagnoses, Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by differences in social communication and interaction and restricted and repetitive behaviours that affect an individual's ability to function in school, work, or other areas of life[1]. The concept of a "Spectrum" was introduced in the DSM-5, which encompassed the autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS)[2]. Recently, there has been a growing debate on the diagnostic criteria of the DSM-5 and the labels it confers[3]. Some members of the autistic community have also called for autism researchers to adopt non-ableist and inclusive language[4].

Despite the increasing global prevalence of autism spectrum disorders (ASD), there is limited information about the prevalence of autism in Africa[5,6]. Most of the global narrative on autism is centred on data from high-income Western countries[7,8].

Existing research on autism in Africa shows that autistic children are diagnosed relatively late compared to autistic children from higher-income countries[9], and most of these children have higher levels of need[10,11]. This may be attributed to delays in the autism 'diagnostic odyssey' which Lappe et al.[12] describe as a "long eventful journey" to an autism diagnosis, characterized by navigating complex educational, social, and medical systems.

De Vries[7] speculates that despite the lack of sufficient epidemiological research on autism in Africa, there may be more autistic individuals in Africa compared to many high-income countries based on the population and geographic size of Africa. Thus, autistic individuals in Africa are likely to either be diagnosed much later in life or may not be diagnosed at all. Below, we review possible barriers to this delay or lack of diagnosis in African contexts as reported in the literature.

Absence of Contextually Relevant Diagnostic Tools

According to Kamp-Becker et al.[13], the current diagnostic "gold standard" for autism is a lengthy and time-consuming procedure that involves direct observation using the Autism Diagnostic Observation Schedule (ADOS) and an interview with caregivers using the Autism Diagnostic Interview, Revised (ADI-R). In 2017, Franz et al.[8] established that no published studies from Sub-Saharan Africa used a combination of developmental history and observational "gold standard" diagnostic instruments such as the ADI-R and the ADOS-2 as typically used in high-income country autism research cohorts[8]. Ruparelia et al. identified the general lack of appropriate services and inadequate standard of available educational and medical infrastructure, including baseline screening tools and referral systems, as a significant challenge in identifying autistic children in Africa[5].

Lack of Professionals with Expertise in Autism

Fusar-Poli et al.[14] stress the importance of clinicians' training and experience in assessing individuals who might be on the autism spectrum. However, this poses one of the major barriers to autism diagnosis in many low- and middle-income countries. Studies in Sub-Saharan Africa have found a lack of autism knowledge and awareness levels amongst health and educational professionals[15–18]. There are relatively few educational professionals who can confidently identify early signs of autism to facilitate the diagnostic process[19]. Few resources are dedicated to building the capacity of educational professionals to identify individuals with autism compared to health professionals. The path to diagnosis would be expedited by increased awareness and training about autism amongst the public and health professionals[5,7–9,20].

Stigma

Another significant barrier to an autism diagnosis is stigma. A study of Hong Kong Chinese families found that the fear of public condemnation of disability caused families to deny an autism diagnosis and socially isolate themselves due to shame and embarrassment[21]. Cultural beliefs play a prominent role in the stigma associated with autism[8,21]. There is usually a delay in seeking orthodox medical help for African children with autism because the aetiology of autism is typically attributed to spiritual causes[18,22]. Perhaps surprisingly, the stigma surrounding autism is not limited to the general populace. According to Bakare and Munir, many African health professionals also subscribe to supernatural causes of autism. Thus, autistic individuals and their families may be negatively impacted by stigmatizing beliefs, which can deter them from seeking help[20,23].

Aim of Study

There is a dearth of autism health services research in Ghanaian contexts, and more broadly in other African contexts, on how autistic children are identified and diagnosed. To address this gap, this participatory study aimed at understanding the barriers to an autism diagnosis from stakeholders' perspectives and to engage stakeholders to action plan potential steps to improve early and accurate identification.

METHODS

Study Design

We conducted a three-phase, participatory mixed methods study with 11 participants (four parents of autistic children and seven health professionals) to understand the barriers to autism diagnosis in the Greater Accra region of Ghana. We utilized a participatory approach[24,25] to engage key stakeholders in identifying barriers and key action steps to ameliorate the identified barriers. We invited one key informant (second author), who is an advocate for neurodiversity and heads a neuro-developmental clinic in a large hospital in the Greater Accra region, to engage with study activities such as recruitment and data collection. Our research question was: How do healthcare professionals and parents/caregivers describe the barriers, facilitators, and pathways to an autism diagnosis in the Greater Accra region of Ghana?

Population and Recruitment

Our key informant helped to purposively recruit and screen parents of autistic children from our study site, a neurodevelopmental unit of a large hospital in Greater Accra, and snowball sampling to recruit healthcare providers involved in identifying and diagnosing autism in the region. All participants were 18 years or older and spoke either English or Twi. Individuals participating in the study had to be parents/primary caregivers of autistic persons who had/were in the process of receiving an autism diagnosis in the Greater Accra region of Ghana or health professionals involved in the identification and/or diagnosis of autism. We recruited a total of 11 participants (four parents of autistic children and seven health professionals). Table I (page 79) below provides demographic information on all the study participants who contributed to all three phases of this research. Table II (page 79) provides more detailed information about the three parents who contributed to phase one (interviews) and their children.

Table I. Demographics of study participants

Participant	Role	Work setting
Araba	Parent	
Esi	Parent	
Baaba	Parent	
Mansa	Parent	
Doctor A	Neuro-paediatrician	Large public hospital
Doctor B	Neuro-paediatrician	Private clinic
OT 1	Occupational Therapist	Large public hospital
OT 2	Occupational Therapist	Large public hospital
SLT 1	Speech and Language Therapist	Large public hospital
SLT 2	Speech and Language Therapist	Private clinic
PT	Physical Therapist	Large public hospital

**The participant names used in the table are pseudonyms.

Table II. Demographics of parents who participated in study.

Parent	Sex of child	Age of child at first concern	Age of child when presented to a health professional	Age of child at autism diagnosis
Araba	Male	18 months	18 months	27 months
Baaba	Female	18-20 months	18-20 months at a hospital visit	36 months
Esi	Male	24 months	41 months to a doctor, 24 months to a friend nurse	41 months

Data Collection and Tools

The study had three phases. During phase one (February to March 2022), the first author conducted semi-structured interviews (see supplemental materials for the interview guide) with three parents of autistic children, asking them to tell the story of how their child came to be diagnosed with autism. Each interview lasted 45-60 minutes and was conducted by the first author via a HIPAA-compliant Zoom platform. At the end of each interview, the first author administered a short survey to the parents to collect quantitative data about the diagnostic odyssey (e.g., age of early signs and diagnosis, type of early signs). After the interview, we sent each parent a participation stipend.

In phase two, the first author and key informant conducted two focus groups with seven health professionals (two neuro-paediatricians, two occupational therapists, two speech and language therapists, and one physical therapist) via a HIPAA-complaint Zoom platform. At the end of the focus group, the first author asked the health professionals to take photos over the next two weeks of their workspaces, assessment rooms, tools and equipment, and other relevant materials that are useful in the process of diagnosing[26] and submit the digital photos to the first author. The audio-recoded interviews were transcribed verbatim (pseudonyms were used for all potentially identifiable names or places); these transcripts, and the first author's notes from the focus groups, were analysed before phase three (see below for details about analysis).

In Phase three, the first author and key informant conducted a final focus group with nine participants (five parents, nine health professionals), using the nominal group technique (NGT)[27]. During this focus group, the first author p r e s e n t e d themain findings from phases one and two and facilitated group discussion to identify and prioritize the major problems and possible solutions for improving early and accurate autism diagnoses in the Greater Accra region of Ghana.

Data Analysis

We used descriptive statistics to analyse the quantitative findings from the parent surveys from phase one.

For the qualitative data (interview transcripts and focus group notes), we used thematic[28] and narrative[29] analysis, keeping stories intact. Our analysis followed Braun and Clarke's[28] thematic analysis, utilizing a 1) theoretical (guided by an a-priori theoretical framework), 2) semantic (focusing on surface-level meanings), and 3) essentialist (theorizing meaning in a straightforward way) design. This approach was chosen based on our research question and study aim, i.e., to understand pragmatic barriers and facilitators to autism diagnosis in this context and to facilitate pragmatic potential solutions to diagnostic barriers. Following the six-step process, the first author manually transcribed the data and read through the data with two other team members to familiarize themselves with the data and jot down initial ideas. The entire team met to generate initial codes based on the a-priori framework and initial readings. The first author and two additional team members coded the transcripts and focus group notes using NVivo; two people coded each document. After all the data was coded, the team met to define and name themes and collaborated on the final report, which was shared with participants during phase 3 for member checking and further discussion. The entire team met throughout the coding process to discuss and clarify codes and collectively analyse the photos from phase two[26]. Each team member independently reviewed all the photos, after which the entire team met to review the photos together, discuss the significance of each of the photos and select the photos that corroborated the themes from the thematic analysis.

Our a-priori theoretical framework for analysis drew from Bronfenbrenner's Bioecological Theory Revision[30] and an adaptation of the US Institute of Medicine's healthcare disparities framework[31]. Our framework focused on three fundamental levels where barriers or facilitators to health services can occur: system, community, and individual (parent/family)[26].

Ethics

The University of Southern California Institutional Review Board (Ethical Clearance Number: UP-21-00992) approved this study. We sought verbal informed consent from all participants before they contributed to each of the study phases. Participants were asked to use pseudonyms in focus groups.

Language

We use identity-first language because it is the preference of many in the autism community[32–35]

FINDINGS

Diagnostic Odyssey

Two out of the three parents interviewed in this study sought professional medical opinions within the same month of their first concerns, while the third parent waited 17 months to seek a medical professional's opinion. All three parents reported the following traits in their autistic children: did not talk as well as other children, some speech skills were lost, problems with coordination, gross motor skills and/or fine motor skills, sleeping and eating problems, high activity level, and wandering.

The neuro-paediatricians in this study were the primary health professionals who gave official diagnoses of ASD to patients. They reported coming to the diagnosis with inputs from occupational therapists, speech and language therapists, and clinical psychologists.

"Because we do not have the standardized diagnostic tools, it's very important then to have the input from a lot of professionals before we make a diagnosis, and we make an effort to do that. Our clinic makes an effort to get the input from the occupational therapist, from the speech therapist, and the clinical psychologist if possible." **Doctor A, neuro-paediatrician**

According to the neuro-paediatricians, it takes an average of two to six visits over a duration of two weeks to two years or more to diagnose (see Figures 1 and 2 below, adjacent). Doctor B, a neuro-pediatrician in a private clinic, described having accessed to standardized diagnostic tools that significantly shorten the diagnostic process.

"so I usually start with an autism diagnostic interview revised schedule which is a detailed interview that helps to diagnose autism and then I do an ADOS, which is an autism diagnostic observation schedule, either from a module 1 to 4 depending on the communication level of the child, and then I usually would add, depending on the unique situation, I would-, I have a teacher interview questionnaire that I put together myself so I either talk to the teacher on the phone, or I give the interview questionnaire to the parents to give to the teacher, and then they fill it and drop it back, and then I add the Gillian Autism Rating Scale which is the GARS, and so I'd usually use these four, so the ADI-R, the ADOS, the GARS, plus the teacher interview before I make up my diagnosis." **Doctor B, neuro-paediatrician**

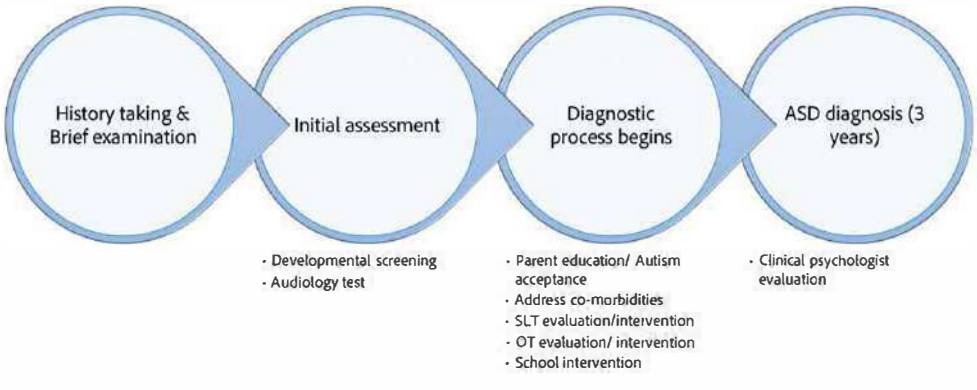

Figure 1: Doctor A's process (3-6 visits)

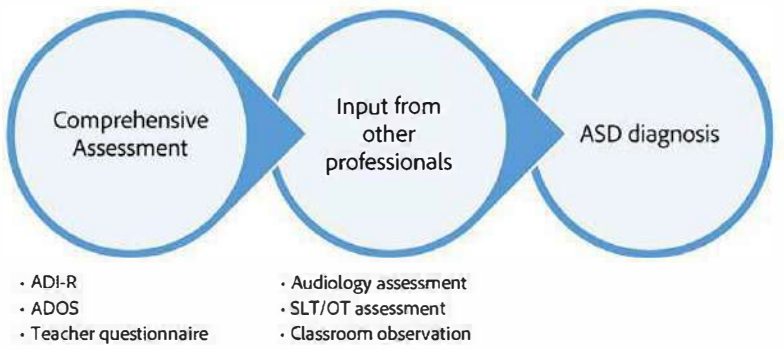

Figure 2: Doctor B's process (1-2 visits)

Factors Influencing the Diagnostic Odyssey

Our qualitative analysis yielded three overarching themes: 1) Systemic 2) Community and 3) Parent/Family factors influencing the diagnostic odyssey, each with subthemes on 'Barriers' and 'Facilitators'. Below we describe each theme with illustrative data excerpts.

Theme 1: Systemic Factors Influencing the Diagnostic Odyssey

Systemic Barriers: During the focus group with the health professionals, they noted that there is currently no official policy on diagnosing and managing autistic individuals in Ghana, and this caused the "burden of diagnosing" to weigh on some professionals. This lack of systemic support also caused disruption in service delivery, as some health professionals believed that the government was not doing much to financially compensate and retain professionals who are directly involved in the identification and diagnosis of autistic individuals. One of the neuro-paediatricians also pointed out that the government does not recognize autism as a "multifaceted diagnosis" that requires the resources of multiple sectors, including health, education, and social work, amongst others, which limits the services and supports available to autistic individuals and their families. There was also no governmental provision of autism services throughout the lifespan, and most existing services were tailored to autistic children. Doctor A, a neuro-paediatrician in a large hospital, said:

"Okay so I think one of the main challenges we have is that there's no official policy on the diagnosis and management of children with autism or even other neurodevelopmental issues as well, and so getting the support from the government system is very difficult, so everything depends on the staff who are choosing to make the diagnosis and that doesn't work at all because you need to have support from the government health system, acknowledging that there are children who are having these issues and need to be diagnosed, unlike most other conditions that you just need a clinician or somebody to put a diagnosis on, this a bit more complex so it needs to multidisciplinary, and it's difficult if the system where you work does not recognize the value of the multidisciplinary action need for autism. So, for me, I see that as a very big gap, because when you even make a diagnosis, autism is not just a clinical diagnosis, it's a social diagnosis, it's an educational diagnosis, you know... it comes with a lot of issues, so if you label a child, then what next? Which school is that child going to go to? Which social services are available to support the child and the parents? So, you know, it's difficult. Handling it as a clinical diagnosis when it should rather be a multifaceted diagnosis, you know with a lot of people coming in to provide the support."
Doctor A, neuro-paediatrician

Parents confirmed that they were only referred to receive medical services like occupational therapy and speech and language therapy after their children had been formally diagnosed with autism. Additionally, they had to bear the entire financial cost throughout the diagnostic process because autism, as a diagnosis, is not covered under the current National Health Insurance Scheme in Ghana. Araba, the mother of an autistic boy, described her financial ordeal:

"Our neuro-paediatrician put us on some medications, in which I earlier said, his father hardly cooperates; sometimes he'll buy it, sometimes he won't buy... then I have to go and look for funds and buy." **Araba, parent**

These parents therefore resorted to seeking out additional services and supports like diet modifications, spiritual consultations and interventions from religious leaders and special school enrolments outside the public health service to compensate for the insufficient governmental support. One of the parents, Araba, described how having limited options for services and support led her to reluctantly enrol her child in a special school because she felt pressurized by the recommendation of a therapist:

"So, I went to a speech and hearing centre somebody directed me to... They also did their assessment, and said he needs to be in a special school, that they would monitor him, they would help him with OT... and those things, and I told them that, I want him to be in a regular school so that he would do the therapies in addition,but they were like, looking at his state, he needs to be in that facility...So since they are also professionals, I didn't want to... you know, not listen to their advice, so we had to enrol him at the special school." **Araba, parent**

During the focus groups, health professionals also stated that the diagnostic and assessment tools needed for autism were costly and required trainings, making them inaccessible to the average practitioner in Ghana. This led to heavy reliance on multidisciplinary assessments, which were often prolonged due to limited collaboration and coordination amongst professionals. One of the two neuro-paediatricians who participated in the study used the ADI-R and the ADOS for diagnosing (see Figure 2 page 80) in addition to input from other professionals, she mentioned that she had received access to the "gold standard" tools and training when she travelled outside the country, whilst the other neuro-paediatrician stated that relied on mainly on the DSM-V, assessments from multidisciplinary professionals and free screening tools available on the internet including the Childhood Autism Spectrum Test[36], Modified Checklist for Autism in Toddlers (M-CHAT)[37], Checklist for Autism in Toddlers[38], Social Communication Questionnaire[39], and the Diagnostic and statistical manual of mental disorders: DSM-[540]. The assessment tools do not include the gold-standard diagnostic materials and have yet to be validated or contextualized for the Ghanaian population.

Other health professionals described using tools they downloaded off the internet or received from visiting colleagues from the global north. All health professionals acknowledged that they had to modify or adapt the tools they used because they were not entirely culturally sensitive. They explained that the way some of the questions in these assessments are phrased makes them difficult for clients to understand, thereby causing clients to answer inaccurately and skewing the results of the assessments. Also, due to cultural differences in activities, a child who is asked to roleplay a task like bathing a doll in an assessment may not meet all the requirements set by an assessment tool validated in a society where the task is performed differently.

Systems Facilitators

Participants listed neuropediatric specialist care, occupational therapy, speech and language therapy, behaviour therapy, and special education as the services available to autistic individuals. Educational and health professionals with knowledge of autism frequently referred clients to specialists who offered these services. Community health workers who were sometimes the first point of contact for autistic individuals and their families were particularly instrumental in the diagnostic process. Baaba, a parent of an autistic girl, narrated her experience with a public health nurse:

"For [my daughter's] diagnosis, we chanced upon it. She started school quite early, I think about a year and two months, and then here in Ghana, we have public health nurses who visit the various schools to give them their immunization when they are due, so one of the nurses observed her countenance in class, I think that was when she was a year and six months. So, they invited us-, the parents, they wanted to speak to us, so we went to the school, and she told us that she thinks our daughter is autistic..."
Baaba, parent

Health professionals from our focus groups also reported referring clients to one another, thus promoting multidisciplinary assessments and interventions. Some of these professionals worked in clinics which had designated multidisciplinary teams that worked with autistic individuals and their families. One of the neuro-paediatricians said:

"So, what helps the process is, if you are in a place...where most of the therapists and specialists are at the same place, that's very easy, so you can have everything done, even if it's not on the same day, it's in the same vicinity and people are knowledgeable to know and direct you as to where to go. So, I think that has been good facilitation, especially for Greater Accra."
Doctor A, neuro-paediatrician

The health professionals also pointed out that technological advancement made it easier to schedule assessments virtually and provide increased support for autistic individuals and their families. Doctor B, who is a neuro-paediatrician in a private clinic, said:

"Technology too has been very good for me. So, technology like, me just picking up the phone and calling the teacher, or me asking them to send me a video, so sometimes they'll say, "Oh, he does this thing." And we're doing [a] one hour [session] and he doesn't do it [within the session]. And then I say, "Okay, when you go home and he does it, take a video", and they'll take the video and send it to me on WhatsApp. So, technology has played a good role. I've done a couple of assessments by zoom also, it wasn't my comfort zone, but I've had to do some like that, and I think that's something we could look into, telehealth for diagnosis." **Doctor B, neuro-paediatrician**

Parents also reported that they had frequent contact with health professionals outside scheduled appointments, and this facilitated the parent-professional relationship and made the diagnostic process easier.

Theme 2: Community Factors Influencing the Diagnostic Odyssey

Community Barriers: Participants expressed that limited knowledge and understanding about autism, including 'early signs,' usually led extended family members, friends, and other members of the community to trivialize the parents' concerns. Esi, mother of an autistic boy, said:

"I realized, no, he's different....and I kept complaining to relatives and friends who were also coming to pick their wards, but then all they said was, "Oh, he's just a kid, he's going to improve with time." And I realized, I asked, "Kwame, how are you?" and he wouldn't say anything. "Kwame, how are you?" he wouldn't say anything... But I realized the other kids would respond, and my friends kept telling me, "Oh, he's just two [years old], with time he'll start talking...you need to be patient," but I was still worried." **Esi, parent**

Community members also had the tendency to attribute autistic traits to spiritual causes, making it difficult for families to initially accept diagnoses, often leading to social isolation of autistic individuals and their families. Baaba, who has an autistic daughter, said:

"We informed our family members, but they also didn't have an idea as to what the autism was about…So, they quickly related it to witchcraft…and it became a serious issue amongst our family... my husband's side and my side." **Baaba, parent**

Baaba also described her experience of community spaces that were not sensory-friendly and accommodating for her autistic daughter, leading the family to limit the use of these facilities.

"When we go to Church and there's music, the loudspeaker, [my daughter will] start screaming....when we're in a crowded area ... when we sit in a public transport, she hates heat...and when we sit in public transport and then the car stops-, she likes to be in constant motion...So maybe when there's traffic and the car halts, she'll scream till the car moves, but now she's stopped all these things, maybe it's because we're trying to stop taking public transport." **Baaba, parent**

Parents identified school enrolment as key to assessing their child's milestones and development. However, some participating health professionals pointed out that teachers and other educational professionals were not well equipped to identify early signs in autistic children and would repeatedly misinform parents about their children's school performance. Esi said,

"I think the first teacher I told, she was saying, 'Oh, with time he'll be better... it could be a delayed development,' that's all they were telling me, that with time he'll be better." **Esi, parent**

Community Facilitators. Participants described a Ghanaian culture of communal engagement and mentioned receiving support and assistance in caregiving roles from family members and friends who understood the autism diagnosis. After receiving an autism diagnosis for her child, Esi described receiving support provided by the teaching staff at her child's mainstream school:

"Because he's slow in getting what is taught in class, after class, the teacher pulls him to her side and then they go over the work all over again, yes, to make sure he understands what is being taught, so I realized an improvement in his academics, yeah." **Esi, parent**

Additionally, health professionals noted that there was an increasing trust in orthodox healthcare amongst the Ghanaian community, as individuals were more likely to patronize orthodox health services in addition to traditional medicine or spiritual intervention.

Theme 3: Parent/Family Factors Influencing the Diagnostic Odyssey

Parent/Family barriers: Both parents and health professionals identified denial of their child's autism as the major barrier to the diagnostic process. The parents' denial was mainly attributed to a lack of understanding of autism's aetiology and prognosis. Baaba described how she struggled to come to terms with her child's diagnosis and how this resulted in her being slow to follow through with the recommendations and interventions of health professionals'.

"When they said autism, quickly it was Down's Syndrome that came to mind... but after reading and then watching videos [about autism], it was difficult. I told you that we were in the denial stages, until about three, four, we had to accept that this is it... so when she [the doctor] diagnosed her, we were sad, but we knew that we had come to the crossroads and this is what we had to do, so we accepted it... we cried, cried, cried and then we moved on...." **Baaba, parent**

Other parent/family barriers identified were the absence of spousal support, time and financial constraints.

Parent/Family facilitators: All parents described a personal resolve to gain knowledge on autism and seek professional support once they had come to an understanding. They talked about reading books, seeking out resources, and consulting people with similar experiences. Esi said:

"I decided to read more about it, yes, I decided to read more on the net, to read more about autism..., what I can do to help calm him down, yes, so I read about it, and I realized, looking at the behaviours, I realized it's true he has autism, so I have to just accept it." **Esi, parent**

All three parents also talk about adopting multiple intervention approaches to address autism including seeking orthodox medical services, diet modifications and spiritual interventions. Araba said,

"As we are praying, I am also doing the therapy, visiting the doctor, making sure he gets his medication, you know."
Araba, parent

Baaba talked about how her husband assumed fulltime caregiving responsibility to assist her autistic daughter when there were not getting the needed services.

"So when my husband came, he resigned from his job to look after her at home... so my husband was in the house, taking care of her, training her... how to hold a cup to drink water, if she's thirsy where she'll go and fetch the water, and all those basic things, you know... feeding her properly, training her on how to eat, we had to train her ourselves at home... so that's what we did after we took her from that school. So, for two years, my husband singlehandedly managed her at home." **Baaba, parent**

Action Steps to Facilitate the Diagnostic Odyssey

During the second focus group with parents and health professionals, participants discussed key findings from phases one and two, came up with action steps, and voted on the order of prioritization of the actions. During the discussion, participants shared that whilst gaining a diagnosis was important, because as a diagnosis does not necessarily lead to funded services or supports, the Ghanaian population may benefit more from communal engagement and education about autism. In other words, early diagnosis may not be a top priority in this context but rather increased awareness and efforts to reduce stigma associated with autism. Because of this stigma, the focus group attendees also shared that some parents and families may prefer to seek private services and supports without a diagnosis as they come to terms with their child's diagnosis.

Based on the information presented and the discussion, the group members were asked to identify key actions to address the barriers and facilitate early and accurate autism identification in Ghana. The group identified four key action points and voted to prioritize them (see Figure 3 adjacent). The group prioritized in descending order, 1) Educating the larger Ghanaian population on autism, 2) Building the capacity of professionals to diagnose, 3) Educating families/stakeholders on caring for autistic individuals, and 4) Collaboration with international organizations to build research capacity in Ghana.

Five participants voted 'Educating the larger Ghanaian population on Autism' as the top priority, five participants voted that 'Building capacity of professionals to diagnose' be prioritized before 'Educating families/stakeholders on caring for autistic individuals, and 8 participants voted 'Collaboration with international organizations to build research capacity in Ghana' as the last priority among the action points raised.

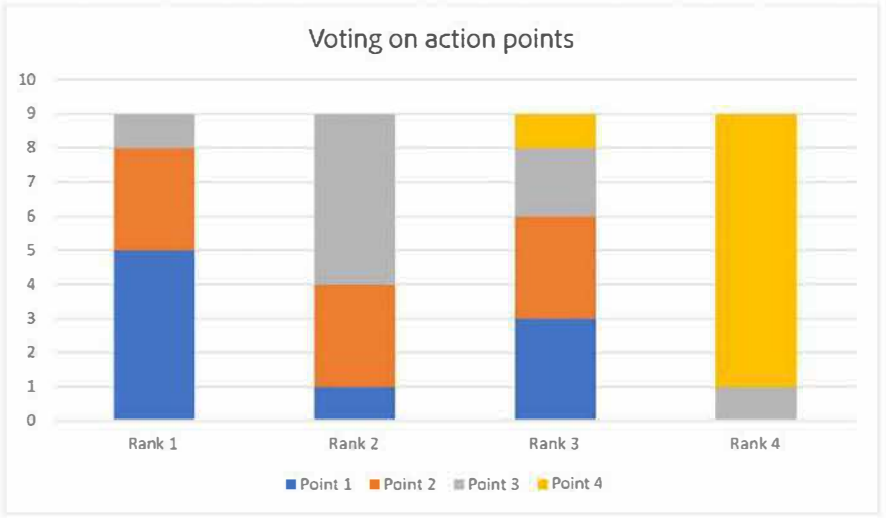

Figure 3: Nominal Group Technique Focus Group Action Points and Ranked Votes

DISCUSSION

In this study, we triangulated multiple data sources to map how autism is identified in the Greater Accra region of Ghana from the perspectives of parents and health professionals, identifying key barriers and facilitators influencing the diagnostic process. This study's findings largely corroborate the existing literature on autism in Sub-Saharan Africa and other developing countries and provide nuanced information on some intersecting factors influencing the autism diagnostic process.

Our study found that there was increasing awareness of autism in Ghana. Despite limitations, health professionals like neuro-paediatricians, medical doctors, occupational therapists, and speech and language therapists contribute to the diagnostic process with the available knowledge and resources. Consistent with other studies, we found that the barriers to the diagnostic process included: *assessment and diagnostic tools used in Ghana are not validated for the local population* [5,8], *there are few professionals in the region equipped to identify and diagnose autism* [15–18], *and that there is a significant stigma associated with autism* [18,22]. These challenges are more acute in the Ghanaian setting mainly because of the limited governmental support for autistic individuals and their families. Research has found that autism costs are high in developed and well-resourced countries mainly due to special education and medical care over the lifespan[41]. While most of these costs are subsidized by governments in developed countries, families and individuals in Ghana must pay out-of-pocket for limited services and support.

Through our qualitative analysis, and in line with previous research, we found that culture plays a role in participants' understanding of and response to an autism diagnosis[42–44]. Denial amongst parents of autistic individuals[45,46] was fuelled by a lack of basic information and the desire to dissociate from the structural stigma[47] surrounding autism. In their state of denial, parents isolated and excluded themselves from their communities. This was particularly problematic as participants in our study described a Ghanaian culture that values communal engagement and socialization. Previous studies have found that families of autistic individuals benefit from having strong social networks [48,49]. It is, therefore, not surprising that the highest-ranking action point from our nominal group

technique focus group was community education to dispel myths and encourage autism acceptance within the Ghanaian community.

Our study revealed that it was only after parents understood the diagnosis that they could accept it [50,51]. Therefore, during the diagnostic process, professionals involved had to educate and counsel families of autistic individuals continuously. Parents also showed resilience and innovation by seeking out information and resources during the 'diagnostic odyssey' [52].

Limitations

Study limitations include a small sample size of parents and health professionals and the absence of the perspectives of educational professionals and autistic individuals. Because we recruited parents from a neurodevelopmental clinic, the ages of diagnoses may not be representative of the general population. Future studies should include larger sample sizes and more diversified stakeholder participation. Researchers should also consider exploring the use of complementary and alternative medicine and therapies associated with autism in countries like Ghana, where there is limited information on the diagnosis and interventions. The strengths of the study include multiple perspectives and data sources, as well as the use of participatory approaches that enabled the identification of potential solutions and priorities that have social validity and are directly applicable to this setting.

CONCLUSION

This mixed methods study describes how autism is identified and diagnosed in the Greater Accra region of Ghana, highlights key barriers and facilitators to the process, and provides stakeholder-identified action steps to improve early and accurate identification, as well as understanding and acceptance of autism, in this context. The barriers and facilitators are grouped under systemic, community, and family factors, showcasing how multilevel intersectional factors contribute to the diagnostic odyssey. Systemic factors included resources and funding from the government, access, and affordability of services. Community factors included support networks and community education and awareness. Family factors included autism awareness and acceptance, financial status, and help-seeking behaviours. Stakeholders in the study prioritized community education to dispel myths and increase autism acceptance in the Ghanaian community.

Recommendations

Based on the findings of the study, we recommend that there should be a multi-level approach to addressing the barriers to obtaining an autism diagnosis. On the systemic level, there needs to be a multidisciplinary collaboration to develop, adapt and validate autism assessment and diagnostic tools for the local population. Collaborative partnerships between healthcare professionals, educators, and community leaders can go a long way to bridge gaps in understanding and services and create a holistic support system for individuals with autism. Governmental policies that prioritize research on autism within the Ghanaian context are needed. Efforts should be made to seek funding opportunities to support autism research and improve autism-related initiatives. This could involve funding services, therapies, and interventions to alleviate the financial burden on families and improve access to necessary resources.

At the community level, campaigns and educational initiatives that focus on dispelling misconceptions, emphasizing inclusivity, and encouraging communal support networks for families of autistic individuals should be implemented to reduce the stigma associated with autism and related conditions.

On the individual level, health professionals should play an active role in providing information, guidance, and emotional support to parents as they come to terms with the diagnosis. Efforts should be made to ensure families have easy access to accurate and reliable information about autism. This can empower parents to seek resources, understand their child's needs, and make informed decisions.

Authors' contributions

Joana Akrofi, Yvonne Brew, and Amber Angell conceptualised and planned the study, drafted and edited the manuscript. All authors contributed to the data collection and analysis and critically reviewed and approved the final manuscript.

Conflicts of interest

The authors declare no conflicts of interest

Acknowledgements

We would like to acknowledge the DREAmS Lab at the Mrs. T. H. Chan Division of Occupational Science and Occupational Therapy at the University of Southern California for the invaluable feedback and support during this research project. We would also like to acknowledge our participants for their time, contribution, and feedback.

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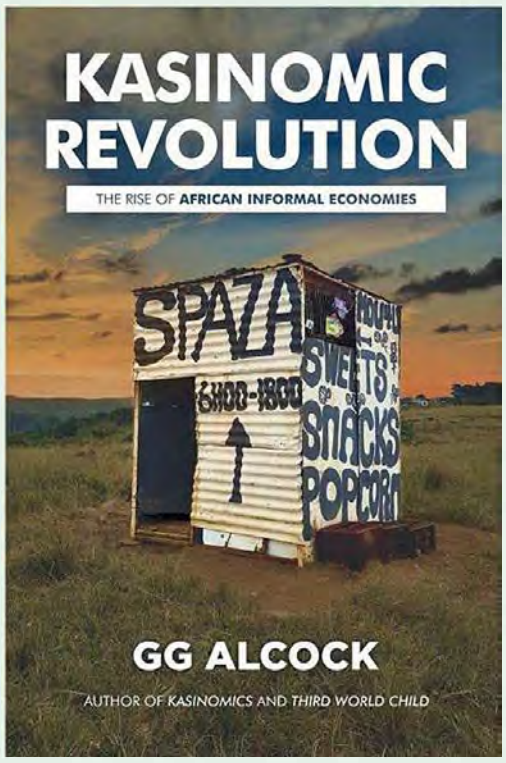

TITLE OF THE BOOK
KasiNomic Revolution: The Rise of African Informal Economies

AUTHOR
GG Alcock

INFORMATION ON THE BOOK
Published: 2018
Name of publisher: Tracey McDonald Publishers
ISBN: 978-0-6399264-7-6
e-ISBN (ePUB): 978-0-6399264-8-3
Available in Paperback: The price R295
Number of pages: 244 pages

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Declaration of bias: The reviewer has no biases to declare. He has no affiliation with the author or publisher

HOW TO CITE
Monareng LL. A review of: *KasiNomic Revolution: The rise of African informal economies by GG Alcock.* South African Journal of Occupational Therapy. Vol 53 No 3. December 2023. DOI: https://doi.org/10/17159/2310-3833/2023/vo;53n3a10

DATES
Received: 28 June 2023
Reviewed: Not peer reviewed
Accepted: 1 July 2023

ISSN On-line 2310-3833

A review of the book KASINOMIC REVOLUTION THE RISE OF AFRICAN INFORMAL ECONOMIES written by GG Alcock

Information about the author

GG Alcock is white and together with his brother, was raised in rural Msinga in KwaZulu Natal by activist parents who lived among the Zulu people. This was against the diabolic apartheid system which was ruling at the time. Consequently, his father was killed when GG was 14 years old. The family lived in a small mud hut beside the Tugela River without basic amenities. Like other boys in Msinga, GG spoke isiZulu and engaged in activities such as stick fighting, herding goats, and hunting birds in the bush and roasting them. Activities by the river introduced GG to business while helping locals cross the river using a ferry at a fare of 5 cents per person and an additional fee for luggage, such as a goat.

Later in life, GG hitch-hiked to Johannesburg, where he did odd jobs such as laying bricks. While in Johannesburg, his previous work includes but not limited to being a shebeen owner, servicing cars, political activist and community worker. GG's current roles and positions include author, founder of Minanawe Marketing, and speaker on various topics, e.g., entrepreneurship, the informal market, diversity and culture. The author is fluent in isiZulu, conversant in most South African languages and affectionately called *gamla or mlungu* (white person) by his peers.

Context and aim of the book

According to the author, this book *"is a murmur in the streets, a grassroots economic rising which has grown organically despite government and business regulation, and which is the future of African economic activity"* [1:xiii]. He is devoted and advocates for the informal economy in Africa. GG highlights how this sector is for an average person who works hard and needs support, not just handouts. He outlines the informal economy's significance and the practical support needed for its success and sustainability. The author also alludes to the legacy of apartheid in the South African context.

How the information is structured

The book has five main parts, each divided into short coherent subsections. These are outlined below. GG indicates awareness and understanding of African practices and traditions ranging from the food people eat, how they talk, diversity, realities, hardships, and values at the grassroots level. He uses his language skills and humour through anecdotes. Some of them are the dancing seller by the traffic lights (robot), the monkey who steals and smokes cigarettes, and the granny in the rural area who is transported to the grant pay-point using a wheelbarrow.

A summary of the main parts of the content

Part 1 KasiNomic Guerrillas

The author shares success stories of the *"unsung heroes of the KasiNomic Revolution"*[1:4] in the informal economy. He indicates that although nuances may vary, these businesses are similar across Africa. GG urges the government to do more to regulate and offer support as these businesses contribute to the economy. Among other things, he outlines the informal economy businesses by focusing on costs and profits, business owners' relationship with the law, working hours, number of dependants fed, inventory, business site, how they got into the business and the type of business. Some of the businesses he covers are The Kasi Greengrocer, which sells green peppers and cassava; Hardbody Chicken Dust, which sells home-reared or live chicken; and Golden Delicious, which sells *amagwinya* (a name for fat cakes in South Africa).

Part 2 KasiNomic Revolutionaries and Counter-revolutionaries In part 2, GG focuses on visionaries with sound value propositions in the informal economy. He takes the reader from the energetic dancing South African traffic lights street seller, through Zambia's *vitumbuwa* (a name for fat cakes in Zabian), east Africa's (Kenya) *boda boda* (motorbike), Nigeria's popular spicy snail soup to the Hello Paisa empire, which has offices in countries such as Malawi, Zimbabwe and the UK. GG describes multi-billion industries, such as the noodles in Nigeria and hairpieces, with reference to South Africa's dark days of the hair pencil test to hair recently being more than a fashion statement. The author is pro the informal economy, keeping its unique local flavour and relevance while receiving the necessary support to thrive. Hence, he applauds some businesses in the formal sector for assisting the informal economy while he warns against cultural appropriation and formalising the informal sector.

Part 3 A Retail Revolution Guerrilla vs Gorilla

In this part, he focuses on spazas (tuckshops), which are shared across Africa, e.g., referred to as *semausu* in Botswana and *nthemba* in Zambia. In South Africa, they are led by the groups of Bangladeshis, Ethiopians, Pakistanis, and Somalis, who own the majority, 85%, of South Africa's spaza shops. He highlights some of the sector's dark side while clarifying misconceptions about immigrants, their logistics of getting to South Africa, their economic contributions and how some build businesses from hawking to wholesale. Beyond the government regulating the informal sector and collecting tax, he proposes Afrocentric practical funding models such as the one developed in Kenya. He also appeals to highly skilled immigrant retailers to teach skills to locals in the informal sector.

Part 4 The Rise of the Afripolitan

The author outlines how Africans modernise while staying rooted in cultural practices such as performing rituals.The concept of community is addressed while hinting at realities such as hardships between communities of the haves and have-nots, which can be traced back to the Group Areas Act of the apartheid government. Moreover, he highlights Africa's uniqueness and that brands targeting these communities should have their finger on the pulse if they are to appeal to them.

Part 5 Africa Rising

GG focuses on economies and businesses that Africans are already engaging in. He unpacks their value chain and reiterates that a better and more sustainable approach is needed to embrace African cultural practices in this modern day.Some businesses are shisanyama, sphahlo,veterinary, muti, goats, and property ranging from backroom rentals to building a house *"brick by brick"*[1:208]. GG puts it into perspective when he shares the story of Omphemetse, who does not qualify for a home loan in the formal sector and uses the brick-by-brick strategy to build herself a decent house.

The author ends by saying, *"I [GG] drive out, turning right at the new Shoprite, and the light blue board offers me 'That home loan from the bank that says YES more often. How can we help you?" I wonder what Omphemetse thinks when she sees that sign?"*[1:230].

Conclusion

The author restates the need for Afrocentric systems, such as building modern villages to accommodate Africa's uniqueness. He condemns the practices of marginalising the informal economy as it contributes to countries' Gross Domestic Production (GDP). GG alludes to the fact that jobs are now beyond the conventional *"8 to 5 job with a payslip"*[1:242] and that communities of ordinary people should not be treated as "breeding grounds for employees"[1:241]. Moreover, he highlights that the colonial and Western systems are unjust to the masses in developing countries. Africa needs no *"bicycle lanes but hawker lanes"*[1:243] where they can trade closer to their clientele without fear of municipalities chasing them.

Relevance of the book

To Africa

Africans' rejection of the encroaching imperial, colonial and Western ways predates the 1884-1885 Berlin conference, which constituted invading Africa. In various spaces, Africans such as Professor PLO Lumumba, Dr Chika Onyeani and Mr Julius Malema still reject these ways and agree that Africans should be producing more and not consuming exports that are not contextually relevant.

Academics support the idea of contextually relevant knowledge, evident in their discourse and deployment of words and phrases such as Afrocentric, decolonising, re-configuration, recurriculation, reimagining and trans-formation. Ramagondo's (2015) work on occupational consciousness[2] and her 2018 World Federation for Occupational Therapy (WFOT) opening keynote speaker speech[3] puts the above into perspective. GG's book is exemplary and narrates realities in Africa, insinuating that there should not be a plug-in-and-play of imported content for Africa.

To Occupational Therapy

The occupational therapy profession is 81 years old in Africa[4], with thousands of registered therapists, professors included, but its pedagogy seems to remain Western and colonial. For instance, prescribed and recommended classroom content such as textbooks, standardised assessments, practice frameworks, and models are not near advocating African realities. The paucity of level 1 research[5] will maintain, if not perpetuate, the colonial status quo. GG's book, a gift to the profession, demonstrates a fertile ground for level 1 research. Colleagues, especially those doing community work and/or vocational rehabilitation, are invited to peruse the book's case studies in parts 1 and 5, respectively, and to find creative ways to share these with, e.g., students. These can add to the occupational

therapy convenient intervention sessions such as face-washing and Morabaraba games.

GG's solution-driven work shows his allegiance to Africa, and it is inspirational. On the other hand, people like Rick Ross, a serial entrepreneur and an artist, get inspired by small to grand work[6:38min]. I can relate to the above as I draw inspiration from basic to iconic deeds. For instance, I could get inspired from:

- ✓ the freelancer who at times a) assists with grocery bags, b) poses as a car guard in a reflective jacket or, c) self-appoints to wash people's cars without their permission whatsoever. His pay ranges from a hand-to-mouth-gesture, a sign of asking for food or a nomayini, signifying anything you have on you;
- ✓ Malusi Langa who packaged his PhD work into a book[7];
- ✓ a fully-fledged professor securing a multimillion grant for a sizable project divided between key role players ranging from international colleagues in academia to clinicians and community-based workers on the ground; to
- ✓ the resistance against the omnipresence of slavery by Queen Njinga Ana de Sousa Mbande of the Kingdoms of Ndongo and Matamba (now Angola).

A common thread from the aforementioned is bringing thoughts to life. In Sepulana, my home language, we say: *mmereko o tšhaba matsogo* "put in the work"; *sethogo se baba mongwayi,* "scratch your own itch", i.e., something occupational therapy in Africa could benefit from.

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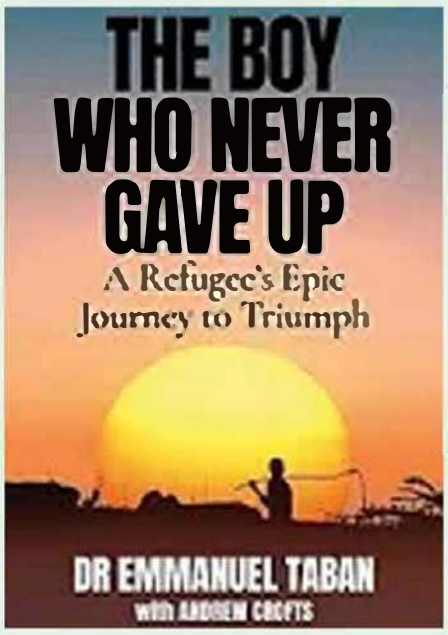
[BOOK REVIEW]



TITLE OF THE BOOK
The boy who never gave up. A refugee's journey to triumph

AUTHOR
Dr. Emmanuel Taban with Andrew Crofts

INFORMATION ON THE BOOK
Published: 2021
Publisher: Johnathan Ball Publishers, RSA
ISBN number: 978-1-77619-126-0
Available in: Paperback - ZAR 267.64
Number of pages: 248 pages

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Declaration of bias: The reviewer has no bias to declare. The author, Dr Emmanuel Taban, happened to be a doctor in the same area facility as the reviewer, Midstream Hill Medical Park, but they do not work together.

HOW TO CITE
Masango J. *A review of: The boy who never gave up. A refugee's epic journey to triumph.* South African Journal of Occupational Therapy. Vol 53 No 3. December 2023.
DOI: https://doi.org/10.17159/2310-3833/2023/vol53n3a11

DATES
Received: 28 June 2023
Reviewed: Not peer reviewed
Accepted: 1 July 2023

ISSN On-line 2310-3833

A review of the book THE BOY WHO NEVER GAVE UP written by Emmanuel Taban and Andrew Crofts

Information on the authors

The book is an autobiography, of Emmanuel Taban's life. Dr Taban, a pulmonologist who currently resides and practices in South Africa wrote his memoirs with Andrew Crofts, a well published author and ghost-writer. Born 1979 in South Sudan, Emmanuel Taban was one of five children. At the age of 14 years old, he was tortured by Sudanese government forces, when he was 16 years old, he was forced to convert to Islam and shortly thereafter he fled the civil war-torn Sudan. Not knowing where to go he ended up in a refugee camp in Eritrea. From here he embarked on a perilous journey south, frequently spending weeks on the streets, and encountering many perils. He trekked south to South Africa by bus and on foot, through Ethiopia, Kenya, Tanzania, Mozambique, and Zimbabwe, relying on the kindness of strangers. Arriving in Johannesburg, South Africa 18 months after he left Sudan. He was determined to finish his education and with the aid of Catholic missionaries, he completed high school, enrol in medical school, qualified as a doctor, and specialize in pulmonology. A crucial finding in the treatment of hypoxaemia COVID-19 patients was made by Dr Taban, because of his competence and dedication as a doctor and his tenacious refusal to be deterred by setbacks. This son of Sudan has overcome tremendous poverty, racism, and xenophobia to become an internationally renowned South African pulmonologist, by never giving up. Andrew Crofts is a ghostwriter and author who has published more than eighty books http://andrewcrofts.com/.

The review

If ever there was a person who embodied passion, perseverance, and constancy, it would be Dr. Taban. He embodies these essential success factors to a tee. The book tells his remarkable life journey. From the worst forms of displacement, homelessness, poverty to freedom and success, a journey of complete transformation and change. Dr. Taban developed his three success principles, which are consistency, passion, and determination (p 243) based on this life experience.

The book has fourteen chapters. It takes the reader on a trip through Dr. Taban's personal experience. *If there was ever a book that deserved to have the word 'epic' in its title, this is it*, as another reviewer[1] of the book puts it. The best thing is that this story is based entirely on true events. The first section of the book describes Dr Taban's upbringing and the challenges he faced in Sudan and conquered. Even though he was raised in a world of extreme poverty, where the entire family resided in a mud cottage with few supplies, he recalls his home as a *loving household.*

The book unearths and reveals the most heart-breaking truth about our African struggles —poor leadership, inequality, and poverty. Sudan is a resource-rich nation, like many other African nations, but it lacks morally strong leaders who could guide it and provide adequate leadership. Dr Taban overcame all of these challenges and adverse situations stronger and more successful. The book describes his upbringing; how he frequently found himself in the thick of civil strife, and how he was not unfamiliar with the bodies of human beings. As a child from a low-income family with few means, Dr Taban's life is essentially the narrative of his struggles to obtain an education. He was imprisoned while pursuing his study, tortured after being suspected of giving information to the enemy. The book details Dr Taban's arduous trek to South Africa. Recounts the many adventures he had while traveling, including living on the streets, traveling occasionally by bus and getting into trouble with the law.

The book bears witness to the fact that churches served as beacons of hope. When Dr Taban arrived in a new city and had nowhere to go, he would seek refuge and aid at churches. Mostly, these would be Catholic churches. Here he was given food, temporary housing, and money. When he arrived in South Africa, he sought refuge from a life on the streets once more by visiting a Catholic church. Here he was helped to get a job, finish high school, and enrolled in medical school, graduating in 2004. In chapter 11 Dr Taban describes his first visit back to Sudan, after his graduation as a medical doctor, under the heading: A painful reunion. There seemed to be nothing positive happening anywhere in his home country, and he criticizes both the politicians and the state of the nation. In the end, Sudan would be divided into two, with South Sudan being founded in 2011. He returned to South Africa and today Dr Taban is recognized as one of the few black pulmonologists practicing in South Africa and with the advent of the COVID-19 pandemic he received international recognition for his work.

Personal reflection of the reviewer, relevance to occupational therapy, South Africa, and Africa at large

The story of Dr Taban elucidates a sad reality that is experienced by many South African occupational therapists, - students, - clinicians and even the patients that we treat, who are from underprivileged backgrounds. It is an undeniable reality that in Africa inequality, poverty, financial hardship, poor leadership and lack of access to resources, still leads to severe occupational injustice and occupational derivation. The lack of exposure and stimulation to a living soul, with no resources and no sense of hope, can account to the constant rise in unemployment rate in the country and ultimately poverty. These factors have a negative impact on occupational engagement and occupational performance.

However, there is an interesting phenomenon that is difficult to understand and one can only make sense of it in hindsight. Despite the environmental difficulties, hurdles and hardship, Dr Taban consistently applied himself, and he never felt sorry for himself. He was determined to be educated, to transform his mind and ultimately change his life and build a better future for his family. He was probably cornered to apply and experience a deeper sense of personal causation and self-efficacy. When we are cornered as human beings, and fight for survival, we learn to trust our instincts, we become intuitive, and rely on the unseen powers and unlimited supply. We surrender to life and become hungry for opportunities. We become humbled and connect to the true deeper sense of life.

Though things seemed not to be favourable to Dr Taban in his journey, I strongly believe that there were some things that were recalibrated in him. He was building capacity and resilience. Truths that must be taught to younger generations *who have life easy*. To not give up when faced with hardship in life. To develop a *consolidated task concept*. The story of Dr Taban reminds me of our late former President Nelson Mandela's journey and specifically his speech during the Rivonia Trail[2]: *"During my lifetime I have dedicated myself to this struggle of the African people. I have fought against white domination, and I have fought against black domination. I have cherished the ideal of a democratic and free society in which all persons live together in harmony and with equal opportunities. It is an ideal which I hope to live for and to achieve. But if needs be, it is an ideal for which I am prepared to die"*. This book supports what we know, that South Africa and Africa need good leaders, current and in the future, who not only seek to empower themselves. It shows how it takes a deeper level of faith and vision to be able to endure hardship and hope for a better future and liberty for all people. Dr Taban's story reminds me that *where there is a will, there is always a way!* One just needs to believe in the small light that they possess in them, and trust in the journey, trust the process! Live in the now, tomorrow will sort itself out. We are only assured of today!

Personally, I can deeply connect with this book. Reading it I had goosebumps throughout most parts of the book and tears here and there, because I could identify with what the writer was going through. It was an emotional read for me! Though not as intense as he did but having to overcome the hardship, and having to live in the things that are not as though they were, keeping the hope alive, having faith and trusting the process and cycle of life – always having to take leaps of faith, in my walk as an occupational therapy student, and professional.

As a qualified occupational therapist, and PhD candidate, I remember when my academic and professional journey started. It was in grade 7 that I started selling maize (just like the boys who stand at the robots in Gauteng, and sell maize, I was one of them). I had no options, and my parents could not afford to buy me clothes and other essentials for primary school, such as school uniform. For me, it was at the University of the Witwatersrand that I started to use a bathtub, shower, eating nice meals at res and being exposed to all the fancy things that I am now enjoying, later. To others these were normal, but to some of us these were fascinating! Then, it makes me wonder how many other African people today, still undergo the same experiences that I did? Just like the great Dr Taban? And yet, this is not taken serious by the government authorities.

For me, I knew nothing about occupational therapy, as a scholar. It took a high school teacher to identify potential in me. He thought that I would be a good occupational therapist and

he listed it as one of my study options, when I was accepted by Wits. The journey was rather rough, from teaching myself how to speak English, to having serious inferiority complex among the white fellow students, overcoming the failing of my first and third years due to inability to understand concepts, sleeping in the library while waiting for my psychology supplementary examinations, not having food at res, being kicked out of res after failing, and traveling with a taxi from Ivory Park, where I was squatting with my sister (sleeping on the floor, for the entire term).

Despite all these experiences, one thing that I can say about occupational therapy is *that it transforms the person that you are.* You must allow the truth of knowledge to hit your heart and have you change the way you live, then you can be a good example and possess great therapeutic use of self. Unfortunately as therapists, we cannot be hypocritical – i.e. preaching self-care to our patients, yet we do not take care of ourselves. All of these challenges and suffering produce perseverance; perseverance, character; and character, hope. These circumstances develop and build resilience in life, Nelson Mandela suffered for the nations, because he had a goal in mind and he was willing to die for it. How we need more such leaders. May God bless Africa!

This book is a must read for all occupational therapists especially those working and living in Africa.

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