### **EDITORIAL COMMENT**

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# COVID-19 - what did/can we learn from this?

"Persistence and resilience only come from having been given the chance to work through difficult problems." Gever Tulley

ur country has only recently started to recover from the devastating effects of the global CO-VID-19 pandemic. These effects impacted every single sector in our society in different ways and in particular, our health and educational sectors. Whilst acute health services were focused on and over-burdened with battling the pandemic, other health sectors such as the care and treatment of chronic and long-term diagnoses and rehabilitation services, were temporarily either suspended or put on the back burner. Primary, secondary, and tertiary education sectors also faced extreme disruption during this time.

These events called for *resilience*: the process of adapting well in the face of tragedy, trauma, threats, or other significant sources of stress. It called for novel and innovative strategies and plans from the healthcare and education providers in an attempt to lessen this impact, not only on the recipients, but also on the providers of these services.

One innovation which has made it easier to adapt to the lifestyle changes thrust upon us by the pandemic, is the use of technology in the classroom and in the delivery of health care. *Telerehabilitation* and the *virtual classroom* are but two examples of the resilience and innovation shown by clinicians and educators respectively during this time.

In this edition, we feature two articles related to CO-VID-19 pandemic: one explores the possible effects of the COVID-19 lockdown on occupational therapy clients<sup>1</sup>, and one comments on the experience of students<sup>2</sup> who, as part of their curriculum requirements, needed to complete a research project without having access to clinical areas due to lockdown. We also plan to publish more related articles in our future editions.

As an occupational therapy journal in Africa, we also know that when such crises come about, the most vulnerable persons in our communities suffer the most. As occupational therapists, our concern is for the most vulnerable persons: the children, persons with disabilities and older adults. This edition features articles on children: one that looks at the promotion of play engagement of children with autism<sup>3</sup> and one that investigates the normative data of two standardised tests to the sensory integration function of South African children<sup>4</sup>. There is also an article on stroke rehabilitation and the therapeutic use of

constraint-induced movement therapy<sup>5</sup>. Death and dying is another element that the COVID pandemic has brought to the fore and Ramano et al's article<sup>6</sup> explores the role of occupational therapy with bereaved individuals. The resilience of the human spirit is also described in the two books reviewed in this edition. The one on taking care of elderly loved one's within your own home<sup>7</sup>. The other shares how masculinity develops in South African townships<sup>8</sup> and the value of mentors and stand-in parents that allow boys to take up non-conforming and non-hegemonic identifies and achieve their personal long-term goals despite the circumstance they grow up in.

Many scholars have recently expressed doubt on whether the publication sector should, at this time, focus on disseminating information on strategies and approaches arising from this latest global crisis. They are of the opinion that it is now 'information after the fact' since globally, the pandemic has been largely under control for 6 months. We, at SAJOT, disagree. There are many threats facing our planet and humanity in general. For example, we know that in Africa, the announcement of life-threatening viruses. such as the current outbreak of Ebola in Uganda9, is an ever-present threat. We believe that access to information, resources, and innovations used and developed, especially during challenging times, helps ensure our resourcefulness and agility in our future responses. Such access could further identify gaps, challenges faced, and successes achieved, and can be integrated into future preparedness and responses when the next crisis hits. None of us can predict when it will occur, or what it will entail; but we have to ensure that we are prepared.

#### Blanche Pretorius Editor in Chief: SAJOT

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### RESEARCH ARTICLE

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# Comparison of the sensory integrative function of South African infants to normative data on two standardised tests

#### **ABSTRACT**

**Background:** The Dunn Infant Toddler Sensory Profile and DeGangi's Test of Sensory Functions in Infants are two standardised tests that are widely used by South African therapists to assess sensory integrative function in infants. There is, however, no research available on the validation of these standardised tests for a South African population. This research determined whether the normative data established in the United States of America on the Infant Toddler Sensory Profile and the Test of Sensory Functions in Infants were valid for use with South African infants between the ages of 7 and 18 months.

**Methodology:** A quantitative cross-sectional, descriptive, correlation study design was used to investigate the equivalence between the normative data from the United States of America and a sample of typically developing South African infants.

Findings: The results indicated that the mean scores for the South African sample in five of the six processing sections of the Infant Toddler Sensory Profile and all quadrant scores, were in the lower range of the typical performance according to the normative data of the United States of America. On the Oral Processing Section and the Sensation-Seeking Quadrant, test results should be interpreted with caution due to the medium effect size indicating clinical differences to the reported norms. A higher percentage of South African infants had a clear definite difference "more than others" score compared to normative data from the United States of America. On the Test of Sensory Functions in Infants, the means of the frequency distribution for deficient, at risk, and typical for all five sections and the Total Test Scores for the South African sample were significantly different from the normative data of the United States of America and the mean scores fell into the lower range or below the range for the typical performance reported in the test manual. **Conclusions and recommendations:** The Infant Toddler Sensory Profile can be used without substantial re-norming based on the findings related to this South African sample. Due to significant differences in scores on the Test of Sensory Functions in Infants, the first author questions the use of the test and recommends further research on South African infants with a larger population group. However, it should be noted that this study had a small sample size and therefore the results should be interpreted with caution and cannot be generalised.

#### INTRODUCTION

Assessment is an essential first step in the occupational therapy process and guides the planning, the type, and intensity of intervention<sup>1,2</sup>. An accurate and valid assessment is important and supports evidence-based practice<sup>2</sup>. Therapists should ask if standardised tests have been validated in the population they are treating, as research has shown that populations often differ in their normative data due to environmental and cultural influences in response to assessments<sup>3</sup>. Thus, it cannot be assumed that the norms of the test manual of a standardised test automatically apply to a different population.

However, before embarking on substantial re-norming of any standardised test, the applicability of the published norms to a specific population should be investigated.

Several researchers, including Anastasi and Urbina<sup>4</sup>, Downing<sup>5</sup>, and Streiner et al.<sup>7</sup>, have reinforced the importance that, in addition to the studies completed by the test authors, independent investigators conduct further psychometric tests on populations other than those assessed by the test authors. These investigations of standardised tests assist in confirming the validity of the published test norms for the population with which they will be used.

The Infant Toddler Sensory Profile (ITSP)<sup>6</sup> and the Test of Sensory Functions in Infants (TSFI)<sup>7</sup> are widely used by South African occupational therapists<sup>8–10</sup>. However, there appear to be no published studies on normative data for populations other than in the United States of America (USA), where the tests were developed. Some international studies have been published that consider the psychometric properties of the Sensory Profile for other populations of older children<sup>13</sup>. One such study conducted by Brown et.al<sup>11</sup> in Australia, found differences between the USA norms reported in the test manual and their study group. This reinforces the need to investigate the diagnostic properties of ITSP<sup>6</sup> and TSFI<sup>7</sup> to establish evidence for the efficacy of these tests<sup>12</sup> for the South African population where research indicates that the tests are used in both clinical practice and research<sup>10,13,14</sup>.

#### **Literature Review**

Sensory development begins during the prenatal period, with the tactile and vestibular systems playing a primary role in the early development of sensory integration. In 1972, Ayres<sup>15</sup> defined sensory integration as "the neurological process that organizes sensation from one's own body and from the environment and makes it possible to use the body effectively within the environment" 15:11. According to Ayres 18, as information enters through the senses, sensory integration takes place, which leads to planning and organising of behaviour. This in turn leads to an adaptive response, as well as learning, and the emergence of occupational engagement and social participation<sup>16,17</sup>. Feedback that occurs leads to the process of restarting another cycle of sensory information intake and adaptation<sup>17</sup>. Actions are then planned according to the interpreted sensory input<sup>16-18</sup>. Each individual has a unique regulatory sensory processing profile, which implies that each person has a different response to sensations, and an individual's sensory processing profile influences the way sensations are interpreted and comprehended.

Therefore, sensory integration has a significant influence on development and is fundamental to the learning, perception, and action of any individual<sup>19</sup>. Inconsistencies in the central nervous system's ability to process sensations lead to poor sensory modulation and/or poor praxis<sup>17</sup>. This can result in difficulties with processing or organising the sensory information needed by the individual to understand their bodies and the world around them<sup>20</sup>. Such difficulties have been named sensory integrative dysfunction (SID). Dysfunction has been reported to occur in all or just some of the sensory systems. Sensory integrative dysfunction can be identified from a very early age and has been found to

lead to the development of dysfunctional parent-infant interaction patterns. These dysfunctional interaction patterns, in turn, have been reported to be affected by the temperament of the infants and have an impact on later learning and emotional development<sup>21</sup>. Since SID has been reported to have consequences for normal development, an accurate assessment of SID in infants is important to correctly identify and treat from an early age, thus facilitating normal development<sup>22-24</sup>. Accurate assessment and early intervention can prevent or minimise the development of behavioural problems, participation restrictions in activities of daily living, and educational activities in childhood<sup>21</sup>.

A method to ensure a valid assessment of sensory integration is to use standardised tests. An advantage of standardised tests is objectivity and quantitative scores<sup>25</sup>. This allows for a valid assessment that leads to focused treatment to address specific dysfunction. A limited number of standardised tests are available to assess SID in infants. A systematic review by Eeles et al.<sup>28</sup> found only three assessments of sensory processing function in the age group from birth to two years. These were the Infant Toddler Sensory Profile (ITSP)6, the Test of Sensory Functions in Infants (TSFI)7, and the Sensory Rating Scale for Infants and Young Children by Provost and Oeter<sup>26</sup>. All three tests evaluate slightly different constructs of sensory processing function, and therefore comparing the results of the tests is difficult<sup>27</sup>. The ITSP and the TSFI assess components of sensory processing and sensory modulation within sensory integrative function<sup>6,7</sup>.

The TSFI<sup>28</sup> is based on the Ayres<sup>15</sup> model of sensory processing and identifies adequate sensory processing and reactivity, in five areas of sensory functioning that develop over the first year of life. That is, tactile deep pressure and reactivity to vestibular stimulation that develop early in infancy and visual-tactile integration, adaptive motor responses, and ocular-motor control that develop slightly later. These subdomains were specifically chosen because they are clinically significant in identifying infants with sensory integrative dysfunction and, particularly, infants at risk of developmental delay, as well as those with difficult temperament<sup>28</sup>. The ITSP is based on Dunn's<sup>13</sup> conceptual model and considers sensory modulation in five sensory processes, placing the interaction between the neurological threshold and the behavioural response on a continuum in four quadrants. The quadrants reflect the neurological threshold, or the number of stimuli needed for the central nervous system to notice or react to stimuli and activate a behavioural response, which indicates the manner in which the infant/child responds to the thresholds. At one end of the continuum, thresholds are high, and more stimulation is needed for the child to notice and react. On the other end of the continuum, the thresholds are low, and the amount of stimulation needed for a child to notice or react is low. Children respond to counteract their thresholds, and a child will either respond passively to the stimulus or exert excessive energy, to respond to the threshold. Quadrant 1: Low Registration and Quadrant 2: Sensation Seeking indicates

different high-threshold responses. Quadrant 3: Sensory Sensitivity and Quadrant 4: Sensory Avoiding indicates different low threshold responses. The ITSP provides a profile of the effect of sensory processing on functional performance in the daily life of the infant<sup>29</sup>.

Both ITSP and TSFI are norm-referenced assessments, where the individual's performance is compared to the performance of other individuals or a normative group. Comparison with others in the reference group is important as both tests are based on observation of infant behaviours, which can only be objectively assessed compared to other infants to identify dysfunction. Although norm-referenced assessments are the most common form of standardised tests<sup>25</sup>, a disadvantage of this is that the norms provided do not necessarily reflect the normal population within all socio-economic backgrounds and cultures<sup>30</sup>. Therefore, it is important to determine whether a standardised test is appropriate for the population in which the therapist intends

This study investigated whether the normative data established in the USA on the standardised ITSP6 and TSFI7 tests to assess sensory integrative function in infants, could be applied to South African infants between the ages of 7 and 18 months.

#### **METHODOLOGY**

#### Study design

To address the purpose of this study, a quantitative crosssectional, descriptive, correlation study design was used to investigate the equivalence between the normative data of the USA and a small sample of typically developing South African infants.

### Study population

Convenient cluster sampling was used to recruit 60 typically developing infants between the ages of 7 and 18 months of age from 17 child day-care facilities in the East Rand area of Gauteng, South Africa. A sample size was calculated using the population of the possible number of infants (approximately 140 infants) in the 17 child day-care facilities. Cochrane's formula was used, to determine that a sample size of 60 participants was needed to represent the population with a 5% margin of error<sup>31</sup>.

#### **Inclusion and Exclusion Criteria**

Full-term infants, born between 37 and 42 weeks of gestation, were included in the study. Infants with a diagnosed birth defect or gestational illness were excluded.

#### **Research Tools**

Three research tools were used to collect data for this study. Demographic sheet - A demographic sheet developed by the first author was used to collect personal information from both parents and the infant. The information collected included parental history, information regarding pregnancy and birth, as well as the medical history of the infant. Infant/Toddler Sensory Profile - is a parent questionnaire that provides scores for infants between the ages of birth and 36 months. There are two classification systems for the ITSP, one for infants aged birth to 6 months and one for infants aged 7 to 36 months. Due to the lack of test-retest reliability and the low coefficient alpha scores for the birth-to-6-month age group, only infants from age 7 months were included in this study. As the TSFI can only be used up to the age of 18 months, infants older than 18 months were excluded from the study.

Parents completed the 48-item judgment-based questionnaire. Each item is judged on a five-point scale that reports the frequency with which infants respond to various sensory experiences. After the parents completed the form, the first author used the specified scoring procedure to complete a summary score sheet indicating both section and quadrant scores. The quadrant grid was completed by assigning scores to the different responses in the following way: a score of one to 'almost always', a score of two to 'frequently', a score of three to 'occasionally', a score of four to 'seldom', and a score of five to 'almost never'. Scores were then added to calculate the total score for each section and quadrant. Once this step was completed, the scores were transferred to a quadrant summary to indicate the range each quadrant score fell within. Each quadrant score falls into the following ranges on a normal distribution (Gaussian) curve (Figure 1, page 9):

- Typical performance range: Scores between +1 SD and -1 SD.
- · Probable difference "less than others/more than others": Scores between -1 SD and -2 SD are described as probable difference "less than others" and this indicates under-responsiveness. Scores between +1SD and +2SD are described as probable difference "more than others" and this indicates over-responsiveness.
- Definite difference "less than others/more than others": Scores less than -2 SD are described as definite difference "less than others" and this indicates under responsiveness. Scores above +2 SD are described as definite difference "more than others" and this indicates over responsiveness (Figure 1, page 9).

Test of Sensory Functions in Infants is a therapist-administered observational test. It is used as a screening tool for SID in infants and is especially valuable when used in conjunction with other developmental tests. This test was standardised for infants between the ages of 4 and 18 months and is specifically recommended for infants with regulatory disorders, developmental delays, and infants that could be at risk of developing sensory processing or learning disorders7. The test consists of 24 items divided into five sub-tests of sensory processing and reactivity. These sub-tests are Deep Pressure, Adaptive Motor Functions, Visual-Tactile Integration, Ocular-Motor Control, and Vestibular Stimulation<sup>7</sup>. Scores fall into the following ranges on a normal distribution (Gaussian) curve (Figure 1, page 9):

- "Normal" range: Scores above -1 SD.
- "At risk" range: Scores below -1 SD but above -2 SD.
- "Deficient" range: Scores below -2 SD.

#### **Research Procedure**

Ethical approval (M110830) for this study was obtained from the Human Research Ethics

Committee (Medical) at the University of the Witwatersrand. The managers of the 17 child day-care facilities granted per-

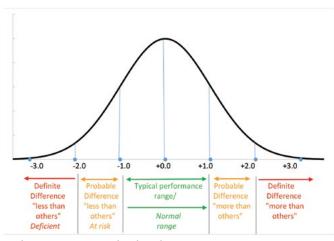


Figure 1: Normal distribution for the score ranges of the ITSP and TSFI

mission for the research to take place in their facility. Managers and teachers handed envelopes to parents containing study information as defined in an approved information sheet and consent forms. Once parents consented to participate by signing the consent forms, they completed the biographical questionnaire and ITPS and these were returned to school in a sealed envelope. The first author then assessed all eligible infants using the TSFI with the help of the teacher of the infant. The teachers' assistance consisted of holding the child on their lap according to the test procedure set out in the test manual<sup>7</sup>. After collecting all data, the tests were scored according to the procedure in the test manuals<sup>6,7</sup>. The data were then transcribed into Excel spreadsheets for analysis.

#### **Data Analysis**

Demographic data, as well as raw scores from both ITSP and TSFI, were descriptively analysed. To compare the scores of ITSP and TSFI, the z-scores of both tests were used and the frequency data were calculated for each component. For both ITSP and TSFI, the mean scores of the South African sample were compared with the range of scores provided for typical infants and toddlers from the USA. This was done for each subtest according to the age bands in the manuals. The significant difference using a chi-square test as well as the effect size (Cohen d)<sup>31</sup> was calculated for the means on the ITSP since the mean values were available in the manual. The effect sizes, which are independent of the sample sizes. confirmed the standardised clinical differences between the South African sample and the USA norms. Since no mean scores have been published for the TSFI, except those for dysfunctional infants<sup>32</sup>, it was not possible to calculate effect sizes (d, Cohen)33 for the raw score data.

For all sections and sub-tests on the two measures, the percentage of participants scoring in each of the standard deviations was compared to the normal distribution. The significance in the frequency of the scores according to typical, probable, or definite differences for the ITSP and typical or deficient (-2SD) or at risk (-1SD) for the TSFI were calculated using a chi-square test.

#### **RESULTS**

The study population consisted of 34 males (56,7%) and 26 females (43.3%). The participants were divided into four age

groups. A small percentage (6.7%: n=4) of the participants were between the ages of 7 and 9 months, while 36.7% (n=22) were between 10 and 12 months. The age group between 13 and 15 months was slightly smaller (16.6%: n=10) than the age group of 16 to 18 months, it was the largest group with 40.0% of the participants (n=24).

# Comparison of mean scores on the tests for the South African sample with the USA data

For ITSP, all sensory processing section scores (Figure 2, below) and quadrant scores (Figure 3, below) were found to be in the lower range of typical scores for infants and toddlers in the USA. Only the Tactile Processing Section score was similar to the scores reported in the ITSP manual, as the mean for South African infants fell at the centre of the range of scores for typical infants and toddlers in the USA.

The mean scores provided in the ITSP manual and the mean scores of this study were compared for two age groups (7 to 12 months and 13 to 18 months). The effect size between the norms was calculated to confirm the standardised differences between the South African sample and the USA norms, to determine the clinical importance of interpreting dysfunction in the South African infant group. The results of this study indicated that all processing sections and quadrants had a small effect size, with the exception of Oral Processing and Quadrant 2: Sensation Seeking, which for both age groups had medium effect sizes ( $d \ge 0.5$ ) (Table I, page 10).

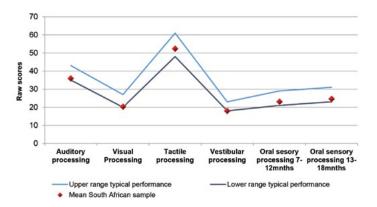


Figure 2: Raw scores of Infant Toddler Sensory Profile (ITSP) processing sections compared to normative data.

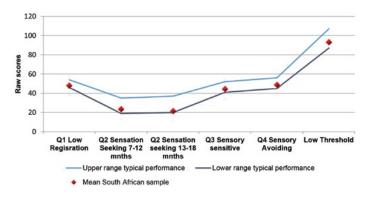


Figure 3: Raw scores of Infant Toddler Sensory Profile (ITSP) quadrants compared to normative data.

Table I: Means Standard deviations, confidence intervals, and effect size on raw score analysis on the Infant Toddler Sensory Profile (ITSP).

7-12 months n= 26					13-18 months n=34 Mean (SD)					
Sensory Processing Section	Manual Mean (SD)	Study Mean (SD)	95% confidence intervals	Effect size	p-value	Manual Mean (SD)	Study Mean (SD)	95% confidence intervals	Effect size	p-value
Auditory Processing	39.80 (3.51)	37.85 (3.60)	36.40 - 39.28	0.28	0.909	38.98 (3.55)	36.47 (4.83)	34.78 - 38.15	0.28	0.817
Visual Processing	22.47 (3.29)	20.30 (2.10)	19.45 - 21.16	0.36	0.877	22.93 (3.40)	20.29 (2.50)	19.42 - 21.16	0.40	0.760
Tactile Processing	54.82 (6.15)	52.65 (7.10)	49.80 - 55.51	0.16	0.923	54.73 (6.11)	50.35 (6.54)	48.07- 52.63	0.32	0.696
Vestibular Processing	19.61 (2.78)	18.69 (3.40)	17.32 - 20.06	0.14	0.989	20.26 (2.44)	17.85 (3.35)	16.68 - 19.02	0.38	0.871
Oral Sensory Processing	33.12 (4.81)	23.08 (3.50)	21.68 - 24.47	0.76	0.229	34.70 (4.82)	24.62 (3.77)	23.30 - 25.93	0.75	0.245
Quadrant 1: Low registration	49.94 (3.86)	47.54 (4.44)	45.75 - 49.33	0.27	0.919	33.47 (8.22)	48.29 (4.30)	46.80 - 49.79	-0.24	0.119
Quadrant 2: Sensation- seeking	33.57 (8.00)	23.46 (5.91)	21.07 - 25.85	0.58	0.185	47.11 (4.66)	21.47 (5.54)	19.54 - 23.04	0.85	0.002
Quadrant 3: Sensory Sensitivity	46.51 (4.66)	45.12 (5.61)	42.85 - 47.38	0.13	0.917	50.28 (3.78)	43.83 (5.51)	41.90 - 45.74	0.30	0.606
Quadrant 4: Sensation Avoiding	50.11 (5.53)	48.88 (6.61)	46.21 - 51.55	0.10	0.982	50.88 (5.30)	48.62 (5.59)	46.67 - 50.56	0.21	0.923
Combined Quadrant: Low Threshold	96.81 (9.85)	94.00 (11.06)	89.53 - 98.46	0.13	0.884	97.89 (9.26)	92.44 (10.26)	88.86 - 96.02	0.36	0.716

Significance p ≤ 0.05

Cohen d - Small effect size = 0.2 Medium effect size = 0.5 Large effect size=0.8

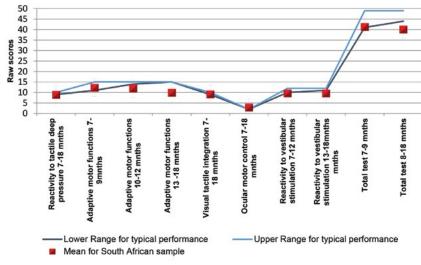


Figure 4: Raw scores of the Test of Sensory Functions in Infants (TSFI) compared to normative data.

For the TSFI it was found that the scores for infants in South Africa on the sub-tests of Adaptive Motor Functions (10 - 12 months), Adaptive Motor Functions (13 - 18 months), as well as the Total Test Score (10 - 18 months) were equal to or below the lower range of scores reported for typical infants and toddlers in the USA (Figure 4, above).

# Frequency of deficits identified in the tests for the South African sample

Mean scores cannot be considered ideal on the type of ordinal data obtained on the ITSP and the TSFI, and therefore the frequency distribution of the scores was determined and considered based on the Gaussian curve (normal distribution) as suggested in the test manual. The frequency data for the ITSP and the TSFI indicated that significantly more South African infants tested within definite difference/deficient ranges according to the USA norms. In the ITSP, the frequency distributions for the South African sample show that a higher percentage of participants fell into the definite difference "more than others" score bracket in a normal distribution for the processing section

(Figure 5, page 11) and quadrant scores (Figure 6, page 11). Very few infants fell into the probable difference "less than others" and the definite difference score bracket.

Vestibular Processing differed significantly from the normal distribution (p = 0.001), with a higher percentage of participants having a definite difference "more than oth-

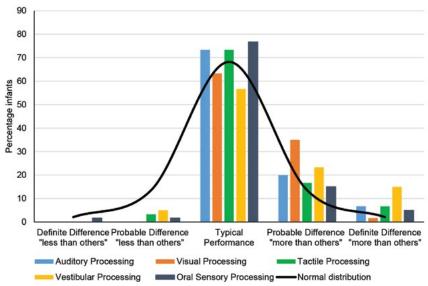


Figure 5: Frequency data for Infant Toddler Sensory Profile (ITSP) processing sections

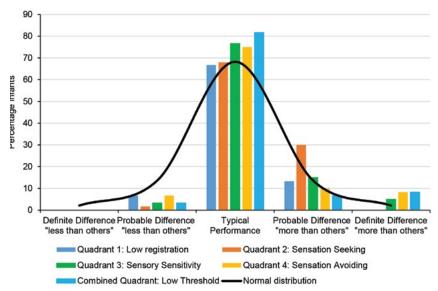


Figure 6: Frequency data for the Infant Toddler Sensory Profile (ITSP) quadrants

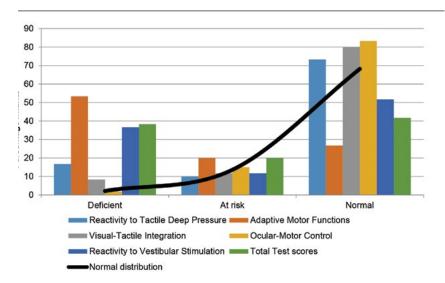


Figure 7: Distribution of scores for the Test of Sensory Functions in Infants (TSFI)

ers", as did Quadrant 1: Low Registration. It is important to note the percentage of infants that fall into the range of definite difference "more than others" in the Vestibular Processing Section (15.0%), as it is much higher than the expected percentage of 4.2% in the normal distribution.

For Oral and Auditory Processing, it also differed significantly from the normal distribution (p = 0.04), with a higher percentage of participants scoring in the typical performance range. A higher percentage of participants also scored in the range of probable difference "more than others" for Oral Processing.

The frequencies for three quadrants differed significantly (p= 0.001 to 0.010) from the normal distribution. These three quadrants, Quadrant 1: Low Registration (13.3%), Quadrant 4: Sensation Avoiding and Combined Quadrant: Low Threshold (8.3%) had a higher percentage of participants who scored in the range of definite difference "more than others". Quadrant 2; Sensation Seeking had a higher percentage of participants with a probable difference "more than others" at 30% compared to the expected 13.5% at this point on the normal distribution.

For the TSFI, the five sub-tests and the Total Test Score differed significantly (p=0.001) from the normal distribution (Figure 7, adjacent). As plotted on the left side of the Gaussian curve (normal distribution), Adaptive Motor Functions (53.3%), Reactivity to Vestibular Stimulation (36.6%) and Total Test Scores (38.3%) had much higher percentages than the expected 2.1% in the deficient range (-2SD), indicating problems with these components in the participants accessed. Sub-tests where a higher percentage of participants scored in the typical range included Reactivity to Tactile Deep Pressure (73.3%), Visual- Tactile Integration (80.0%) and Ocular-Motor Control (83.3%) which was higher than the expected 68.2%.

For both tests, it was observed that the sections related to vestibular processing had high percentages of infants that tested within the definite difference/deficient ranges.

#### **DISCUSSION**

The USA sample for ITSP totalled 589 infants, with 301 males (51.1%) and 287 females (48.7%), while the USA sample for TSFI had 288 infants, with 130 males (45,1%) and 158 females (54,9%). Therefore,

the gender distribution in the South African sample of 60 infants was similar to the male-female distribution in the USA samples for the ITSP, although the sample size was smaller. The age groups of the infants could not be stratified with a similar number in each of the age ranges of two months. This can be attributed to the fact that child day-care facilities have fewer infants under 9 months, since this age group requires a higher infant-to-carer ratio. Due to inclusion and exclusion criteria, the study participants were considered typical infants with no reports of major medical problems since birth.

#### Infant/Toddler Sensory Profile (ITSP)

The mean scores for the South African sample were in the lower ranges of the typical performance range according to the normative data found in the ITSP. The positive effect sizes of the South African sample mean that the scores were all lower than those of the USA sample with the exception of Quadrant 1: Low Registration for infants 13 to 18 months of age. These children may present as more passive because they do not notice or detect changes in sensory situations to a greater extent than the younger children in the sample. This may lead to infants appearing content and not receiving stimulation from caregivers, when, in fact, they need more stimulation.

Except for Quadrant 2; Sensation Seeking, none of the means for the South African sample differed from the mean scores for the USA sample. This was confirmed by effect sizes of d < 0.4, which is considered acceptable as it indicates that the groups have a 70% overlap. This was confirmed in a study by van Jaarsveld et al.<sup>34</sup> on the use of the Sensory Integration and Praxis Test in the South African population where they indicated that an effect size of d > 0.4 presented challenges in terms of interpretation of test results and the test had to be adjusted for the South African population<sup>34</sup>. The results of this study indicated that only in the Oral Processing Section (0.76 and 0.75) and the quadrant score for Quadrant 2: Sensation Seeking (0.58 and 0.65), there might be some challenges in interpreting the test results on this South African sample. Therefore, the ITSP could be used on similar South African samples, as there is less than half a standard deviation between the means.

When comparing the frequency data with the expected normal distribution, a significant difference was found for five of the nine sections and/or quadrants. To determine the clinical importance of these differences in interpreting dysfunction in South African infants, it was therefore important to establish if these differences indicated a higher percentage of participants with a probable and definite difference on the Gaussian curve (normal distribution) relative to the USA sample. The SA sample was found to tend to the "more than others" scores on the ITSP, indicating over responsiveness to sensory input. Particularly for probable and definite differences for the Vestibular Processing Section at 38%, which significantly deviates from the normal expected 15.7% on the normal distribution when the definite and probable difference "more than others" sections are combined. This section tests the infant's ability to process movement inputs and the infant's response to movement<sup>6</sup>. As the results of the Vestibular Processing Section deviated significantly from the normal distribution, the results from this section should be interpreted with care in South African samples.

Significant differences were also found between the expected and actual frequency for the Auditory and Oral Processing Sections, with more of the South African sample scoring in the typical range. For Oral Processing, more participants (23%) also tested within the probable and definite difference range "more than others". Oral processing tests the infant's ability to process sensations within the mouth thus the infant's response to taste and touch stimuli in the mouth<sup>6</sup>. Difficulties with oral sensory processing can lead to feeding problems, as it is found that children with these difficulties often have a diet of limited variety because they avoid food with certain textures 16,17. Separate norms for the interpretation of the results could be required, and thus the results of the Oral Processing Section on the ITSP should be interpreted with caution in South African samples.

The Combined Quadrant: Low Threshold scores showed a significant difference from the expected USA frequencies in the normal distribution, with more participants in the South African sample falling into the typical performance range. A significant difference was found for the frequency of the scores for Quadrant 1: Low Registration and Quadrant 4: Sensation Avoiding with percentage scores in both quadrants tending towards the "more than others" ranges. Thus, participants in this sample showed more dysfunction in the low-threshold quadrants. Therefore, this aspect needs to be further researched since a significant difference was found for the South African sample for Quadrant 2: Sensation Seeking when the means were compared for the different age groups. This confirms the need to investigate the difference between the age groups.

For the interpretation of quadrant scores, Dunn's theoretical model of sensory processing, based on the infant's neurological thresholds, was used with passive response (low registration and sensory sensitivity) and active response (sensory seeking and avoidance of sensation) that usually results in one quadrant appearing to dominate when reacting to sensory input. The interaction between the continua may be seen with the other patterns of responsiveness also present<sup>6</sup>. Therefore, it is important to remember that behaviour of infants/toddlers consistent with one of the quadrants, on its own, is not sufficient to conclude that dysfunction is present. In the presence of performance difficulties in activities of daily living, behaviour consistent with the quadrants can help identify the reasons for their behaviour and also help to find ways to address the problem6.

#### Test of Sensory Function in Infants (TSFI)

The raw scores obtained from the South African sample were compared with the normative data found on the TSFI score sheet. The sub-tests that scored in the lower ranges of typical performance were Reactivity to Tactile Deep Pressure (7 - 18 months), Adaptive Motor Functions (7 - 9 months), Visual-Tactile Integration (7 - 18 months), Ocular-Motor Control (7 - 18 months), and Reactivity to Vestibular Stimulation (7 - 12 months). Other sub-tests, namely, Adaptive Motor Functions (10 - 12 months) and (13 - 18 months),

Reactivity to Vestibular Stimulation (13 - 18 months), and the Total Test Score (8 - 18 months) scored below the normal range. Reactivity to Vestibular Stimulation subtest assesses the infant's reaction to different movements. According to the interpretation information, an infant with a deficient score may be considered posturally insecure and should be referred to an occupational therapist for further testing of neuromotor functions and other vestibular-based functions<sup>9</sup>. Since the mean score for the South African sample fell outside the range of typical infants in the USA, these infants would therefore be identified as deficient if assessed with this test.

Comparing the frequency data with the expected normal distribution, determining the frequency of participants scoring deficiencies, at risk, or typical, confirmed the results discussed above, with higher percentages of participants scoring as deficient. It is expected that only 2.1% of children will have scores within the deficient range. However, the results showed that the frequency scores for the Adaptive Motor Functions Subtest, the Reactivity to Vestibular Stimulation Subtest, and the Total Test Score were significantly higher. The Adaptive Motor Functions Subtest reflects the infant's ability to initiate and motor plan exploratory movements when handling textured toys. According to the information used for the interpretation of the test scores, these infants with poor adaptive motor functions would also be further tested for abnormal neuromotor functions and delayed motor skills<sup>7</sup>.

According to the test developer, if an infant obtains scores below the cut-off scores for the 'normal' range in the Total Test Score, it is indicative of potential problems. According to these criteria, 58,3% of the test population would therefore have scores indicative of potential problems. These children can be considered to be at risk for, or even considered to have abnormal sensory reactivity and processing. If an infant then also has delays in cognitive or motor skills, they should be referred to an occupational therapist to determine if intervention is needed. It is also recommended that infants with 'deficient' scores on the total test score or particular subtest scores be monitored throughout their preschool years for deficits in other areas of sensory integration, such as motor planning, visual motor skills, or bilateral motor coordination<sup>7</sup>. Therefore, it is important to know if the test accurately assesses an infant. If not, unnecessary referrals and further testing will be performed.

Since all sub-tests and the Total Test Score of the TSFI differed significantly from the population of the USA, this may result in unnecessary referrals and assessments when using the TSFI in South Africa. Therefore, the use of the test on South African samples is questioned. To use the TSFI with accuracy in South Africa, the sub-tests would need to be standardised on the population. The test items themselves may also be at fault since research by Jirikowic et al.<sup>32</sup> suggest that TSFI scores should be interpreted with caution and should only be used in conjunction with other tests. The findings of this research study support this suggestion.

#### Limitations of the study

The results of this study must be viewed with caution, as it was limited by the very specific homogeneous sample as all

participants attend child day-care facilities in a geographical area with middle to high income. This makes it difficult to generalise the findings to other infant groups in South Africa. The study had a small sample size. Therefore, the results should be interpreted with caution and cannot be generalised.

Due to the lack of a gold standard assessment tool for SID for this age group, the tests were compared to scoring on a normal distribution based on research on a sample, based in the USA.

#### **CONCLUSION AND RECOMMENDATIONS**

The mean scores for the ITSP fell into the lower typical range of the USA data. The mean scores for the age group 13 to 18 months differed significantly from the USA means and the means for the Oral Sensory Processing Section and Quadrant 2: Sensation Seeking, showed clinical differences from the USA means with a medium effect size. The frequency differed significantly compared to the normal distribution for five of the nine sections and quadrants. The high percentage for the definite and probable difference "more than others" for Vestibular Processing Section and Quadrant 1: Low Registration indicates that a typical SA sample can be identified with problems in these components that appear to differ from those reported for infants in the USA. This further indicates that the scores from these sections should be interpreted with caution in South African samples.

The results of this study indicated that using the USA normative data to score the TSFI on South African samples is even more problematic. The infants in the South African sample scored outside the lower ranges in the sections for Adaptive Motor Functions (age groups 10 to 12 months and 13 to 18 months), Reactivity to Vestibular Stimulation (13 to 18 months), as well as the Total Test Score (8 to 18 months) compared to the sample from the USA. A significant difference was found for the frequency of the deficient, at risk and typical percentages on a normal distribution for all the sub-tests and the Total Test Scores. According to the results of this study, to use the TSFI with confidence in South Africa, the sub-tests would need to be standardised for this specific population.

Therefore, the following recommendations are made in accordance with the findings of this study:

- It is recommended that further research be done on the use of ITSP and TSFI in a South African population.
- As the study had a small sample, it could be inaccurate to generalise the findings, and it is therefore recommended to do the study on a larger South African sample. This needs to include participants from a diverse demographic and socioeconomic population.
- It is recommended that further research is needed on the influence of the child's day-care environment on the development of sensory integration function in infants.

#### **Author contributions**

Marica Botha completed this study towards a Master's degree in occupational therapy and was responsible for the conceptualisation of the study, data collection, and analysis. She drafted the original manuscript, edited the manuscript,

and approved the final version to be published. Denise Franzsen was a study supervisor, guided conceptualisation and design of the study and was an expert in data analysis and interpretation supervision. She revised it critically for intellectual content, supervised the writing and revision of the manuscript and approval of the final version to be published. Lyndsay Koch was a study supervisor and guided the process from the conceptualisation and design of the study and revising it critically for important intellectual content. Approval of the final version to be published. The authors agree to be responsible for all aspects of the work and to resolve all questions related to the accuracy and integrity of any part of the work.

#### **Conflicts of interests**

The authors have no conflicts of interests to declare

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### A review of occupational therapy services within an acute public tertiary hospital in KwaZulu-Natal, South Africa

#### **ABSTRACT**

**Introduction:** The provision of occupational therapy services in providing a minimum essential service in public health institutions in South Africa are currently guided by a quality control measure by the National Department of Health.

**Aim:** To review the occupational therapy services in an acute, public tertiary hospital from 2015-2019 and to compare this with the expectations of these services in a tertiary hospital to identify potential gaps in service delivery.

**Method:** A single site, retrospective quantitative audit from 2015-2019 was completed at one tertiary hospital. Patient-related and occupational therapy service data were included. 18579 patient entries were captured. The analysis included descriptive and inferential statistics of mean, standard deviations, frequency tables, percentages, and ANOVA.

**Results:** Findings indicated a consistent decline in the mean values of, the number of therapists attending to patients, number of patients, assistive devices issued, total time of patient units and consultations, total time spent on ward rounds, clinics, and meeting attendance. The number of student therapists attending to patients, splints, pressure garments and issued wheelchairs showed an increase in trend across the reviewed years. **Conclusion:** Inadequate human resources and budget systems are potential gaps in occupational therapy service delivery in an acute public tertiary hospital.

#### INTRODUCTION

The provision of occupational therapy services in public health institutions in South Africa is currently guided by the National Core Standards, which is a quality control measure implemented by the National Department of Health (NDOH)<sup>1</sup>. These activities are considered critical in providing a minimum standard of essential servicel. Human resources, infrastructure, and essential equipment, among other criteria, are highlighted as minimum standards to deliver a service<sup>2</sup>. High-quality, cost-effective rehabilitation services are of paramount importance in providing positive outcomes for the recipients of the services<sup>3</sup>.

In South Africa, the restructuring of the health system in South Africa is anticipated through the impending introduction of a National Health Insurance Scheme (NHI) aims to include access to quality healthcare whilst minimising financial risk. Documenting a comprehensive situational analysis of service delivery will provide evidence on providing appropriate quality and quantity of occupational therapy services in line with the standards set by national health programmes<sup>4</sup>. However, there are limited documented reviews on occupational therapy services for the various hospital levels in the KwaZulu-Natal (KZN) province. This study aims to review the services rendered in the occupational therapy department of a designated acute public tertiary hospital from 2015 to 2019 and to identify potential gaps in service delivery.

The Occupational Therapy Practice Framework IV (OTPF): domain and process<sup>5</sup> was used as a framework for this study. The framework articulates the oc-

cupational therapy contribution to promoting the health and participation of persons, groups, and populations through engagement in occupation<sup>5</sup>. With reference to the OTPF, a healthcare organisation is a diverse system influenced by various factors such as performance patterns and skills of human resources, the context of the healthcare setting<sup>5</sup>.

#### LITERATURE REVIEW

#### The South African Health Care System

South Africa has an estimated population of 549569007, most of whom access health services through public sector clinics and hospitals. Public health services are divided into primary, secondary, and tertiary and further categorised into district, regional, tertiary, central and specialised institutions to allow an efficient drainage system of the population accessing health services8. Currently, the expenditures in both private and public sectors are approximately equivalent and, in combination, total 8.5% of gross domestic product (GDP). The private sector serves 16% of the population, while the public sector serves 84%9.

Due to the two-tiered private-public contrast in health-care delivery and the healthcare staffing crises, access to quality and adequate occupational therapy services are limitations confounding persons with disabilities (PWD) living in South Africa<sup>10</sup>. High-quality, cost-effective therapy and rehabilitation services are of paramount importance in providing positive outcomes for the recipients of the services<sup>3</sup>. These services including occupational therapy services are audited to ensure that they meet the compliance standards of the NDOH<sup>11</sup>.

#### **Rehabilitation Services**

Access to appropriate rehabilitation services influences the possibility of and the ability of PWD to lead an economically independent life and actively participate in society<sup>12</sup>. In South Africa, hospital-based rehabilitation services are aligned with medical services prescribed by regulation for different hospital categories. However, it is noted that the scarcity of appropriate rehabilitation impairs the quality and type of service, as there is little to no proof of effective service delivery, which could be used to motivate for resources. Limited research has been conducted regarding the outcomes of rehabilitation services at secondary, tertiary, and specialised levels<sup>13</sup>. There is an inequitable distribution and high vacancy rate of rehabilitation service providers at the different levels of care<sup>13</sup>. In addition to the need for healthcare service providers, the NDOH, KZN has instated a moratorium on allied health posts since 2016, which has significantly impacted rehabilitation services and human resources, particularly in occupational therapy<sup>14</sup>.

Access to appropriate and affordable assistive devices and technology (mobility, communication, and daily living) which allow PWD to participate equally in society are also evident

within the KZN public health system. These challenges are associated with constrained budgets, poor access, ineffective referral systems and poor knowledge of the prescription and issuing of assistive devices and technology<sup>14</sup>. Without access to these devices, person(s) with disabilities, face unsafe discharge or endure prolonged periods of hospitalisation. They remain dependent on institutions providing services and continue to experience difficulties securing rights to education and employment<sup>12</sup>.

#### Occupational therapy in tertiary hospitals

Occupational therapy has been noted as the only spending category that has been shown to reduce hospital readmissions<sup>15</sup>, length of stay and successful transition and discharge<sup>16</sup> with the implications of patient flow influencing patient outcomes, staff performance and costs<sup>17</sup>. KwaZulu-Natal has four tertiary hospitals supporting 45 district hospitals, and 14 regional hospitals within 11 health districts, with a total of 75 therapists distributed amongst all its hospitals servicing a population of just over 11 million people<sup>14</sup>. Thus, occupational therapy intervention at a tertiary hospital is essential for optimal patient functioning and turnover and reducing the burden on the tertiary facility<sup>14</sup>, since most KZN district hospitals are not fully equipped with transport, health- care related services, occupational therapy personnel and resources.

A skill set for acute, tertiary care is crucial for successful tertiary occupational therapy services. Currently, in South Africa, there are no documented skills and knowledge sets to define the role of occupational therapy in an acute, tertiary hospital. Furthermore, there are no speciality areas in occupational therapy recognised by the Health Professionals Council of South Africa (HPCSA), which are viewed as vital for tertiary care. Skills such as clinical reasoning, lateral thinking, time management, and further experience and support from senior therapists with specialised skills are also critical for rehabilitation services in an acute, tertiary hospital<sup>18</sup>.

# Occupational therapy services in the designated acute public tertiary hospital

#### **Human Resources**

Disparities in occupational therapy human resource distribution negatively impact rehabilitation service provision and equitable health and rehabilitation outcomes<sup>19</sup>. According to the proposed organisation and post establishment for this study site, in 2018, the occupational therapy division should have ideally been staffed with 19 occupational therapy healthcare professionals<sup>20</sup>. To curb expenditure, the moratorium on allied health posts by the NDOH, KZN (2016) indicates that no more than six posts were filled at this tertiary hospital<sup>14</sup>.

#### **Budget Systems**

Budget restrictions influenced by medical inflation and ex-

change rate fluctuation cascade through all levels of service delivery<sup>21</sup>. The cost-constrained economic environment does not prioritise equipment and assistive devices budgets, further impinging on services rendered<sup>22</sup>.

#### **METHODS**

This study involved a retrospective occupational therapy file audit over five years at a single site.

#### Setting

The location of the study is a public, acute tertiary hospital within Pietermaritzburg, uMgungundlovu district. This hospital is a referral hospital offering tertiary services to Area Two of KZN, which comprises the Western half of KZN. It includes the following five health districts: Harry Gwala, Amajuba, uMgungundlovu, uThukela, uMzinyathi, with a total population of 4.5 million<sup>6</sup>. This acute public tertiary hospital currently provides approximately 84% of the total recommended tertiary services. It is fully supported by all services (ICU, radiology, diagnostic, blood bank, laboratory, and other services)<sup>23</sup>.

#### Sampling

All hard-copy statistical data forms over five years (2015-2019) from the occupational therapy department were included in the sample. Patient-related data and occupational therapy service data were reviewed. Outreach clinic statistics were excluded due to the single occasional outreach service, which did not directly affect the study site. The years 2015 to 2019 were selected as statistical data forms were deficient in significant variables before 2015. The year 2020 was excluded due to the effects of the COVID-19 pandemic.

#### Data Collection, Analysis, and Data Management

A phased approach was used in the overall management of data. The duration of data collection was approximately four months. Collated documents such as hard-copy statistical forms (inpatient, outpatient, monthly summary sheets) and hard-copy wheelchair records were reviewed. These documents were stored within the occupational therapy department and were accessible to the research team. A diagnostic profile category list was compiled with various specialities of surgical, medical, orthopaedics, paediatrics, and oncology; this list included several other diagnostic profiles that were inclusive of the above specialities. The principal author captured all the data and was acquainted with the numerical key-value system and diagnostic profile sub-category list. Workbooks were compiled for patient-related and occupational therapy service data using SPSS version 21 software<sup>24</sup>. Raw data equivalent to temporal units were converted into time values (hours). The first author captured data for each variable according to the numerical key values in the SPSS system software. The values were inputted on a single-entry basis and organised monthly from January 2015 to December 2019. The data were then cleaned using SPSS software. Phase 1: Patient data were aggregated using SPSS software. Patient details such as hospital number, age, gender, patient status (in-patient or out-patient), patient demographics, sub-specialities and diagnostic profile categories, month visited, base hospital and district, were captured. A categorised diagnostic profile list was developed against the primary diagnoses into surgical, medical, orthopaedics, paediatrics and oncology. These variables were further analysed with descriptive statistics of mean, standard deviation, range, frequencies, and percentages.

Phase 2: Service data of occupational therapists were aggregated as cases per year from 2015 to 2019 and matched accordingly with the variables of (i) time spent on patients, meetings, and ward rounds, (ii) number of patient consults and (iii) intervention rendered with regards to splints, pressure garments, wheelchairs, and assistive devices and technology.

Analysis also included mean values, standard deviation, and minimum and maximum values on a yearly basis. The statistical differences in the means of patient-related data and occupational therapy service data were evaluated using one-way analysis of variance (ANOVA) throughout the five years of the review with the significance level set at p<0.05.

#### **Ethical Considerations**

Ethical approval was obtained from the University of KwaZulu-Natal (UKZN) Humanities and Social Sciences Research Ethics Committee HSSREC/00002364/2021. Ethical clearance was also obtained from the Department of Health (National Health Research and Knowledge Management) NHRD Ref. KZ\_202006\_033 to allow access to the public acute tertiary hospital. Informed consent was obtained from the chief executive officer of the hospital and the assistant director of the occupational therapy department.

#### Reliability and Validity

This study's reliability and validity were ensured by having a single user (principal author) input the data according to allocated numerical coding on the SPSS system software. Having one individual input the data ensured that data collection was formed from the same set of data sources, thereby ensuring consistency, reliability, and validity of data collection<sup>25</sup>. De-identification was observed by allocating each patient a patient code and maintaining the anonymity of personal patient information such as name and surname. Data aggregation occurred by combining related variables to form occupational therapy service data and patient-related data categories. Further data aggregation occurred through descriptive statistics of mean, minimum and maximum values, and ranges of data.

#### **RESULTS**

A total of 18579 consecutive patient documentations occurring during 01 January 2015 and 31 December 2019 were reviewed. Of these 43.4% (n=8069) were out-patient consultations and 56.5% (n=10503) were in-patient occupational therapy treatment sessions.

**Human resources:** The range of occupational therapists providing services to patients at one point in time was between three to six occupational therapists and zero to four occupational therapy students (Table I, page 19).

**Patient care:** Patient population consisted of in-patients and out-patients. Monthly, an average of 316 patients received

Table I: Occupational therapy service data (2015-2019)

Occupational Therapy Service Data	Summation of January to December Data per year					
	2015	2016	2017	2018	2019	Total
Range of occupational therapists providing services to patients	4 - 5	5 - 6	3 - 5	4 - 6	4 - 5	3 - 6
Range of occupational therapy students providing services to patients	0 - 2	0 - 1	0 - 1	0 - 3	0 - 4	0 - 4
Total time unit ward rounds and clinics (hours)	315.0	435.5	257.0	201.25	128.75	1337.50
Total time unit meeting (hours)	266.5	342.3	292.8	186.7	107.8	1196.1
Total time of patient (in-patient & out-patient) units (hours)	4623.3	5059.3	4381.3	4722.0	3797.8	22583.70
Total number of patient consultations (in-patient & out- patient)	8347	8297	7634	7583	6176	38037
Total number of patients (in-patient and out-patient)	4058	4235	3650	3904	3167	19014

Table II: Splints, pressure garments, assistive devices, and wheelchairs

Splints, Pressure garments, Assistive devices, and Wheelchairs	Summation of January to December Data per year					
	2015	2016	2017	2018	2019	Total
Total number of splints fabricated (inpatient & outpatient)	593	615	654	672	546	3080
Total number of pressure garments fabricated (inpatient & outpatient)	336	274	330	266	347	1553
Total number of assistive devices issued to patients (inpatient & outpatient)	22	15	4	19	43	103
Total number wheelchairs issued to patients (inpatient & outpatient)	38	23	18	21	26	126

occupational therapy services, an average of 180 in-patients and 136 out-patients. Statistics indicate an increase in patient units in 2016 and 2018, while those from 2015 and 2016 indicated an increase in patient consults (inpatients and outpatients) (Table I. above).

**Occupational therapy service data:** Statistics indicate a steady decline in time spent on ward rounds, clinics, and meetings since 2017 (Table I, above).

Patient Diagnostic Profile: Of patients were referred, diagnostic data for 18488 was captured and 39.2% were found to have orthopaedic conditions such as upper limb fracture. spinal conditions, tendon, nerve injuries, hand sepsis, brachial plexus injuries, hands not otherwise specified (NOS), upper limb amputations and orthopaedic NOS. Over a quarter (26.2%) of patients were paediatric, with paediatric neurology NOS, prematurity, and cerebral palsy (CP) being the most common diagnosis. Surgical patients constituted 22.5% of the patient profile, with most referrals from plastics and reconstruction and burns units. Medical patients (9.3%) included cerebrovascular accidents (CVA), neurological conditions NOS and medical conditions NOS being the most common. A small percentage (2.7%) of the patient profile was oncology (See Figure 1, adjacent). The highest percentage of patients were from Northdale hospital (NDH) (14.9%), Edendale hospital (EDH) (3.2%), Church of Scotland hospital (COSH) (4.1%) and Greytown hospital (2.7%) respectively, and the health districts with the highest percentage of referrals include uMgungundlovu (19.4%), uMzinyathi (7.9%) and uThukela (4%) (Figure 1, adjacent).

#### **Orthoses and Assistive devices and Technology**

The results demonstrate a steady incline in the yearly average of splints fabricated (3080), wheelchairs issued (110),

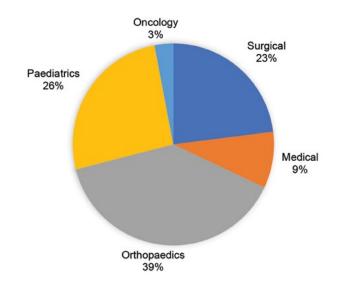


Figure 1. Patients' Diagnostic Profile (2015-2019) (n=18488).

pressure garments fabricated (1553), with a steady decline of assistive devices issued (119) for the period 2015 to 2019 (Table II, above).

During this review, a comparison between patient-related and occupational therapy service data was made to identify trends for the five years under review (Table III, page 20). The analysis reveals statistically significant differences in the number of occupational therapists providing services to patients, the yearly number of student therapists attending to patients, the number of patients, total time of patient units and consultations, total time spent on ward rounds, clinics and meeting attendance and the total number of assistive devices issued. However, fabricated splints, pressure garments, and issued wheelchairs were not statistically

Table III: Differences in patient-related and occupational therapy service occupational therapy service data (2015-2019)

Patient-related and occupational therapy service data	F= value	p value
Number of occupational therapists providing services to patients	4.963	0.002*
Number of occupational therapy students providing services to patients	14.177	0.000*
Total time of patient (inpatient & outpatient) units (hours)	4.144	0.005*
Total number of patient consultations (inpatient & outpatient)	3.820	0.008*
Total number of patients (inpatient and outpatient)	3.903	0.007*
Total time unit ward rounds and clinics (hours)	9.398	0.000*
Total time unit meeting (hours)	4.806	0.002*
Total number of splints fabricated (inpatient & outpatient)	1.053	0.388
Total number of pressure garments (PG) fabricated (inpatient & outpatient)	1.034	0.398
Total number of assistive devices (AD) issued to patients (inpatient & outpatient)	3.270	0.018*
Total number wheelchairs (WC) issued to patients (inpatient & outpatient)	0.206	0.934

<sup>\*</sup>Significant at p<0.05

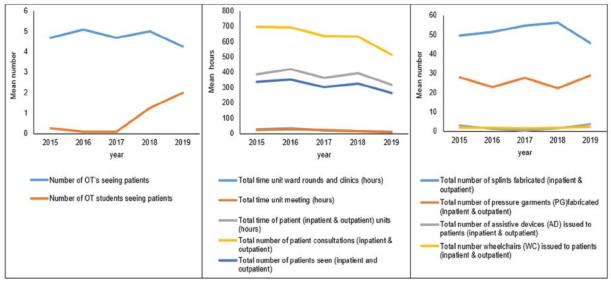


Figure 2. Monthly average of patient-related and occupational therapy service data (2015-2019).

significant across the reviewed years.

A cursory review of the yearly trends of the variables and further analysis revealed a consistent decline in the mean values of these variables from 2015 to 2019 except for variables such as the number of occupational therapy students, the number of splints, pressure garments fabricated, and wheelchairs issued. These variables portrayed an increasing yearly trend in their mean values in Figure 2, above

#### **DISCUSSION AND IMPLICATIONS**

This study reviewed the trends of services rendered by one occupational therapy department situated in a public, acute tertiary hospital in KZN and determined the potential gaps in service delivery. The implications from this study will guide the operational plans and services of the occupational therapy department at this public, acute tertiary hospital.

In terms of **human resources**, the occupational therapy services in KZN are widely spread, with the recommendation being one occupational therapist to 10000 head population<sup>26</sup>. However, the study outcomes show an average of three to six occupational therapists is servicing a population of 4.5 million. Based on the World Federation of Occupational Therapy recommendation, 450 occupational therapists should service the given population, this further indicates

the paucity of employment of occupational therapists in KZN and a significant weakness in South African health systems is inadequate human resources<sup>27</sup>. Only 31% (6/19) of posts were filled at any given time in this public, acute tertiary hospital. The moratorium on allied health posts in KZN since 2016 impacted recruitment.

Although the United Nations Convention for Person(s) with Disabilities (UNCRPD) (2006) outlined the necessity to meet global needs for Person(s) with Disabilities, with challenges being the inequitable distribution of rehabilitation workers<sup>28</sup> the moratorium inferred that rehabilitation posts could be sacrificed to save costs for patient care<sup>13</sup>. Occupational therapy posts remained on the essential health service list but with no prioritisation of these services, to date, occupational therapy human resources remain strained in KZN's public health system<sup>14</sup>.

In terms of **patient care (units and consults)**, a recommended service ratio ranges from one occupational therapist to 100 patients<sup>29</sup>. This public, acute tertiary hospital has seen an average range of 363-1072 patient consults between three to six occupational therapists, indicating the patient care services are within and beyond the recommended service ratio range.

Concerning **occupational therapy service data**, administrative tasks, clinical tasks, and ward rounds are pivotal in

hospital-based care, enhancing the quality of care, improving communication; patient care and strengthening multi-professional training<sup>30</sup>. This public, acute tertiary hospital demands that essential job duties include clinical work that encompasses ward rounds, clinic attendance, case studies, etc. and meetings to co-ordinate care. Statistics indicate a steady decline in time spent on ward rounds and clinic attendance since 2017, after which more time was spent on direct patient contact than meetings, ward rounds and clinic attendance. The OTPF indicate that healthcare contexts, performance patterns and skills of healthcare human resources directly influence occupational therapy service data<sup>5</sup>.

Considering orthoses, assistive devices, and technology, splinting maintains mobility, prevents the development of contractures, promotes the functionality of the limb, and assists with good cosmetic and functional results<sup>31</sup>. A widespread modality of scar and oedema management is utilising pressure garment therapy<sup>32</sup>. The number of fabricated splints, pressure garments or assistive devices issued is always a priority in using equipment and budget expenditure. Other variables may include the capacity at a base hospital to manufacture these items, availability of material and equipment and waiting times, and the diagnostic profile. There may be various contributing factors to fluctuations in splint design and construction, pressure garment design and fabrication and issue of assistive devices; in relation to the OTPF which include client factors of clients, performance patterns and skills of human resources and health care contexts5.

In terms of the **patient diagnostic profile,** occupational therapists are involved in rehabilitation programmes for orthopaedic, medical, neurological, and paediatric patients. Services range from provision of splinting, pressure therapy, activities of daily living (ADLs), training of activities mobilisation programmes, vocational rehabilitation, therapy and education, leisure management, home visits and adaptation of home environments<sup>33</sup>. Concerning the OTPF intervention of client factors are directly influenced by healthcare contexts and performance skills and patterns of human resources<sup>5</sup>.

With reference to the **specific diagnostic intervention**, the following findings prevail:

- Occupational therapy role in Orthopaedics focuses on community resettlement, splinting and independence in ADLs<sup>34</sup>. Based on the occupational therapy intervention, it can be assumed that most orthopaedic conditions require splinting, assistive device issues and rehabilitation.
- Occupational therapy intervention for Paediatrics promotes engagement and participation in daily life roles<sup>35</sup>. Occupational therapy therapeutic intervention could involve rehabilitation, wheelchair or buggy provision and splinting.
- The role of occupational therapy in Surgical involves rehabilitation, oedema management, prevention of contractures and deformities through splinting, mobilisation, scar management and ADLs<sup>3</sup>. Based on the occupational therapy intervention, it can be assumed that most surgical and burn injuries will require splinting management or scar management.
- Occupational therapy in Medical is an imperative field of practice; neurological conditions affect performance

- in ADLs. Occupational therapy attempts to diminish or compensate for cognitive, perceptual, or motor deficiencies<sup>36</sup>. Occupational therapy intervention in neurological conditions could involve splinting and or assistive device issue and rehabilitation.
- Occupational therapy in Oncology is centred around supportive care and includes ADLs, lymphoedema, strength, range of motion, cognitive and perceptual intervention, pain management and palliative care<sup>37</sup>. Occupational therapy intervention includes rehabilitation, assistive devices and technology, and wheelchair procurement. Oncology is the most underserviced discipline in this public, acute tertiary hospital.

This public, acute tertiary hospital follows specific referral channels<sup>6</sup>. The highest percentage of patients are from Northdale hospital (NDH) (14.9%), Edendale Hospital (EDH) (3.2%), Church of Scotland hospital (COSH) (4.1%) and Greytown hospital (2.7%). The health districts with the highest percentage of service include uMgungundlovu and uMzinyathi and uThukela indicating that these three districts are supported more than the other two districts. Several outpatient statistical forms were incomplete for base hospital entries, and therefore, a conclusive percentage was unable to be achieved for patient profile demographics.

The recommendations from this study include, policy and protocol review and implementation to guide the specific services within an acute public tertiary hospital, a further diagnostic classification category system to guide specific diagnostic profile categories, departmental influence to ensure proper documentation of statistics and further studies occupational therapy best practice guidelines that are contextually appropriate to various healthcare institutions.

#### Limitations of the study

Hard copies of statistical forms were consulted thus, illegible handwriting influenced data collection. Several statistical entries were incomplete for demographics, gender, and diagnostic profile categories, therefore, influencing patient-related data. Furthermore, wheelchair statistics were incorrectly recorded on the statistical forms, thus influencing assistive devices and technology data. Not all diagnostic profile categories have been included in the diagnostic profile list thus limiting and containing the diagnostic profile category for this study.

#### **CONCLUSION**

Challenges facing the healthcare system in South Africa are unequal distribution of resources, and slow progress in restructuring the healthcare system, including strategies adopted by the government to improve the quality of healthcare delivery<sup>27</sup>. The study results affirm the inter-relatedness of the occupational therapy practice framework domains of occupations, contexts, performance patterns and skills and client factors<sup>5</sup>. A tertiary hospital demands expertise and appropriate resources to provide an effective and efficient service. Based on the trends demonstrated in this study, it can be assumed that human resources and budget systems will define the next decade within the occupational therapy department as these directly affect the occupations, per-

formance patterns and skills of human resources in this field of practice and ultimately the intervention and outcomes of the healthcare system. A possible influencing variable may be the lack of knowledge about occupational therapy service delivery hence the moratorium on posts. Another influencing factor may be the channelling of an already constrained budget. Representation and participation in management evaluations, interventions and processes could improve the intervention and outcomes in a public, acute tertiary hospital. Innovation and pathway referrals remain some of the solutions to constraints in an acute public tertiary hospital.

#### **Author contributions**

Prashika Ghela completed this study towards a master's degree in occupational therapy degree and was responsible for the conceptualisation of the study, data collection, analysis and drafting of the original manuscript. Pragashnie Govender and Michael Olgunlana were supervisors of the study and guided the process from conceptualisation and design of the study to drafting and revision of the manuscript. All authors approved the manuscript for publication.

#### **Conflicts of interests**

The authors have no conflicts of interests to declare.

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## Occupational therapists' perspectives on the impact of COVID-19 lockdowns on their clients in Gauteng, South Africa - a qualitative retrospective study

#### **ABSTRACT**

**Introduction:** In March 2020, the South African government responded to the threat of the COVID-19 pandemic by issuing a national lockdown, calling a halt to all non-essential services and movements, including most occupational therapy services. Occupational therapy clients had no access to treatment during this time and may have experienced occupational injustices.

**Aim:** We explore occupational therapists' perceptions of the influence of COVID-19 lockdowns on rehabilitation clients in Gauteng, South Africa.

**Methodology:** We analysed secondary data collected in July 2020. The original qualitative study assessed occupational therapists' perceptions of the influence of COVID-19 on their service delivery. Sixteen occupational therapists participated in asynchronous on-online focus group discussions. The therapists worked in public and private settings in Gauteng. This study focussed on the influence of COVID-19 lockdowns on clients as perceived by occupational therapists. All data relating to the influence of COVID-19 lockdowns on clients were extracted from the original dataset using ATLAS. ti and then thematically analysed using deductive reasoning.

**Results:** Five themes emerged from the data. Occupational therapists felt that clients had altered clinical presentation due to infection prevention and control measures (Theme 1). Therapists also felt that the quality of services was negatively impacted, which was detrimental for clients (Theme 2); that their clients experienced occupational injustice due to disrupted services (Theme 3) that vulnerable populations experienced the greatest challenges (Theme 4) and that clients' experienced positive impacts or benefits during the COVID-19 lockdown (Theme 5).

**Conclusions:** In future pandemics, decision-makers need to carefully consider the impact of disrupted service delivery for occupational therapy clients, especially vulnerable populations. A syndemic approach is recommended for occupational therapy service delivery during a pandemic. Tailor-made recommendations that are needed for vulnerable populations in South Africa are proposed.

#### INTRODUCTION

In March 2020, the South African government implemented a nationwide lockdown to curb the spread of the SARS-CoV-2 virus, also known as coronavirus<sup>1</sup>. The spread of coronavirus disease (COVID-19) has impacted health systems across the globe. During the early days of the pandemic, the South African government imposed a level five lockdown, halting most economic activities, except for essential services which were permitted to continue working on site<sup>1</sup>. In South Africa, many clients had even less access to rehabilitation services during the COVID-19 lockdowns.

South African communities are affected by economic inequalities, high unemployment rate, existing non-communicable diseases, people living with disabilities and almost 30% of the population depending on social grants from the government<sup>2</sup>. Almost 70% of South Africa's population depends on public

health care provided by the government<sup>3</sup>. Some researchers have described the COVID-19 pandemic as a syndemic<sup>4-6</sup>. A syndemic is when a health condition is aggravated by contextual and social factors such as poverty, discrimination and structural inequalities, which lead to unfavourable outcomes<sup>7</sup>. In South Africa, the interactions between social structures (such as poverty, population density, poor access to health care and homelessness) and a health condition such as COVID-19 may have led to increased morbidity and mortality8. Lockdowns are likely to have reduced access to health care and rehabilitation services, placing a greater responsibility on clients to manage their own disabilities or conditions. These circumstances which occupational therapy clients encountered support the views of McMahon<sup>4</sup>, Singer and Rylko-Bauer<sup>5</sup> and Bragazzi<sup>6</sup> that COVID-19 is a syndemic rather than a pandemic.

The COVID-19 lockdowns affected both clients' access to health care and their human rights, including the right to privacy, safety, food, security, information, freedom of expression, and freedom of movement9. From an occupational therapy perspective, people may experience occupational injustices if they are unable to meet their needs due to social, environmental and political factors beyond their control and are unable to engage successfully in meaningful occupations<sup>10</sup>. Occupational injustice may manifest as occupational deprivation, imbalance or alienation. Occupational deprivation occurs when people are deprived of their normal occupations<sup>10</sup>. Occupational imbalance happens when people work too hard or too little<sup>10</sup>, and occupational alienation includes the subjective experiences of isolation, powerlessness, frustration, loss of control and estrangement from society or the self, due to engagement in an occupation that does not satisfy inner needs<sup>11</sup>. To date, the level of occupational injustice experienced by clients seeking occupational rehabilitation during COVID-19 lockdowns has not been explored.

People seeking rehabilitation services are generally vulnerable or may have certain disabilities, and feel the effects of emergencies such as climate change, natural disasters, health crises and warfare more acutely due to societal barriers<sup>12-14</sup>. Vulnerable populations may feel the effects of occupational deprivation, imbalance and alienation more acutely when they cannot do what is necessary and meaningful in their lives due to external restrictions15. These restrictions may include unemployment, poverty or poor access to health care services<sup>15</sup>. During the early COVID-19 lockdowns, especially levels four and five, infection prevention protocols deprived many clients of the opportunity to participate in groups, access leisure participation and manage their health independently. In South Africa, the elderly and those with comorbidities were most deprived since they had to stay home to protect their health and could not participate in activities outside their homes<sup>16</sup>. Rehabilitation services were not prioritised during the early lockdowns, and people with disabilities who relied on services such as wheelchair upgrading, seating and maintenance were negatively affected<sup>17</sup>. The restrictions and protocols to control the COVID-19 pandemic were foreign to most people, who had to change routines and perform tasks differently, which may have caused frustration and loss of control.

In South Africa, people with disabilities in rural areas experience occupational injustices and barriers to accessing health care, particularly rehabilitation services. COVID-19 lockdowns caused further restrictions and more barriers to maintaining levels of functioning in the community. In addition, fear of contracting the virus made it more difficult for people to access healthcare services, and this made them vulnerable to survive the COVID-19 pandemic<sup>18</sup>.

The effectiveness of infection prevention control (IPC) measures to control the spread of the virus has been recognised by the medical fraternity. Still, little is known about the impact of IPCs on clients who need to manage their non-communicable diseases or continue their lives with a disability. The influence of having to forfeit rehabilitation services in a pandemic has not been investigated. Many clients in South Africa suffered unanticipated negative consequences during the pandemic<sup>5</sup>, and this study presents a narrow glimpse of the impact of COVID-19 lockdowns on public and private healthcare rehabilitation clients from the perspectives of occupational therapy clinicians.

#### **METHODOLOGY**

This study forms part of a qualitative study by Uys et al<sup>19</sup> who explored the perceptions of occupational therapy clinicians in private and public healthcare settings on the impact of the COVID-19 pandemic lockdown restrictions on rehabilitation services in Gauteng, South Africa in July 2020. The services of occupational therapists in South Africa were severely impacted as they were categorised as non-essential services and not permitted under level five lockdown restrictions. Only telehealth options could be provided to some service users<sup>19</sup>. Sixteen participants were purposively selected to include occupational therapy clinicians registered with the HPCSA who work in private or public settings; postgraduate occupational therapy students working as clinicians in different fields of practice or clinical occupational therapy supervisors from University of Pretoria and University of the Witwatersrand with access to email and virtual meeting platforms. Stratified sampling was applied to ensure different settings and practices were sampled. The variations included private and public settings, and various types of practices including paediatrics, mental health, vocational rehabilitation, physical rehabilitation, and school-based occupational therapy clinicians<sup>19</sup>.

The sixteen participants were randomly divided into two groups of eight and invited to participate in online focus groups. The focus groups were facilitated on Blackboard, the University of Pretoria's learning management system. Participants completed an online consent form and a demographic questionnaire before accessing the asynchronous, online focus groups which were facilitated over a period of one week<sup>19</sup>. Online focus groups were

preferred over face-to-face groups as they were convenient and comfortable for participants<sup>19</sup>, provided access to diverse participants, and adhered to the South African social distancing regulations during the Covid-19 lockdown restrictions during the data collection period of July 2020. Six main questions were posed to the participants of the focus groups on the influence of Covid-19 on their practice as a clinician and on their ability to provide compassion and care to their service users. Participants were able to respond to the questions electronically in their own time, within the allocated week. Probing questions were used to obtain rich information from participants. The participant responses were collated and the transcription used for analysis. The data were analysed using ATLAS.ti software (version 8)20 and guided by Braun and Clarkes'21 six steps of thematic analysis to generate codes and themes which were identified from the responses to form a coherent presentation of findings and identify the topic of conversation.

The need for the secondary analysis was identified after the original data were analysed. Unexpectedly the original transcriptions contained rich information on the effect of the COVID-19 lockdown restrictions on occupational therapy clients which was beyond the scope of the original study. Participants' responses were reanalysed to explore the influence of COVID-19 pandemic lockdowns on clients in a variety of settings from the perspectives of occupational therapy clinicians. A retrospective, secondary analysis design permits re-analyses of the data outside the limits of the original study objectives<sup>22</sup>.

The original online focus groups were recorded and available as digital transcriptions. Although the data for this study were extracted a year after the primary data were collected, the data are still applicable to understanding how occupational therapy clients were impacted by early COVID-19 lockdown restrictions.

The data were imported from a Microsoft Word document into ATLAS-ti software (version 8)20 for analysis. Using the software, codes were generated from the data, and sorted into themes and subthemes. Quotations that support the subthemes were selected and reported with a participant code. The participant codes reflect the setting where the occupational therapy clinicians treated their clients. The first two digits represent the participant number, the third digit is the gender of the participant (Male of Female), the fourth and fifth digit represent the field of practice (Sb being school-based; Pa paediatrics; Ph physical and/or neurological conditions; Di being a district hospital; LP being long term psych and AP acute psych; Mx a mix of conditions and VR vocational rehabilitation. The last two digits indicated whether the participant delivered services in private (Pr) or public (Pu) healthcare settings.

Data were analysed using the observe, think, test and revise (OTTR) process described by Basakarada<sup>23</sup>. This is an iterative process which ends when all data have been organised into themes and subthemes. The researchers also did cross-case comparisons to see if occupational therapy clinicians reported similar or unique experiences in public or private settings.

#### **Ethical considerations**

Ethical principles such as confidentiality and non-maleficence were considered, and data were already de-identified in the original dataset. The authors used professional judgement regarding informed consent for the use of the primary dataset for secondary analysis<sup>24</sup>. Participants had consented to the original study and were aware that their opinions would be used for research purposes. The study was approved by the University of Pretoria's Faculty of Health Sciences, Research Ethics Committee prior to commencing the study (Ethics ID: 436-2020). Permission was obtained from the principal investigator to perform a secondary qualitative analysis to answer a new research question on the existing primary dataset containing data from the two asynchronous, online focus groups<sup>19</sup>.

#### **RESULTS**

Five themes evolved from the data. Themes and subthemes are supported with quotations. The frequency of quotations per subtheme indicates the richness of the data.

# Theme 1: Influence of IPC measures on the clinical presentation of service users

Occupational therapy clinicians reported that IPC measures had a large impact on the clinical presentation of clients, especially children, mental health care users (MHCUs), the elderly and on the families of clients. According to occupational therapy clinicians, many children did not understand why the restrictions were implemented, including masks, changed routines and not being allowed to interact with friends. These regulations increased anxiety and confusion in children. In occupational therapy settings, clinicians reported that some children were stimulated by the odour of cleaning products. Due to social distancing protocols, these children could not use sensory integration equipment, including swings and hammocks to modulate their behaviour, which aggravated their insecurity (Table I, page 26).

In hospital settings, social isolation rules prevented mothers from comforting their children in burns wards and those with acute malnutrition. Occupational therapy clinicians reported that MHCUs in long term facilities could not be visited by their families and could not receive extra food and cigarettes. In some cases, forensic wards were closed down and MCHUs could not leave the wards (Table I, page 27). Due to social distancing rules, MHCUs were not allowed to attend occupational therapy pre-vocational programmes. Most MHCUs earn a stipend from the products they make in the pre-vocational programmes and thus their limited incomes were further restricted. The effects of institutionalisation for MHCUs were further compounded by IPC regulations.

Occupational therapy clinicians reported that MHCUs were negatively affected by mask wearing which limited their ability to communicate. Many MHCUs could not rely on facial expressions, a smile for acknowledgement or lipreading to find comfort. Occupational therapy clinicians reported an increase in symptoms of anxiety, irritation and depression among MHCUs. Group therapy was restricted to three to five members due to social distancing. Mask wearing also disrupted the dynamics of group therapy, and curative fac-

Table I: Theme 1, influence of IPC measures on the clinical presentation of service users

Subtheme	Frequency	Quotation
Children	8	"The children with sensory or emotional regulation challenges have battled a lot. The masks, health risks and changes in routine showed a marked increase in anxiety." P8FPaPr "explaining to her (a child) that we cannot hug our friends anymore resulted in a melt down and 2 day long silent treatment." P12FSbPu "The smell of cleaning products affected the arousal levels of the children (e.g. became agitated, said it smelt like a hospital, did not have access to their favourite swings or activities.)" P8FPaPr "In my setting children sees therapy as their safe space, a constant and a space of freedom. They are very confused with all the new restrictions in therapy, can't modulate on the hammock." P12FSbPu "Increase in paediatric burns, severe acute malnutrition, treating screaming children who have gone for the longest time not being held by their mother." P16FPhPu
Mental health care users	12	"MHCUs are preoccupied about the fact they no longer are receiving visits from their families (due to regulations) and also that they are not receiving any goods from home." P2MLPsPu "The MHCUs have already lost visitation from their families and parole (to leave the ward)." P2MLPsPu "Patients are no longer allowed to leave wards and thus unable to attend pre-voc programmes out of the ward." P2MLPsPu "Wearing masks negatively affects communication. MHCUs that rely partially on lipreading withdraw from groups and become quiet." P10MAPsPr "They do not have the mental resources to be as motivated to attend therapy as one would expect." P6FAPsPr "Social distancing within occupational group therapy negatively impacts the cohesion needed to move forward with the group and facilitate other curative factors." P6FAPsPr
The elderly	9	"In our Frail Care setting we had a COVID-19 outbreak, and the residents had to stay in their rooms for 3 days, groups were cancelled until recently, no eating in the dining room, no visiting hours, no real contact with staff members - using agency staff they do not know." P15FPhPr "Not eating in a dining room -social event - residents lose their appetite and not drinking enough fluids, lost weight." P15FPhPr "More disorientation and not having a day program led to not being orientated to time and place." P15FPhPr "Talking less where we had residents that are known to complain - stopped complaining or requesting." P15FPhPr "Residents scared of other residents - so when they could join groups again - they opted not to." P15FPhPr "Not mobilising - we experienced a definite decline in balance and mobility with more falls." P15FPhPr
The family	5	"Not being able to run groups or do home visits is a major concern for me as I work in a district hospital in a rural area. Some mothers really benefit from one another's support and having sessions with patients in their natural setting has shown to be beneficial to them and their care givers." PIIFDiPu "Doing family education is challenging as families are not allowed inside the wards." PI4FMxPu "Family education sessions are brief and upon discharge." PI6FPhPu "They rely a lot more on us as their therapists for emotional support as their families aren't able to visit them." P7FPhPr

tors could not be facilitated. Occupational therapy clinicians reported that MHCUs were less interactive in group therapy sessions, where group members started to communicate through the therapist and not with each other. The loss of therapeutic impact resulted in MHCUs being less motivated to attend groups.

Occupational therapy clinicians reported that the elderly was severely affected by IPC regulations, especially those in care homes. In care homes, the elderly was forced to eat in their rooms and no longer in the dining hall. Many residents socialise in the dining hall, which could not happen due to IPC measures. These elderly residents experienced loss of appetite; they stopped taking in fluids and lost weight. Elderly residents could not visit their family members and friends, which increased feelings of loneliness, blunted affect and depression. One occupational therapy clinician reported that the elderly stopped their usual complaints and talked less. Some residents were scared of being infected and imposed self-isolation on themselves, not even attending the groups that were still available. Physically, the elderly became less mobile due to staying in their rooms and exercising less, which increased their risk of falls.

Many occupational therapy clinicians reported that fami-

lies were negatively impacted by lockdown regulations. In rural areas, support groups for mothers with children with disabilities were discontinued and therapists could not do home visits. Families were not allowed in the wards, which resulted in insufficient family education and families could not support their family members emotionally.

# Theme 2: Influence on service quality for service users

This theme reflects that occupational therapy clinicians felt that clients did not have access to good quality rehabilitation services due to IPC measures. The types of services rendered changed due to COVID-19 restrictions and other services could not be rendered at all. Therapeutic relationships between therapists and clients were affected and resources were limited.

Occupational therapy clinicians reported that certain resources were in great demand during the COVID-19 lock-down. Participants in hospital settings reported that wheel-chairs were in high demand because many clients were discharged before receiving optimal rehabilitation. While the turnover of patients was high, procurement of resources for rehabilitation was delayed (Table II, page 27). Many clients did

Table II: Theme 2, influence on service quality for service users.

Subtheme	Frequency	Quotation
Resources	11	"The limited resources make 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 as the level of commitment to collaborating needs to be a joint effort." P16FPhPu "Very slow procurement procedures as many companies are working remotelywe are low on our occupational therapy consumables." P11FDiPu
Service restrictions	17	"In my setting children see therapy as their safe space, a constant and a space of freedom. They are very confused with all the new restrictions in therapy, can't modulate on the hammock, can't play with the rice or beans, if another friend played with the plastic animals we need to wait for it to sterilise in the Milton. all so confusing to little bodies." P12FSbPu "Family meetings on Zoom - Joint session and carer training not adequate with isolation protocol." P15FPhPr
Therapeutic relationships	6	"To add - in Mental Health we have a strong focus on interaction and social connectedness as therapeutic objectives and given the social distancing rules, mask wearing and reduced number of clients per group, our clients are losing out significantly on some of the benefits of group therapy." P6FAPsPr "Wearing masks negatively affects communication. MHCUs that rely partially on lipreading withdraw from groups and become quiet. MHCUs cannot read each other's facial expressions and struggle to communicate non-verbally." P10MAPsPr

Table III: Theme 3, Experiences of occupational injustices.

Subtheme	Frequency	Quotation
Occupational deprivation	10	"Patients are no longer allowed to leave wards and thus unable to attend pre-voc programmes out of the ward." P2MLPsPu "seeing the effects of Occupational deprivation on young and old has been challenging." P16FPhPu "The learners at our school has limited access to technology or data therefore no therapy was provided during the initial lockdown." P1FSbPu
Occupational imbalance	8	"So during the level 4-5 lockdown we realised that not all learners are engaging in remote learning. Weekly I posted a video of a peer, teacher or myself motivating learners." PIFSbPu "The prolonged impact of the pandemic has led to clients being very exhausted." P6FAPsPr
Occupational alienation	12	"In our Frail Care setting we had a COVID outbreak, and the residents had to stay in their rooms for 3 days, groups were cancelled until recently, no eating in the dining room, no visiting hours, no real contact with staff members - using agency staff they do not know." P15FPhPr "changes in routine showed a marked increase in anxiety." P8FPaPr

not receive therapy or assistive devices during the COVID-19 lockdown. Some occupational therapy clinicians chose to provide services through Telehealth which came with difficulties. Not all clients had access to technology therefore they received limited services. Occupational therapy clinicians tried to compensate for limited hospital inpatient stays by providing more elaborate home programmes. Some occupational therapy clinicians felt that home programmes were not as efficient as face-to-face therapy.

COVID-19 restrictions such as social distancing, reduced contact time and wearing of masks affected general therapeutic programmes. Some occupational therapy clinicians mentioned that group therapy in their work environments was cancelled. Some clients opted not to return for group therapy when restrictions were eased due to fear of contracting the virus.

According to occupational therapy clinicians, therapeutic relationships were negatively impacted by COVID-19 restrictions. This was primarily seen in group therapy, especially with MHCUs and young children (Table II, above). Some occupational therapy clinicians mentioned that therapeutic relationships are essential when working with autistic children. Not being able to interact personally with these

children limited their therapeutic relationships.

#### Theme 3: Experiences of occupational injustice

Occupational therapy clinicians felt that clients experienced occupational injustices during the COVID-19 lockdowns. Occupational injustices included occupational deprivation, occupational imbalance, and occupational alienation (Table III, above).

Occupational therapy clinicians reported many examples of occupational deprivation experienced by clients. Therapy in schools was stopped during school closures (Table III). Learners who relied on therapy in schools were severely deprived during closures. At this time, many learners had to engage in remote learning, and lack of cellular data and resources meant no therapy during the first lockdown.

Hospitals could treat a limited number of outpatients, and consequently, some clients experienced long intervals without receiving therapy. High-risk populations such as preterm babies, babies with hypoxic ischaemic encephalopathy, adults with cerebrovascular incidents and parents with children with cerebral palsy stopped going to hospitals for their sessions because families and clients feared contracting the virus.

Table IV: Theme 4, exposing vulnerable populations.

Subtheme	Frequency	Quotation
Service users with socio-economic challenges	10	"Unemployment was an issue prior to COVID, malnutrition and other social problems, COVID has just amplified the problem." P16FPhPu "We have had to look at the vulnerable populations we serve as our largest catchment area even prior to COVID had substantial socio-economic challenges and have had to evaluate whether accessing therapy vs the risks of exposure on the taxis and community are really high as we border both City of Ekurhuleni and City of Joburg municipalities and those have had the highest statistics from the start of the pandemic." P16FPhPu "People do not want to test in their communities and are battling to survive so they do not want to know if they are positive." P16FPhPu
Children's needs being neglected	18	"As we are close to an informal settlement where kids were fully dependent on the school nutrition programs." PI4FMXPU "Increase in paediatric burns, severe acute malnutrition, treating screaming children who have gone for the longest time not being held by their mother, seeing the effects of Occupational deprivation on young and old and the difference between poverty and middle classed clients." PI6FPhPu
The elderly population facing severe challenges	15	"Also managing an occupational therapy practice at a frail care with total lockdown, no visitor, anxious residents, residents passing away." P15FPhPr  "Residents had to stay in their rooms for 3 days, groups were cancelled until recently, no eating in the dining room, no visiting hours, no real contact with staff members - using agency staff they do not know." P15FPhPr

Occupational therapy clinicians reported that MHCUs in long term wards could not attend pre-vocational programmes which provided them with a stipend (Table III, page 28). These MHCUs were deprived of income. The elderly in residential care facilities were also isolated, could not enjoy meals in the dining halls and experienced occupational deprivation and social seclusion.

COVID-19 lockdowns disrupted therapy programmes and daily routines, resulting in occupational imbalance for clients. Even when learners returned to school in a phased approach, many learners still could not receive optimal or balanced therapy because they did not attend school daily. The prolonged occupational imbalance of COVID-19 lockdowns has resulted in pandemic fatigue for many clients (Table III, page 28).

Change or loss of roles, fear and the "new norm" resulted in occupational alienation for many clients. Occupational therapy clinicians reported that some families became overwhelmed and struggled to cope with all the changes and caring for their loved ones. Family education was limited because family members were not allowed into wards. Children were confused by all the new restrictions and struggled to understand why they had to wear masks, sanitise and social distance. Some patients experienced disorientation to time and place due to a lack of routine. Group therapy to facilitate interpersonal learning was done with masks, fewer members in the group and social distancing. These new rules alienated clients, who could not see facial expressions or communicate clearly, choosing to speak through the therapist. Occupational therapy clinicians reported that clients could not achieve therapeutic goals, which led to increased levels of anxiety and fear (Table III, page 28).

#### Theme 4: Exposing vulnerable populations

Occupational therapy clinicians from public hospitals and residential care facilities were concerned about the impact

of the pandemic on vulnerable populations, including unemployed people, the elderly and children (Table IV, above). Pre-COVID-19 socio-economic challenges were amplified during the pandemic.

Occupational therapy clinicians reported that clients were struggling to cope with life as it is. According to occupational therapy clinicians, many clients had no intention of going for COVID-19 testing if they experience symptoms because they would rather not know their status. Occupational therapy clinicians also reported that clients were afraid of travelling to hospital using public transport due to the risk of contracting the virus. Many clients missed their rehabilitation sessions and further struggled to cope with everyday challenges.

Occupational therapy clinicians mentioned that children were a vulnerable population since many school-going children with disabilities depended on school nutrition programmes. Staying at home during COVID-19 lockdowns meant that many children experienced hunger. Where possible therapists contacted families and put them in contact with government feeding schemes. Participants reported that this was hard to observe and to see the effects of poverty on children (Table IV, above).

Occupational therapy clinicians also felt that the elderly in residential care settings were in the vulnerable population group as they were affected by the isolation and not receiving any visitors. With COVID-19 outbreaks in these residences, they had to stay in their rooms, were not allowed to eat in the dining room and all therapy groups were terminated (Table IV, above). This impacted their mobility and general emotional state.

#### Theme 5: Positive impact on service users

Even though COVID-19 lockdowns caused difficulties, challenges and sudden changes, Occupational therapy clinicians still felt there were positive outcomes for clients (Table V, page 30). Occupational therapy clinicians had to invent al-

Table V: Theme 5, positive impact on service users

Subtheme	Frequency	Quotation
Alternative ways of delivering therapy	10	"We started sending feedback via videos/voice notes to the family of patients who are unable to visit due to the lockdown. We saw that the families respond really well towards receiving feedback and are generally more positive than just receiving an email." PTFPhPr  "Attempts were made to support the Gr 10 to learners using YouTube and WhatsApp. The focus was motivation.PIFSbPu  Weekly I posted a video of a peer, teacher or myself motivating learners." PIFSbPu  "I then created a WhatsApp broadcast group with short video clips of activity ideas I made with my own children, to motivate my therapy children to play (preferably outdoors) and be active, especially because many of them have been at home, spending many hours on a screen." P8FPaPr  "For a lot of clients continuity of care and more regular interaction has taken place because of telehealth. P4FVRPr  Perhaps a greater awareness as we have access to our clients in their unique context with telehealth." P4FVRPr  "Fortunately, I now have a little more access to my children as I can have home programmes delivered to their homes." P12FSbPu
Service users taking ownership of their interventions	5	"This was received positively, as there was not "pressure" to do certain things by a certain day or time and many parents sent little video clips back to me where their children tried some of the activities at home." P8FPaPr  "The clients that have participated in the home program had to take on more responsibility and ownership. Which meant also that they were able to better understand what was expected from them." P13FPaPr  "Our parents who have babies with club feet and orthopaedic patients have been much more compliant with home programs and it is evident that they are taking their management seriously than before since there are longer periods that pass between sessions." P16FPhPu

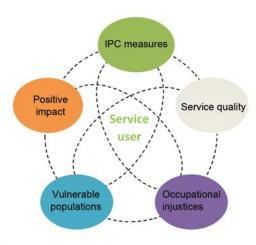


Figure 1: The multi-factor influences of COVID-19 on occupational therapy service users

ternative ways to continue services. Occupational therapy clinicians could interact regularly with their clients using Telehealth. Intervention plans were sent to families who could not visit due to the COVID-19 restrictions using videos and voice notes. Occupational therapy clinicians reported that some parents were able to call them with feedback on their clients' progress at home. Many clients appreciated the alternative communication and services they received through Telehealth.

Occupational therapy clinicians reported that clients took a greater responsibility for their therapy, were more aware of their ability to help themselves, and did not depend only on therapy received through face to face contact. According to occupational therapy clinicians, they could still help their clients, even indirectly, by supporting their strengths and empowering them to take responsibility for their own treatment

One occupational therapy clinician reported that clients with orthopaedic conditions were more compliant with home programmes. Parents took greater responsibility and ownership for managing their children with clubfeet than before the COVID-19 lockdowns (Table V, above). Occupational therapy clinicians reported that feedback and communication with their clients improved.

These five themes represent the complex nature of the impacts of COVID-19 lockdowns on occupational therapy clients' experiences, according to occupational therapy clinicians. Although these themes share several commonalities, each theme had unique features. Figure 1, adjacent depicts the occupational therapy client at the nexus of the themes. Our analysis shows that clients may have been impacted by multiple factors and in some cases, one client could have been affected by all five themes. For example, an elderly person in a care facility can be viewed as a vulnerable person who has been severely affected by the IPC measures (no visitation from family) which led to occupational deprivation (no social contact with the outside world and aggravated by not being allowed to go to the dining hall) and in the end receiving poor quality of care (could not benefit from Telehealth as the resources were not available).

### DISCUSSION

One of the major theoretical underpinnings of occupational therapy is that of occupational justice10 and this study highlights the occupational deprivation, imbalance and alienation experienced by occupational therapy clients during the initial stages of lockdown in Gauteng. The implementation of IPC measures such as isolation and face masks have mitigated viral transmission. These benefits may have been at the cost of other important therapeutic factors associated with occupational therapy. According to occupational therapy clinicians, lockdown restrictions had many unan-

ticipated negative consequences which impacted families, children, MHCUs and the elderly.

A position paper on mental health care, compiled by a group of experts, including clinicians, mental health experts and MHCUs reported similar consequences of COVID-19 regulations and came up with recommendations for better service delivery in the future<sup>25</sup>. These experts recommend acknowledging the mental health consequences of IPCs for MHCUs, families, the elderly and children and providing support via therapeutic programmes<sup>25</sup>. These recommendations are commendable but are suitable for high-income countries. In our study, occupational therapy clinicians reported specific challenges such as children with burns who could not be comforted by their mothers, the elderly who were isolated and long term institutionalised MHCUs not being allowed any visitors. Tailor-made recommendations are needed for these populations during a pandemic, such as empowering service users to take more responsibility on their intervention as well as having access to Telehealth.

In South Africa, occupational therapy clinicians reported that the quality of services dropped due to procurement procedures. At the start of the COVID-19 pandemic, health executives worldwide started competing for medical resources that were in high demand such as personal protective equipment<sup>26</sup>. With the high demand for certain resources, procurement of other resources became slow. In our study, occupational therapy clinicians reported a high demand for wheelchairs for clients, which was seldom met. Some clients were discharged without receiving assistive devices and could not be rehabilitated or cared for at home. COVID-19 lockdowns also limited access to occupational therapy interventions and rehabilitation services<sup>27</sup>.

In our study, occupational therapy clinicians reported that group therapy, which is especially valuable for psychiatric patients<sup>28</sup>, was extremely difficult to facilitate during the early COVID-19 lockdowns. However, the findings of this study indicate that a large number of service users were deprived of the benefits of group therapy due to restrictions such as wearing masks and social distancing. This affected the therapeutic relationships of therapists with the service users and amongst service users themselves<sup>28</sup>. In South Africa, many clients stopped participating in therapy, especially if the therapy was difficult to access in the first place. This may have aggravated illnesses, requiring more intervention from occupational therapy clinicians. Many people from low socio-economic backgrounds cannot access services such as Telehealth<sup>27</sup>. Even though some clients had access to Telehealth, occupational therapy clinicians felt that these services could not replace face to face intervention, which is similar to views expressed in Luck et al.<sup>29</sup> In our study, occupational therapy clinicians reported that certain clients benefitted from Telehealth interventions. Parents were able to send video clips of their children at home to demonstrate how they implemented the home programmes given by therapists. The occupational therapy clinicians in turn gave feedback on those videos. It is likely that these clients were private sector clients, who had access to cellular data.

COVID-19 lockdown restrictions constituted a serious

barrier for providing and accessing care<sup>29</sup>, which resulted in occupational injustices. Occupational therapy clinicians reported that elderly care home residents were restricted to their rooms, could not eat in dining halls, had reduced mobility and had limited or no interaction with other patients. These isolation measures disrupted programmes and clients became disorientated and more isolated due to fear of contracting COVID-19, and experienced a decline in mobility and balance. The elderly could not participate in meaningful occupations because they were deprived of participating in daily activities, had no alternative treatment programmes and were alienated due to the 'new normal'.

Learners who relied on occupational therapy intervention were deprived of therapy when schools closed down. A policy brief by The Organisation for Economic Co-operation and Development (OECD)<sup>30</sup> also indicated that vulnerable children from low-income families and those with disabilities/special educational needs fall behind when isolated and deprived of learning opportunities and extra services such as therapy.

In our study, occupational therapy clinicians reported that certain clients were empowered by the additional challenges of having to deal with COVID-19 lockdowns. Therapists reported that clients started to take greater responsibility for their own therapy, resulting in positive outcomes at home. Luck et al.<sup>29</sup> also reported that clients had to prioritise selfmanagement and start to rely more on themselves during the pandemic.

In South Africa the unemployment rate (expanded definition) was at 44.4% in the second quarter of 2021<sup>4</sup> and more than 18 million people (30% of the population) were receiving social grants from the government<sup>3</sup>. This paints a bleak picture of the economic status of the country and it should thus not come as a surprise that participants in this study reported on the suffering of vulnerable populations (children, the elderly, mental health care users and those with socio economic challenges) during COVID-19. Even without a pandemic, these populations need support and are more prone to infections and other health conditions.

There is a need for a syndemic approach<sup>5,7</sup> to the CO-VID-19 pandemic in South Africa since rehabilitation clients often have to deal with social injustices, as well as their own impairments. Many clients had to deal with the crisis of the pandemic without access to therapy. This study highlighted the crisis that service users experienced and this triggers a need to address the inequalities that a large portion of service users experience in South Africa. It is thus the responsibility of occupational therapists to review their preparedness and response to the rehabilitation needs of clients during a pandemic or similar event. The experiences reported in our study are similar to those experienced by people with disabilities during the influenza pandemic  $^{31}$ . Vincent et al.  $^{31}$ recommended that adequate health communication and planning should involve people with disabilities to ensure services continue during the influenza pandemic. This is important for South Africa since there were no clear guidelines to ensure that COVID-19 measures were disability-inclusive during the initial stages of lockdown<sup>17</sup>.

A set of guidelines on how to manage a pandemic with a

syndemic approach in occupational therapy could include: monitoring the health and coping needs of service users; assessing the social determinants of health on the everyday life of service users; food security programmes (including small-scale food production at home such as food gardens); alternatives to continue outpatient services; advocate special permission for community health workers to continue with home visits and extend rehabilitation services to the homes of clients, issuing of wheelchairs and assistive devices in times of crisis; long-term institutions with adapted visitation rules and more support for homeless persons and the elderly.

#### Limitations of the study

One of the limitations of this study is that we report on the perceptions of occupational therapy clinicians and not their clients. The researchers identified the need for a secondary analysis since occupational therapy clinicians expressed valuable insights into the effects of the COVID-19 lockdowns on their clients. The source of data is thus not a comprehensive account of the service users' point of view. A follow-up study with the voices and lived experience of the clients is needed. These findings cannot be generalised to other settings. The study was done during the first wave of COVID-19 in South Africa. Experiences of the impact of consequent waves after the first wave (from August 2020) are thus not captured in this study. A longitudinal perspective with more focus on changes over time is necessary.

#### CONCLUSION

The COVID-19 pandemic has impacted the lives of people in many different ways: how people live, learn, work, play and socialise. Occupational therapists in this study shared their perspectives of how their clients were affected during the initial stages of the pandemic. The five themes indicate that different areas of occupations were affected for clients. Vulnerable populations were mainly affected and needed more support which could not be easily provided due to COVID-19 restrictions. Occupational therapy clinicians highlighted challenges as well as positive points and strategies such as the use of Telehealth, which could help to empower clients in the future.

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#### Conflict of interest (COI) declaration

The authors declare that there are no opposing interests that may affect this study.

#### **Author contributions**

Nthabiseng Phalatsewas the lead author who planned and organised the study. The sections of the article were divided among authors, Eileen du Plooy, Henry Msimango and Veronica Ramodike each contributed to the writing of the article. Daleen Casteleijn did the final editing and references.

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## Occupational therapists' perceived ability to treat and assist bereaved individuals to find new meaning in life through engagement in therapeutic activities

#### **ABSTRACT**

**Introduction:** Previous studies on bereavement have focused on the implications for bereaved individuals from behavioural and psychological perspectives. Limited literature discusses occupational therapists' perceived ability to treat bereaved individuals and how activities can be used to create new meaning to their lives.

**Method:** A descriptive qualitative design was employed in the study to elicit occupational therapists' perceived ability to treat bereaved individuals find new meaning in their life. Thirty-five occupational therapists were recruited, and nine participated in two focus groups. Data collected were thematically analysed.

**Findings:** Three themes emerged, namely: (1) activities used in occupational therapy creates opportunities for new meaning to life after loss of a loved one, (2) appropriate occupational therapists' helping skills and professional behaviour to assist and treat the bereaved, and (3) perceived barriers to positive outcomes in treating the bereaved.

**Conclusion:** Bereaved individuals often have impaired performance in occupations and emotional processing. The effects of bereavement were addressed using the appropriate occupational therapist helping skills and professional behaviour to guide holistic, occupation-based and client-centred treatment. Bereaved individuals were treated through purposeful activities, facilitation of therapeutic groups and self-management skills training which seemed to create opportunities for new meaning in their life. Occupational therapists need to be cognisant of the barriers that negatively influence the positive outcome of occupational therapy services.

#### INTRODUCTION

Bereavement denotes the objective situation of a person who has experienced the loss of someone significant through death<sup>1</sup>. The objective situation of bereavement includes a range of grief and mourning responses<sup>1</sup>. Grief is a process in which cognitive, social and existential adjustment take place<sup>1</sup>.

Seven percent of bereaved individuals do not cope effectively with the loss, which develops into complicated grief<sup>2</sup>. Complicated grief afflicts bereaved individuals and is associated with severe disruption of functioning<sup>3</sup>. The situation of bereavement affects the quality of life by placing mental, physical, and emotional strain on a bereaved individual<sup>4</sup>. It further affects occupational engagement and participation, and the bereaved individual's life roles and body functions5, which indirectly affect their health and well-being. Bereavement also impacts on how bereaved individuals participate in occupations such as activities of daily living (ADL), leisure tasks, social participation and work<sup>6,7,8</sup>.

When bereaved individuals cannot function in their daily occupations, they tend to experience occupational imbalance, which indicates that they require occupational therapy intervention to restore their optimal occupational engagement and participation<sup>5</sup>. The bereaved individuals tend to struggle with the bewildering sense of meaninglessnessl. Occupational therapists focus on meaning recons-

truction<sup>5</sup> and occupational participation<sup>6,8</sup>. Consequently, occupational therapists use occupations or therapeutic activities to create meaning for bereaved individuals<sup>9</sup>.

A study carried out in Australia proved that there is a lack of education amongst most health care professionals (including occupational therapists) on working with bereaved individual10 and Breen11 advised that there is a need for up-to-date and easily accessible grief education for grief counsellors. Daddah, Bombarda, Frizzo and Joaquim<sup>9</sup> were concerned that there was a shortage of publications produced by occupational therapists for bereaved individuals. Furthermore, a shortage of evidence-based research that guides education on needs of children with grief issues in school-based settings results in the potential lack of confidence and competencies among occupational therapists to treat bereaved individuals of all ages who suffer from unresolved grief<sup>12</sup>. The feeling of incompetence contributes to the general view among occupational therapists that grief should be addressed by other health care professionals12. In addition, this perspective acts as a barrier for occupational therapists to provide treatment for bereaved individuals.

Through a literature search, the researchers of this article found limited evidence that supports the use of occupational therapy in treating bereaved individuals<sup>6,9</sup>. Furthermore, there was a paucity of literature in the South African context which discusses occupational therapists' perceived ability to treat bereaved individuals find new meaning in life through engagement in therapeutic activities even though the death of someone significant is a painful and often devastating life event<sup>3</sup>. Therefore, the objectives of this study were to describe: (1) occupational therapists' ways of facilitating meaning for bereaved individuals, and (2) occupational therapists' perceived barriers in treating bereaved individuals.

#### **Literature Review**

Bereavement involves adjusting to an altered reality after loss<sup>13</sup>. The ways of adapting to altered reality cannot be generalized, as reactions to death are diverse and unique<sup>14</sup>. However, the impact of bereavement is gauged by the nature of the relationship with the deceased, the amount of support received, and the resilience of the bereaved person<sup>15</sup>. When these factors are unfavourable to the bereaved individual, it may result in complicated bereavement or prolonged grief disorder<sup>15</sup>. Complicated bereavement or prolonged grief disorder affects a bereaved individual's quality of life by causing mental, physical and emotional strain<sup>4</sup>. Individuals who experience the loss of close relationships may experience impairment in occupations and disruption of roles and be unable to perform certain activities associated with role fulfilment<sup>6</sup>. The impact of bereavement on roles, occupations and quality of life may lead to a need for occupational therapy intervention.

Occupational therapists are responsible for enabling meaningful occupational engagement and creating occupation-based intervention<sup>8</sup>. According to Hoppes and Segal<sup>5</sup>, engagement in occupation is key to meaning

reconstruction. Meaning reconstruction is the process of bereaved individuals' effort to find meaning¹. Meaning is the transcription of the bereaved individuals' narratives, experiences and or values. Therefore, the use of meaningful activities has therapeutic and occupational value in organizing behaviour, which allows for a sense of individuality and contributes to the development of a sense of purpose¹6. Some obstacles may hinder a healthy grieving process. These include not acknowledging one's grief, not reflecting true feelings of grief, lack of social support systems, having inadequate time for grieving, and difficulty facing individual mortality⁰¹¹o.¹¹¹. Therefore, the study aimed to describe the occupational therapists' perceived ability to assist and treat bereaved individuals in finding new meaning in life through engagement in therapeutic activities¹¹¹.

#### **RESEARCH METHODOLOGY**

#### Study design

A descriptive qualitative design<sup>17</sup> was used to enhance the researchers' ability to contextualize bereavement in its complexity<sup>9</sup>. Using a descriptive qualitative design, we were able to describe the occupational therapists perceived ability to treat bereaved individuals and their experiences of using therapeutic activities in this context<sup>17</sup>. A descriptive qualitative design allowed for the description of multiple viewpoints from the perspective of the participants who took part in the study.

#### Study setting

The two focus groups were conducted at two venues located in Pretoria/Tshwane. All the occupational therapists worked in Gauteng Province and practised in mental health care settings. They treated patients with various psychiatric diagnoses, including major depressive disorder due to bereavement. The clinical occupational therapists provided both individual sessions and group therapy, whereas the academic occupational therapists included in the study taught and provided clinical supervision for the mental health module to undergraduate and postgraduate occupational therapy students.

#### Study population and sampling

The target population included qualified occupational therapists practicing in academic, public, and private psychiatric hospitals in the Gauteng Province of South Africa. All the occupational therapists were registered with the Health Professionals Council of South Africa (HPCSA). The researchers recruited participants using purposive sampling<sup>17</sup>. Purposive sampling<sup>17</sup> was used to recruit occupational therapists working in mental health care facilities or teaching mental health. The researchers considered participants who had experience and knowledge of working in mental health. The inclusion criteria considered qualified occupational therapists registered with the Health Professions Council of South Africa (HPCSA) as independent practitioners, cur-

rently working in mental health care facilities or teaching mental health in Pretoria/Tshwane. The exclusion criteria were occupational therapists practicing in other fields such as pediatrics, physical, neurology, geriatrics, and vocational rehabilitation.

A recruitment invitation was formulated and sent to a list of known occupational therapists working at various private and public psychiatric practices and a university in Pretoria/Tshwane via email, SMS or WhatsApp. As there were no responses to any emails, the researchers telephonically contacted occupational therapists on the list to recruit them to participate in the study. Thirty-five occupational therapists were contacted and nine occupational therapists consented to participate in one of two focus groups.

#### **Ethical clearance**

This research was approved by the Research Ethics Committee of the Faculty of Health Science at the University of Pretoria (ethics clearance number 803/2019). All the ethical principles of respect for person, principles of justice, principles of beneficence and non-maleficence were adhered to throughout the study17. The participants completed an informed consent form prior to their participation in the study. The researchers ensured voluntary participation, anonymity and confidentiality of participants with a participant number one to nine to protect the participants' identities.

#### Data collection procedure

All participants filled in demographic data forms. The demographic data form included their gender, ages, qualifications (undergraduate and postgraduate), years of experience working in mental health and psychiatry, and place of work. The researchers focused on the objectives of the study as guided by Brink, van der Walt and Rensburg<sup>17</sup> to formulate questions for the focus group interview guide. The moderator, one of the researchers, is a qualitative researcher trained by the university to facilitate focus group discussions (FGDs). The first FGD was held at a university in Pretoria and the second one at a private clinic in Pretoria/Tshwane. The moderator used an interview guide with open-ended questions to facilitate the FGDs. The moderator clarified the participants' responses using probing questions to expand their perceptions and experiences. The moderator asked summarising and concluding questions to clarify what had been discussed and to allow for final thoughts on the topic<sup>17</sup>. Each focus group lasted approximately two hours and both focus groups were audio recorded. The other researchers took field notes during the FGDs.

#### Data analysis

The recordings were transcribed verbatim and analyzed thematically. Data were analysed inductively using a bottom-up approach17. Data analysis occurred as suggested by Braun and Clarke18. The researchers read through the transcripts to familiarise themselves with the depth and breadth of the data18. Initial codes were individually generated. Lists of codes were identified across the data set. Similar incidents of codes were sorted and grouped and given the same name17,18. These codes were sorted, grouped and collated into categories<sup>18</sup>. Groups of categories gathered from quotes were pooled together to clearly define and name themes<sup>17,18</sup>. Potential themes were generated. Themes were reviewed and refined. The researchers identified the essence of each theme. The researchers defined and named the themes. The researchers interpreted the themes against the research aims, objectives and problem statement<sup>18</sup>. The researchers ensured that the themes were concise, coherent, logical and non-repetitive<sup>18</sup>. The researchers met face-to-face to discuss and agree on the themes, which were then finalized. Once the thematic analysis was completed, findings were sent to all the participants via email for member checking. All the participants agreed with the list of themes and quotes, and offered some minor alterations.

During the field notes, the other researchers wrote down their observations during FGDs in a descriptive manner as descriptive field notes. At the end of the FGDs, the researchers met and reflected on their thoughts and the meaning of their observations. The field notes were typed. The typed notes were coded and merged into the thematic analysis.

#### Measures to ensure trustworthiness

Fieldnotes and FGDs were means of collecting data to ensure maximum data uptake and triangulation. Field notes, FGDs and the findings were compared to existing literature17. Member checking and triangulation ensured the credibility of the data. As part of member checking, all the participating occupational therapists validated the findings and confirmed that the findings reflected their views<sup>17</sup>.

#### **FINDINGS**

All nine participants were women. Their ages ranged from 24 to 73 years, with an average age of 41.3 years. Their average years of experience in psychiatry and mental health was 16.3 years, and six of the nine participants had 10 or more years of experience in this field. All participants had completed a Bachelor of Occupational Therapy degree. Two participants had an additional postgraduate diploma, and four had a master's qualification in occupational therapy. Six of the participants (66.7%) were employed in the private sector, one (11.1%) was employed in the public sector and two (22.2%) were working at a higher education institution (Table I, page 37).

The three themes that emerged in the study are discussed as 1) activities used in occupational therapy create opportunities for new meaning to life after loss of a loved one, 2) appropriate occupational therapists helping skills and professional behaviour to assist and treat the bereaved, and 3) perceived barriers to positive outcomes in treating the bereaved. The themes and categories of this study are summarised in Table II (page 37)

# THEME 1: Activities used in occupational therapy create opportunities for new meaning to life after loss of a loved one

This theme deals with the opportunities facilitated by occupational therapists to enable bereaved individuals to create new meaning in their lives after loss of the loved one.

#### Table I: Summary of demographic information

Demographic Information	n (%)	
Number of participants	9.0 participants (100%)	
Gender percentage	9.0 (100%) female	
Percentage with postgraduate qualifications	6.0 (66.7%)	
Percentage with no postgraduate qualification	3.0 (33.3%)	
Percentage working in government/public sector, private sector and university	1.0 (11.1%) government/public sector 6.0 (66.7%) private sector 2.0 (22.2%) universities in Pretoria	

#### Table II: Occupational therapists' perceived ability to treat bereaved individuals

Themes	Categories
Activities used in occupational therapy creates opportunities for new meaning to life after loss of a loved one	Engagement in purposeful activities to facilitate emotional processing and hope Redefining life roles Self-management skills training
Appropriate occupational therapists     helping skills and professional behaviour to     assist and treat the bereaved	Application of critical and creative thinking Facilitation of therapeutic groups Supportive role in empowering bereaved individuals Connection through the use of self Educator's role in imparting information
3. Perceived barriers to positive outcomes in treating the bereaved	Inadequate undergraduate education on bereavement Complexity and diversity of bereavement Unmanageable External challenges Societal pressure for immediate healing

The theme highlights the creation of new meaning to life of bereaved individuals through engagement in purposeful activities to facilitate emotional processing and hope, redefining life roles, and self-management skills training.

#### **Theme 1 Categories**

# Engagement in purposeful activities to facilitate emotional processing and hope

Participants felt that engagement in purposeful activities enabled bereaved individuals to recognise their vision for the future. Purposeful activities allowed for the creation of meaning, which gave them something to do and possibly something to love and look forward to. Occupational therapists should give bereaved individuals an opportunity to create hopeful meaning for themselves by allowing them the freedom of choice and to make their own decisions. Two participants alluded that occupational therapists created meaning of hope for bereaved individuals.

"We [occupational therapists] allow that person [bereaved individual] to find out that they can create hope themselves. I [occupational therapist] prefer that you give them [bereaved individuals] that space and opportunity to find that hope again". (Participant number 8)

"I'm just saying that there is an emotional part but there's a functional activity part. So, while they are doing that emotionally they are venting out, they are letting go you know it can be very emotional and get healing which gives them some hope." (Participant number 2)

Occupational therapists are equipped with unique skills such as therapeutic relationship skills and the use of self to

guide bereaved individuals using purposeful activities that are important to the individual. The participants mentioned that using purposeful activities might effectively address the dysfunction engendered by emotional aspects of bereavement. This includes facilitating distraction and emotional processing:

"...the occupational therapist is a master of distraction. We [occupational therapists] always have been keeping their mind off things, transferring focus onto something else. It can be applied perfectly with your bereaved person to address their emotional aspect." (Participant number 7)

"...you help them to journaling, for instance, it's a very, very effective way writing letters. This writing of letters [goodbye letter to the deceased] might address the emotional aspect of bereavement" (Participant number 1)

Participants expressed that bereavement consists of a functional and emotional aspect. Both aspects influence one's occupational performance and psychological well-being. It was further expressed that the bereavement process is emotional due to overwhelming thoughts, questions, and feelings, which add to the complexity of bereavement. 'Crafts', 'mosaic', 'journaling', 'writing letters', 'making memorial boards', 'pot plants' and 'scrapbooking' were examples of activities that facilitated emotional expression in addressing the bereaved individuals' emotional and functional aspect as remarked by participants.

"...you can use things like creative arts, you can use things like mosaic for instance...as long they are meaningful and culturally relevant" (Participant number 2)

"...the activity because you need to find something, where

you can kind of release the emotional component and work through it and get it out there where you can deal with it and usually journaling, is some of the best ways to do it or to create something like scrapbooking or a memory board" (Participant number 1)

#### Redefining life roles

There was consensus amongst the participants that bereavement affects bereaved individuals' roles, habits, routines and rituals. Bereavement deprives people of the meaning attached to their life roles, habits or routines, and rituals. Occupational therapy interventions refine the roles, habits or routines of bereaved individuals as highlighted by the participants:

"...you have to help [the bereaved individual] to find meaning in this role or that role or change the way [they] do it so that it's still meaningful." (Participant number 3) "I think [occupational therapy] is the most unique and equipped profession through certain activities [sic] give meaning back to people. To get them to refocus, refine, and define their roles and through that give new meaning in their lives." (Participant number 1)

#### Self-management skills training

The participants emphasized self-management skills-training as an important part of occupational therapy interventions with bereaved individuals. They further expressed that occupational therapists could coach bereaved individuals about self-management skills while enabling them to engage in activities to address their occupational disruption. One participant listed various self-management skills and the avoidance of overwhelming emotions. Specific selfmanagement skills that occupational therapists used with bereaved individuals included mindfulness, exercise, yoga, stress management, assertiveness skills and boundaries, which formed part of the occupational therapy sessions that facilitated adaptive emotional outlets. This is highlighted by two participants who said:

"...if you give someone a specific technique that they do and teach stress management, mindfulness, exercise, yoga – a specific technique." (Participant number 7)

"Assertive in a sense that if you want to grieve, if you feel like I want to cry it doesn't matter what the society prescribes for you at the time has lapsed you know. That you are able to own that today I don't feel okay I want to cry and also that you know you are able to access other support groups." (Participant number 2)

#### **THEME 2: Appropriate occupational therapists** helping skills and professional behaviour to assist and treat the bereaved

This theme deals with the appropriate occupational therapists helping skills and professional behaviour to assist bereaved individuals. The theme focuses on the helping skills and professional behaviour described by the participants that occupational therapists need to provide to bereaved individuals. These helping skills and professional behaviour of occupational therapists are: the application of critical and creative thinking, facilitation of therapeutic groups in occupational therapy, supportive role to empower bereaved individuals, connection through the use of self, and educator role in imparting information.

#### Theme 2 Categories

#### Application of critical and creative thinking

Under this category, findings are that occupational therapists required the application of critical and creative thinking as there was no specific method to treat bereaved individuals. The occupational therapist should be able to select, adapt, and use activities that are purposeful and relevant by consistently applying their critical and creative thinking. Application of critical and creative thinking were further highlighted by participants as important because bereavement is a complex process that cannot be treated in isolation. As a member of a multidisciplinary team, occupational therapists should have helping skills such as empathy, encouragement and patience which relates to critical and creative thinking. They should allow the bereaved individuals to process their challenges during their grieving journey. This was echoed by participants who remarked as follows:

"...bereavement is a complex cognitive thing that you need to be able to reason about. It must have that [critical] reasoning ability and the emotional maturity to deal with it and that people know that, that it will not be fixed or [use a] recipe that you can apply." (Participant number 1)

"...it's part of the narrative [reasoning] - there's triggers, there's stressors - this is something, a challenge that has come into their lives, and now they can't process it well enough so that they can continue." (Participant number 8)

#### Facilitation of therapeutic groups

Therapeutic groups in occupational therapy is used to enable the bereaved individuals to learn from other group members while creating new meaning for themselves. The participants supported the use of therapeutic groups. They cited that therapeutic groups in occupational therapy facilitated social participation and interaction and allowed the bereaved individuals to give and receive feedback in a safe environment.

"That is something that we can do [with bereaved individuals] in a support group or [...] an environment that we can share because people also tend to share nicely with people who have been through similar... if you have experienced or you have you can relate it helps..." (Participant number 3)

"...a huge one might be the universality; to know that you are not alone, knowing that the therapist is there with me, or another group member [...] it's creating that connection [group cohesiveness] ...." (Participant number 9)

#### Supportive role in empower bereaved individual

In the FGDs, the supportive role of an occupational therapist was identified as an enabler that empowers bereaved individuals. This is supported by the participants who said:

"To allow them to speak up about their loss and accept help [for] them by going out to the right people to support and help them in their environment, to get the right people involved." (Participant number 1)

"...so, I feel it's the [occupational therapists] role to be there and advocate and empower them [bereaved individuals]" (Participant number 2)

#### Connection through the use of self

The participants shared that the use of self is important as it allows the bereaved individual to feel connected and comforted by the occupational therapist during occupational therapy intervention. Occupational therapists should use facilitation skills during therapy to build rapport and therapeutic relationship with the bereaved individual. This could be guided by the client-centred approach as it allows the occupational therapists to have respect, rapport, empathy and collaboration. This approach also allows bereaved individuals to make their own decisions and to be able to connect with the occupational therapist to have a sense of comfort. This is supported by the participants whose utterances follow:

"All the skills that you should be developing like listening, being available and understanding your role as yourself [occupational therapist] in the process are important" (Participant number 8)

"...use of self is very important. Sometimes it's just comfort that you want to give [...] you need to be able to restrain yourself from giving a solution and just sit and listen and let them bring it while you are there with them." (Participant number 2)

#### Educator's role in imparting information

From the FGDs, it was suggested that occupational therapists should fulfil an educator's role in educating bereaved individuals on the bereavement process and how to engage and cope with the emotional aspects of bereavement. This is highlighted by the participants who stated that:

"...clients need at least the knowledge to know what the process [of bereavement] entails, and that people will go through the process in different ways." (Participant number 1)

"...you at least discuss the grieving process and how it fits in at different places and stages." (Participant number 5)

# THEME 3: Perceived barriers to positive outcomes in treating the bereaved

This theme highlights the perceived barriers to the positive outcome of occupational therapy to treat the bereaved

individuals. These barriers comprised of occupational therapists' inadequate undergraduate education and training, complexity and diversity of bereavement, unmanageable external challenges and societal pressure for immediate healing.

#### **Theme 3 Categories**

# Inadequate undergraduate education on bereavement

Most participants voiced that formal learning and practical training on bereavement were not adequately taught at undergraduate level. The participants' comments below bear witness to that:

"I feel that [bereavement] wasn't touched on enough in my training... maybe it wasn't taught in a way that allowed us to have this understanding." (Participant number 9) "...I think still it would make things so much easier [for the occupational therapist] to have a point of reference to work from regarding bereavement." (Participant number 1)

Two participants stated that bereavement is not a linear process in contrast to what is taught at undergraduate level. The focus is on the Kübler Ross model and other different models are not taught. Inadequate understanding of the process of bereavement created a shortfall in the occupational therapists' competency to address bereavement:

"... [occupational therapists] would only be with that client for a very short part of the bereavement journey. It's a long journey, and it's not a linear one." (Participant number 7)

"It must be an interactive approach that doesn't reinforce this 'stuck'.... For me, it's integrative – the interaction of different therapeutic modalities and models." (Participant number 9)

#### Complexity and diversity of bereavement

The treatment of bereavement is complicated by the complex and diverse nature of bereavement. Bereaved individuals experience the process uniquely as their construct of death differs. This is supported by the participants' observations:

"... it's so individual, everybody is an individual and it depends on what and where they are in the grief process." (Participant number 3)

"... [occupational therapists] must also have space to debrief, so they can continually give the best care, because I think sometimes the reason for 'avoiding', is that I don't have the capacity at the time to be with the patient in this, but if I'm monitoring myself, making sure that I'm meeting my own needs and constantly debriefing and be sure that I'm not holding onto the patient's stuff, will give me a better opportunity to be there." (Participant number 9)

#### Unmanageable external challenges

It was noted that unmanageable external challenges hindered effective occupational therapy intervention. Some challenges included occupational therapists' limited time and resources. Occupational therapists working in the private sector experienced additional pressure as treatment depended on a bereaved individuals' medical-aid funds and available financial resources. This point is elaborated by participants who said:

"...there's time and money [needed], we must progress [recover], we must go home quickly [discharge from hospital], and we must think of our goals." (Participant number 8)

"...if your medical aid is depleted [in private facilities] it means I'm [occupational therapist] not available." (Participant number 2)

#### Societal pressure for immediate healing

It was opined that certain societal expectations negatively influenced the success of occupational therapy. These social expectations influence a bereaved individual's ability to adjust to change, their capacity to cope and their well-being. Society is known to avoid coping with loss, which can influence the healing process. This societal pressure impacted on occupational therapy treatment and bereaved individual ways of healing. These were supported by the participants who elaborated that:

"...I'm thinking of society's idea of 'move on'..." (Participant number 9)

"...internally they did not mourn properly, and people [bereaved individuals] are left to do their mourning and bereavement alone." (Participant number 4)

"...death is an awkward thing for everybody in that group. Nobody wants to speak about it. Nobody wants to talk with you." (Participant number 7)

The evidence from the societal pressure highlights the need for support for the bereaved individuals and education to the society at large as society needs to understand bereavement meaningfully.

#### **DISCUSSION AND IMPLICATIONS**

This study provided insight into the occupational therapists' perceived ability to treat bereaved individuals to find new meaning in life through engagement in therapeutic activities. Overall, the findings highlight that occupational therapists are in the ideal position to facilitate the opportunity for bereaved individuals to create new meaning to their life through engaging in purposeful activities to address emotional processing and hope. According to Neimeyer<sup>19</sup>, an involuntary search for meaning is essential to adapt to the altered reality after the loss of a loved one. Occupational therapists can guide and ease this involuntary search for meaning to life by engaging bereaved individuals in pur-

poseful activities. Bereavement affects one's meaning attached to life and occupational engagement in purposeful activities. Freitas<sup>20</sup> indicated that bereavement leads to a loss in the sense of life and imposes the demand to create new meaning.

The findings from the present study suggest that activities provide hope and that doing creates meaning, which corroborates the idea that meaning emerges from occupations that bring purpose to life<sup>8</sup>. This is further supported by Frankl's<sup>21</sup> idea that meaning emerges when one has something to do, something to love, and something to look forward to. This agrees with the findings of this study which advises that activities should be meaningful, client-centred, and relevant to the bereaved individual's individuality, circumstances and environment. This is further supported by the Occupational Therapy Practice Framework<sup>8</sup> which has a core belief in the connection between occupation and health as well as the use of occupation to create meaning.

It was evident from the findings that occupational therapists need to consider the importance of functional and emotional aspects of bereavement. Kersting and Wagner<sup>22</sup> found that reactions to bereavement include impairment in day-to-day functioning and emotional processing. Hence, the findings of this present study support the concepts of occupation-centred practice as bereavement leads to regression and disengagement in occupations. A study by Hoppes and Segal<sup>5</sup> which focused on reconstructing meaning through occupation after the death of a family member: accommodation, assimilation and continuing bonds found that bereaved individuals do not adjust to the way they perform occupations, but rather, alter certain occupations. The use of practical activities to address occupational needs was recommended by the participants of this present study.

Bereavement deprives the bereaved individuals the meaning attached to their life roles, habits or routines and rituals, which indicates that occupational therapists should aim to address and transform bereaved individuals to redefine their roles in treatment as stated in the present study. Batista et al.<sup>23</sup> found that some bereaved individuals tend to isolate themselves from social situations and others feel a sense of guilt when performing leisure tasks. The findings of this present study also pointed out that some activities no longer held the same meaning and were therefore discontinued. Hoppes and Segal<sup>5</sup> concur with the findings of this present study when they point out that individuals may change their career, perspective of work, or increase work engagement as a coping strategy.

It was evident from the participants' discourses that occupational therapists should assist bereaved individuals in redefining their roles, habits, routines, and rituals because they might influence what they opt to do, love, and look forward to in their lives. The findings of this present study strongly suggest that it was part of the occupational therapist's role to intervene when bereaved individuals struggled to adapt to their changed performance patterns. This concurs with findings by Dahdah and Joaquim, 6 that bereavement causes a change in lifestyle, abandonment of roles or an inability to perform co-occupations by the bereaved individual. Furt-

hermore, Dahdah et al.º alert us that a bereaved individual might experience a need to continue to fulfil their prior roles and daily routines. This is, however, not always possible when one loses a loved oneº. The participants from the present study suggested that an occupational therapist should guide bereaved individuals to redefine their roles and routines according to their values, interests and abilities, so that they can adopt new habits.

In the findings of the present study, the occupational therapists agreed with each other that emotional venting was essential in treating the bereaved individual. It was also noted in the FGDs that bereaved individuals may find meaning, which is linked to their involvement in purposeful activities. The participants of this present study mentioned that activities could be used as a source of distraction to shift one's focus from the preoccupation with thoughts associated with the loss. Additionally, they mentioned that activities aid in the emotional processing of the loss by dealing with feelings expressively. Similar findings also cite expressive activities to help bereaved individuals to understand loss and distract them from overwhelming feelings<sup>6</sup>. Activity examples mentioned by the participants of this present study included mosaic, pot plants, journaling, writing goodbye letters, making memorial boards, memory boxes and scrapbooking. This is consistent with Neimeyer and Thompson<sup>25</sup> who stated that music, poetry, and visual arts are effective treatment modalities.

Suppression of emotions impedes healing; therefore, the approach should rather be to empower the bereaved individual to process uncomfortable feelings. The findings of this present study emphasise that coping skills should not be used to suppress emotions, but rather allow bereaved individuals to experience and process uncomfortable emotions. These findings suggest that occupational therapists can transfer self-management skills through coaching so that bereaved individuals can manage the functional and emotional consequences of bereavement. In the present study, some examples of self-management skills that might be used as part of the therapy sessions were identified and included mindfulness, exercise, yoga, stress management, assertiveness skills and boundaries.

The findings further indicate that occupational therapists need to possess the application of critical and creative thinking to guide the success of occupational therapists' ability to treat the bereavement individual and provide holistic assessment, use of activities, and work within an interprofessional team. The findings further highlight that applying critical and creative thinking enabled the occupational therapists to form an integral, holistic understanding of the bereaved individual and facilitate a client-centred occupational therapy intervention. The American Occupational Therapy Association (AOTA)<sup>8</sup> asserts that occupational therapists are skilled in evaluating all aspects of a client related to the context of the environment. Hence, the supportive role of the occupational therapist to empower bereaved individuals is significant in a supportive environment that enables provision of effective treatment services in helping the bereaved individuals. As Dhillon et al.27 stated, the occupational therapists provide education, services, support, and improve function.

These findings are further supported by the benefit of facilitating therapeutic groups that enhance social inclusion, support, and activity participation. Consequently, the findings corroborate with Ramano, de Beer and Roos<sup>26</sup> who found that occupational therapy groups offer feelings of belonging, sharing and opening up as part of support and healing.

It emerged from this present study, that occupational therapists have an educator role, which necessitates imparting information during the treatment of bereavement. These findings indicate that the educator role involves the use of psychoeducational approaches to teach the bereaved individual on what the bereavement process entails. It is important to educate the bereaved individuals that bereavement is not a linear process. Therefore, the education role is strengthened by the continuous therapeutic relationship that allows the bereaved individual not to feel alone during the bereavement process. There is a significant link between therapeutic relationships and treatment outcomes in various settings, specifically in occupational therapy in mental health<sup>28</sup>. The participants of this present study echoed the importance of connecting with the bereaved individual through the use of self and building rapport with the bereaved individual. Research shows that the development of rapport is crucial to occupational therapy success8.

There are perceived barriers to the positive outcome of occupational therapy to treat the bereaved individuals. The findings of the present study pointed out barriers to positive outcome such as inadequate undergraduate training on bereavement. This led to lack of confidence amongst the occupational therapists with no point of reference to help the bereaved individuals. Alers<sup>29</sup> questions whether the existing competencies of occupational therapy graduates match the demands of the profession. This highlights the lack of sufficient education on bereavement in occupational therapy where the study took place. Breen<sup>30</sup> raised a concern that insufficient education causes most clinicians to make use of stage-based theories. The Kübler Ross<sup>31</sup> grief model is taught in undergraduate education and most occupational therapists use this model to understand and guide bereavement. None of the participants in this present study mentioned any contemporary models, such as the Dual-Process model<sup>32</sup>. The Dual-Process Model describes the oscillation between confronting and denying emotions associated with grief between the phases of bereavement<sup>32</sup>.

Bereavement is diverse and complex as bereaved individuals experience the process uniquely and seek treatment at different points in the process of bereavement. A participant in this present study warned that an occupational therapist who uses their own experience of death as guidance for the intervention might miss the unique needs of a bereaved individual. The findings of this present study are consistent with a systematic review by Dahdah et al. which reported that bereavement is a complex event that is different for each bereaved individual. One's construct of death also influences how one processes loss. Additionally, time and resources are unmanageable external challenges that affect the success of occupational therapy. Poverty and resource

limitations in South Africa restrain occupational therapists from providing services adequately<sup>29</sup>.

It has been found that adverse social pressure for immediate healing acts as a barrier to one's ability to cope with bereavement. Participants agreed that society is known to take an avoidance and awkward approach towards coping with a loss, which in turn influences the healing process. An unsupportive social environment and dysfunctional family dynamics are associated with more significant psychological distress and complicated grief symptomatology9. This is a further challenge as a bereaved individual's progress might be impacted by lack of social support and follow-ups.

#### Limitations

A limitation to this study is that it only focused on occupational therapists practicing in Tshwane/Pretoria in Gauteng.

#### CONCLUSION

It is evident from the findings that occupational therapists perceived engagement in therapeutic activities as essential to creating opportunities for new meaning for bereaved individuals. Engagement in therapeutic activities offer bereaved individuals an opportunity to adapt to their altered reality. Due to the diverse emotional and functional challenges associated with bereavement, occupational therapists perceived ability to help bereaved individuals should be occupation-based, holistic and client centred. Occupational therapists can also help to redefine the life roles of bereaved individuals by helping them to adapt to their routines, roles, habits and rituals. The facilitation of therapeutic groups might allow bereaved individuals to experience support and equip them with self-management skills that might enable them to cope with their loss. Occupational therapists were concerned that perceived barriers to positive outcome of occupational therapy in treating bereaved individuals was associated with inadequate undergraduate education and training on bereavement, the complexity and diversity of bereavement, unmanageable external challenges, and societal pressure for immediate healing. Feedback from the participants about occupational therapy perceived ability to treat bereaved individuals was valuable to improve the possible positive outcome of occupational therapists to help the bereaved individuals. It might be essential for undergraduate occupational therapy education and training to include the treatment of bereaved individuals. The authors of this study encourage more occupational therapy research that focuses on the effectiveness of various occupational therapy interventions to help bereaved individuals.

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#### **Author Contribution**

Marike de Jager, Wilmari Pretorius, Tara Oldfield, Daniela Scriba and Bridget Moriti were 4th Year students in the year 2020 and the main study was completed as part of their 4th year research project and Enos Ramano was their research supervisor. All the authors contributed to this manuscript for publication.

#### **Conflict of Interest (COI)**

The authors have no conflict of interest to declare.

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## Promoting the play of children with autism spectrum disorders: Contributions of teachers and caregivers

#### **ABSTRACT**

**Introduction:** The play of children with autism spectrum disorder (ASD) can be negatively impacted on by difficulties linked to their diagnosis, however, people present in the children's contexts can positively influence their engagement in play. Teachers and caregivers, being significant role players participating in the contexts of children, are well positioned to promote the engagement of children in play.

**Research design:** This paper reports the findings of a qualitative descriptive study which employed semi-structured interviews to explore and describe the ways in which three teachers and two caregivers supported the engagement of children with ASD in play.

**Findings:** The theme, Acknowledging, Accommodating, and Adapting, describes how the caregivers and teachers supported the play of children with ASD. The multiple ways in which they promoted the children's engagement in play is unpacked in the following categories: creating and affording opportunities for the child to direct their own play; recognising, caring for, and making preferred play materials available, and purposeful pairing with specific playmates.

**Discussion:** Caregivers and teachers have experiential knowledge of the play interests and the ways in which children with ASD play. They skilfully draw on this knowledge to implement an array of strategies to promote the play of children with ASD. **Conclusion:** Given their instrumental role in supporting the play of children with ASD, occupational therapists should be encouraged to continue to partner with and learn from caregivers and teachers. This will align with collaborative practice and enhance the development and implementation of relevant and sustained interventions focused on the occupation of play in children with ASD.

#### INTRODUCTION:

Play is primary occupation of children and occupational therapists aim to promote children's participation in play in order to advance their development, health and well-being¹. Playfulness refers to a child's approach and disposition to play and is determined by the child's skill in demonstrating the four elements of playfulness: intrinsic motivation; internal control; the freedom to suspend reality; and framing².

A child's play should be explored in context to identify how various human and non-human factors in these contexts, shape their engagement in play<sup>3,4</sup>. A structured context is one in which there is adult facilitation and play is shaped by a set of guidelines for children

to follow<sup>3</sup>. In contrast, unstructured play environments are child-centred, familiar to the child and their interests, responsive to the cues which the child initiates and supportive of the child's cognitive development, independence and playfulness<sup>3</sup>. Ideally play needs to be framed in an unstructured way so that the child can engage with flexibility and spontaneity<sup>5</sup>. Some children may however require more assistance from people in their environments to promote their engagement in play. One such group, are children with autism spectrum disorder (ASD) who are often reliant on people in their environments to promote their play and playfulness<sup>5,6</sup>.

ASD is a lifelong neurodevelopmental condition<sup>7</sup> characterised by rigid ways of thinking and a limited range of interests8. Children with ASD experience challenges with engagement in play9. They tend to be less playful than their typically developing (TD) counterparts and their play has a repetitive element<sup>10</sup>. Prominent people present in the contexts of children are caregivers and teachers, who spend a lot of time with children and thus have the potential to shape their engagement in play through altering and adapting the play environments of the child in ways that create opportunities for sustained engagement in play<sup>6,11,12</sup>. Gaining information from these significant people in the lives of children has the potential to build on the collaborative intent of occupational therapy practice<sup>13</sup> and generate knowledge which can inform the development of familycentred occupational therapy play-based interventions for children with ASD.

Previous research describes various strategies used by caregivers and teachers to promote the play of children with ASD. Román-Oyola et al<sup>(2018)14</sup> described how caregivers sought out interactions and play activities that were intrinsically motivating for their child. They deliberately created play opportunities that the child was interested in doing and immersed themselves in the type of play the child had already established. Parent education, modification of play materials or environments and modelling an adult, peer, or a video, were beneficial strategies used by the caregivers to improve the play participation of children with ASD<sup>15</sup>.

While the above research findings document some of the strategies to promote play, it is important to recognise that

play differs in context16 and in turn, the strategies that are used to promote play engagement, may also differ across contexts. Promoting play in context, calls for perspectives from the caregivers and the teachers living in these different contexts.

In this paper, we present the findings of a study which explored and described how caregivers and teachers living in Cape Town promote the play of children with ASD, highlighting their consideration of the environmental factors (play space, play objects and playmates) that supported and/or hindered the play of the children with ASD. The strategies used by the caregivers and teachers are described in relation to the method of scaffolding presented in Vygotsky's<sup>17</sup> social cultural theory of the zone of proximal development. This theoretical framework was selected after an inductive approach to analysing the data, to help with interpreting the findings. Vygotsky introduced the concept of the zone of proximal development to describe the actual development and the potential development of the child. Scaffolding refers to the actions which people in the child's context take to support the child to develop in line with their developmental trajectory<sup>17</sup>. Scaffolding in relation to the child's play would involve systematically adjusting, first increasing, and then withdrawing the amount of assistance offered to a child to initiate and sustain their engagement in play<sup>17</sup>.

#### **METHODOLOGY**

The ways in which caregivers and teachers promote the engagement of the child with ASD in play is a poorly understood phenomenon in South Africa, as evidenced by paucity of literature in this area. A qualitative descriptive research design (QD) adopting an exploratory approach was thus well suited to gain insights from the participants about the strategies and approaches they used 18. Participants were purposely selected in line with the below inclusion criteria, due to their knowledge and experience of the nature of the children's play and their perspectives of their role in promoting the play of children between three and eight years of age.

Teachers were the primary educators of children (spending no less than 15 hours per week with the children) and who had interacted with the children for at least three months (one school term).

Table I. Overview of the demographic information of the participants

Caregiver's name*	Michelle	Tamara	Candice	Sam	Allison
Age of caregiver	45 years	40 years	26 years	41 years	44 years
Gender of caregiver	Female	Female	Female	Female	Female
Current occupation	Full-time mother	Full time administrative clerk	Teacher at Blue school	Teacher at Blue school	Teacher at Blue school
Relationship to child(ren)	Biological mother	Biological mother	Child's educator	Child's educator	Child's educator
Names* of child(ren) with ASD	John	Damian	Tatenda	Tawanda and Tendai	Shaun
Gender of child(ren) with ASD	Male	Male	Male	Male	Male

\*All names are pseudonyms

Caregivers were those persons who provided the most consistent form of care to the children (spending no less than 48 hours per week with the children).

Convenience and snowball purposive sampling techniques were used to recruit participants. The final sample consisted of five participants (three teachers and two caregivers). Table I (page 45) gives an overview of their demographics. The three teachers worked in one inclusive primary school in a middle to high income suburb in Cape Town. The Blue school (pseudonym) adopts a play-based curriculum to accommodate the diverse learning needs of both typically developing children and children with various barriers to learning between the ages of 0-7 years of age. The caregivers who took part in the study were both mothers of a male children with ASD. Both lived in Cape Town and shared similar demographic characteristics.

A total of five (four face-to-face and one telephonic) semistructured interviews were conducted with the participants at a time and place convenient to them. The development of the questions presented in the interview guides was informed by play theory8 and included questions encouraging caregivers and educators to share how they promoted the engagement of the children in play in line with their consideration of play space, play materials and play mates. A pilot study was undertaken to ensure the questions were clearly formulated and related to the study aim and objectives. An occupational therapist supervising final year occupational therapy students working with children with ASD, and one caregiver of a child with ASD, reviewed the interview guide. They suggested that two separate interview guides be created, i.e., one for the caregivers and one for the teachers, and they also advised on the inclusion of further probing questions. These suggestions were included in the final versions of the caregiver and teacher interview guides.

Data were analysed thematically, drawing on an inductive approach. The audio data were transcribed and checked for accuracy by research pairs. The transcribed data were then reviewed extensively to generate codes manually in a code book. Codes were then grouped together in categories. The categories were then collated and organised into two themes. The first theme, Playful, but on their own terms, was generated from the descriptions the caregivers and educators shared about how the children with ASD played. These descriptions reflected their detailed understanding of the diagnostic features of ASD and the impact of these features on the play engagement of the children. The second theme Acknowledging, accommodating and adapting which is the focus of this article, details the specific ways in which the caregiver and educators promoted the engagement of the children with ASD in play. This theme is foregrounded to acknowledge the significant contributions which caregivers and educators make to promoting the engagement of children with ASD in the occupation of play. The following strategies were applied to ensure trustworthiness: member checking with the participants to ensure an accurate and complete account of their interviews was captured, gaining, and presenting a rich description of the participants and their contexts, peer reviewing by a skilled research supervisor, and maintaining a detailed audit trail.

#### **Ethical considerations**

Ethical clearance was obtained from the Human Research Ethics Committee, Faculty of Health Sciences, University of Cape Town (Ethical clearance number 2018/0838). Ethical principles of informed consent, privacy, and beneficence were adhered to throughout the research process. Each potential participant was adequately informed about the study process and their right to abstain or withdraw from participation without reprisal. To ensure privacy, all data collected were held in confidence and pseudonyms were used to ensure anonymity. Furthermore, personal information which could be linked back to the participants was not presented. The caregivers and teachers were assured that the focus of the study was not evaluative of their performance but rather, an appreciation of their strengths in promoting the play engagement of children with ASD.

#### **FINDINGS**

The theme Acknowledging, accommodating and adapting and its associated categories presented in Table II (below) describe the various ways in which caregivers and teachers promoted the play of the children with ASD.

**Table II. Themes and categories** 

Theme	Categories
	Creating and affording opportunities for the child to direct their own play
Acknowledging, accommodating, and adapting	Recognising, caring for, and making preferred play materials available
	Purposeful pairing with specific playmates

## Category one: Creating and affording opportunities for the child to direct their own play

Participants acknowledged the need of the children to be in control of the focus and flow of their play. They shared how they created and encouraged opportunities for the children to direct their own play by adopting a non-directive approach and following the lead of the children during play. They also recognised the positive impact of this approach on sustaining the children's engagement in play.

"So I don't force him to play with anyone or play a certain game...and if he's okay then we do it and if he doesn't want to do it, I, I don't let him do it." (Tamara)

"...they just go where they go and we follow..." (Sam)

"The benefit is to teach him independent play and my son, it (play) relaxes him, it (play) unwinds him so they kind of like de-stress." (Michelle)

Participants facilitated the autonomy of the children, encouraging the children to choose the play activities that they wanted to engage with.

"So, I will allow him to choose what play he wants to, whether he wants to play with the TV or play with the equipment." (Michelle)

"So, whatever it is that they like, they can go and fetch it and then go play on their own, if they want to do that" (Sam)

A wide variety of different types of play materials were made available in the play spaces to ensure that the children had options that they could freely choose from.

"we have our educational toys, we have our story books, we have our art materials, we have uh, for the fine motor, we have objects for children that's very uh, uh, weak in their fine motor we have our own little um, um, toys that we work with them, so ja, we have, we have quite a lot of toys for them, so we see to all, to all the kids." (Allison)

"They can play with anything that they like. There's a little (feely) box that we have, so whenever they feel the need to go and play with it or take it out, and then they can go and fetch it." (Sam)

## Category two: Recognising, caring for, and making preferred play materials available

In line with affording opportunities to play through adopting a child-led approach and structuring the environment to create opportunities for the children to choose what to play, participants also drew on their knowledge of the specific play material preferences of the children and prioritised creating opportunities for the children to play with the play materials aligned with their interests.

"So, whatever he loves we have at our disposal..." (Candice)

"Okay um, I mentioned too that I cannot plan so it's basically what comes to mind and what I know your (child), you know like(s), like, the park example or kicking the ball or just leaving him and he's now lately into marbles, like he's got something new now, marbles is like now his in thing" (Tamara)

"I ask the assistant just to take him out. Just go and play outside. Go and run. Go and jump on the trampoline. Go and play in the sandpit because he loves to play." (Candice)

"...so, when you have a very big book and you start with music which he loves then Shaun will take note of that book, see, so he loves, uh, Shaun actually learns through music as well, he loves music. I'll put stuff there that I know that he likes" (Allison)

Candice and Sam drew on what they had learnt about the children's fondness for various types of sensory play and set up their contexts with play materials which afforded the children the chance to engage in multi-sensory play.

"...the children learn through their senses and we are

taught that, so everything that we do in the class, we make sure that we are, they are engaged in activities that they can touch, feel, smell, listening as well." (Candice)

"And we make it colourful and they know where the resources are, and inviting and attractive as possible as we can. It has to be colourful, adorable, it must be attractive to them so that they might want to go play." (Sam)

Michelle recognised the play materials her son enjoyed playing with at school and provided these play materials in the home context.

"I put up a white board for him to write which he was very excited at the beginning because he does it at school." (Michelle)

The children's intense interest in and preference for particular play materials led to the participants seeking out play materials which were durable and going to great lengths to care for these play materials.

"So the things that is set out is durable..." (Candice)

"Like I know the ball, where they need to sit on the ball just to strengthen their core, they can't sit still, that we don't leave out because then the other children will play with it also. So, we also want to keep their resources for them. You know, that is for them, and we have, like in movement, I'll take it out and everybody can experience it. But for them specifically, we keep it separate for them so that the other learners know that, you know, these are the things that they play." (Sam)

### Category three: Purposeful pairing with specific playmates

Caregivers and teachers strategically promoted the social play of the children with ASD by purposefully pairing the children with playmates who due to their own skill in play or age, were well positioned to support the engagement of the children with ASD in social play. The educators and caregivers also involved themselves in the play activities of the children as playmates, to initiate and sustain their engagement in play.

"You know, I will have two of my strong boys playing with him...because they talk more, and they, and they, they play with the ball so it's not that rough games that they normally play and Shaun likes these two boys to play with, so they you know he likes the ball and then they will show him what else to do, so when we do a movement he will show, they will show him, so he will follow these boys as they are playing." (Allison)

Sam described how the children with ASD often preferred to play with younger playmates. She drew on this preference, encouraging them to play with younger playmates.

"But you'll find that sometimes they adapt more to the

younger children. You know, because they feel, that there are certain things that they can do that's on the younger level whereas they struggle. So our motto is that rather be leaders in a younger group than struggle and tag along in the older group. We mostly, we encourage them to play with the younger ones also." (Sam)

Sam described how the children with ASD did not engage with other children in the absence of their preferred playmates. To address this, she encouraged other children in the class to be friend and play with the children.

"They (the children with ASD), there are the ones that plays with just specific children. So when the child is not here, they feel lost, but then you encourage them to play with others or encourage the friends just to take that one along because their friend is absent today." (Sam)

The caregivers and teachers also strategically involved themselves in the play activities of the children, as playmates, to initiate and support the sustained engagement of the children in play.

"....so I'll just join in on him playing marbles and, and board games" (Tamara)

"...but I, I must be in that circle, so then he plays with, say, he likes playing with them and they like playing with him, but the moment I move out of the circle then Shaun moves, so if I will say to him Shaun, we need to play with the other children then he will say "NO!" So I said no, but if I leave, he follows" (Allison)

"So I would go to them, and I would ask him to come join me, and then I will initiate play..." (Sam)

Sam described herself to be a constant playmate, who drew on her own playful nature to engage the children with ASD in play.

"So we play all the time. They, I'm the teacher that will be on the floor, roll with them and they will jump on me and stuff like that. So that's how we play or if we're in the playground I'd go and play with them, I go on their level and play with them, like in the sand. But wherever they are, I would play with them." (Sam)

In summary, the participants recognised that opportunities to engage in play were increased when they acknowledged and accommodated the need of the child to direct their own play. Participants were intentional in providing the children with access to their preferred play materials to sustain their engagement in play. They purposefully paired the children with ASD with specific playmates who supported their engagement in play. They also strategically positioned themselves as playmates in the play engagements of the children with ASD, eliciting their own playfulness, to encourage the social play of the children with ASD.

#### DISCUSSION

This study aimed to explore and describe the ways in which caregivers and teachers promoted the play of children with ASD. Participants drew on their understandings of the unique play styles of the children with ASD and adapted their approaches to accommodate the children's need to direct their play. They also altered and adapted the environment to create opportunities and motivate the children to engage in play.

## Child directed play is facilitated by creating spaces that foster the children's internal locus of control and their motivation to play

Participants recognised the value of following the lead of the children in play. Child-directed play was facilitated by acknowledging the children's need to be in control of how they would engage in play. Participants were not coercive in their approach to encouraging the play of the children. They allowed the children to choose what they wanted to play with, and where they wanted to play. Participants described how the children engaged longer in play when they were in control of the conditions of their play, choosing how they wanted to play, and what they wanted to play with. Allowing choice in play fosters a sense of control and sustains the intrinsic motivation of children to engage in the play activity<sup>19,20</sup>.

Play spaces have the potential to either promote or limit play<sup>3</sup>. Caregivers and teachers skilfully adapted play spaces in ways that allowed the children to select from a wide variety of play opportunities which they recognised as being favoured by the children. Some of the adaptations to play spaces included the provision of preferred play materials in easily accessible places and allowing time to play with these materials. Participants also tried to ensure that the child's preferred play materials were available across contexts, that is in both the home and school context. Similar findings were reported in a study by Román-Oyola et al.<sup>14</sup> who described how parents deliberately created play opportunities that the child was interested in. Skaines, Rodger, and Bundy<sup>8</sup> describe the provision of secure play spaces, inclusive of a variety of toys, to encourage engagement in play.

## Play materials selected to elicit the internal control and motivation of the children

Play materials are important in fostering motivation and supporting the participation of children in play21. The participants in this study were keenly aware of the specific play interests of the children, describing in detail their preferences for specific play materials. They made these play materials available to the children and went to great lengths to ensure that these materials were kept safe when the children were not playing with them. They also recognised the importance of selecting play materials which were durable. Drawing on the knowledge they had gained via their training, participants also created play stations containing different types of sensory play materials, which the children could explore, and which could provide them with multi-sensory stimulation opportunities. Bentenuto et al.<sup>22</sup> describes how multi-sensory play materials sustain the play engagement of the child with ASD.

## Playmates supporting the development of social play selected to promote the children's framing

Children with ASD are likely to have deficits in social skills<sup>23</sup>. Participants described how the children tended to choose solitary play. They extended on their promotion of the social play of the children by purposefully pairing the children with ASD with specific playmates, who they had observed to show skill in scaffolding play with the children with ASD. Their intentional choice of the pairing demonstrated the participants' skill in promoting the social play engagement of the children with ASD. These highly supportive measures to support play engagement have been described in prior studies<sup>6, 23-25</sup>.

Vousden et al.<sup>26</sup> found that children with ASD struggle with framing, an important aspect of social play, referring to the ability of the child to interpret and respond to both verbal and non-verbal social cues<sup>2</sup>. In a study by Román-Oyola et al.<sup>14</sup> parents of children with ASD explained that the best way to encourage the social play of their children was to enter into the type of play the children had already established. This was displayed in the present study when participants described when and how they would join the existing play scheme of the children often as a playmate, to initiate and sustain the engagement of the children with ASD in play with them and/or their peers.

Participants were committed to promoting the play engagement of the children. They drew on their understanding of the play of the children and described a variety of ways in which they promoted their play. These ways resonated with the method of scaffolding, described in Vygotsky's<sup>17</sup> social-cultural theory of the zone of proximal development. Vygotsky introduced the concept of the zone of proximal development to describe the actual development and the potential development of the children. Scaffolding is a central approach which allows support for the child to develop in line with their developmental trajectory. In action, scaffolding play involves systematically adjusting the amount of assistance offered to a child to match or slightly exceed the level at which the child can independently play with peers<sup>17</sup>. The process relies on finding the right amount of support without impeding the natural flow of play. The adult might initially provide intensive support by directing the play and modelling behaviour. As the children gain confidence in their play together with peers, the adult begins to withdraw the intensity of their support, offering only intermittent and subtle support. As the children become fully engaged in reciprocal play with peers, the adult withdraws to the periphery of the group, allowing the children to practice and try out new activities

The participants showed skill in recognizing the zone of proximal development of the children in relation to their play. They used their knowledge about the specific nature of the children's play engagement and linked this with an experiential understanding of the children's playfulness, to promote the play of the children. They drew on various scaffolding approaches, such as, adapting, altering, and accommodating to promote the play engagement of the children. They acknowledged that they needed to be non-

coercive and follow the lead of the children. They were fluid with structure and altered the context and routine to create opportunities for play, with consideration of where the children were at in terms of their play engagement, as well as their specific play preferences. They adapted their approaches to encourage interactions with specific playmates, and subtly immersed themselves into the play of the children to encourage more extensive and sustained engagement, when needed. They also withheld their support when the children initiated their own engagement in play.

#### **Strengths and Limitations**

This study only reflects the perspectives of five participants drawn from two groups of significant others, that is, caregivers and teachers, from one school context. All participants were female and living in middle to upper income contexts. Subsequent studies should aim to include the perspectives of male participants, female children, and participants from lower income contexts. A case study design, inclusive of observation, will generate data which will enhance the description of how a child's play engagement takes place in context, as well as how it can be promoted in context.

Despite these limitations, the study data presented caregiver and educator perspectives of the insightful ways in which they promoted play in children with ASD, in both the home and school context. Gaining this information is an important step in advancing collaborative practice, as sharing experiences will positively inform interventions focused on promoting play in children with ASD.

#### CONCLUSION AND RECOMMENDATIONS

Caregivers and teachers used a variety of strategies to promote the play engagement of children with ASD. These strategies aligned with scaffolding in that the participants maintained a careful balance between providing and withholding structure and assistance to promote the play of children with ASD, with consideration of the children's zone of proximal development. To advance collaborative, relevant and family centred practice, it is recommended that spaces be created for caregivers, teachers, and occupational therapists to come together to share knowledge, resources, and strategies so that children with ASD can receive the benefit of multiple inputs intending to support their play in and across contexts.

#### **Author contributions**

Pamela Gretschel conceptualised and supervised the study and prepared the original draft for this paper. Nyaradzai Munambah guided further conceptualisation and assisted with editing of the manuscript. All other authors collected and analysed the data. All authors edited and finalised the manuscript.

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#### **Conflicts of interests**

The authors have no conflicts of interests to declare

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# Knowledge and perception of occupational therapists and physiotherapists on the use of constraint-induced movement therapy for stroke rehabilitation in South Africa

#### **ABSTRACT**

**Background:** Rehabilitation therapists are expected to manage upper extremities difficulties following stroke by using effective treatment approaches. Constraint-induced movement therapy (CIMT) facilitates upper extremity functional recovery in patients after stroke; however, in South Africa, its application is not well documented.

**Aim:** To assess and compare the knowledge and perception of occupational therapists and physiotherapists on the use of CIMT for stroke rehabilitation in South Africa.

**Methods:** A descriptive cross-sectional design using a self-administered online questionnaire was distributed via the two national professional societies. Data were analysed descriptively and the Mann-Whitney U and Kruskal Wallis tests were used to make inferences.

**Results:** Of 108 respondents, 49.1% (n=53) were occupational therapists, and 50.9% (n=55) physiotherapists. A higher level of education (p=0.037) and working specifically with stroke patients (p=0.050) are significantly associated with better CIMT knowledge and perception. The profession of the participants was not significantly associated with their knowledge and perception of CIMT.

**Conclusion:** This study demonstrates gaps in the knowledge of CIMT as a treatment technique for upper extremity impairment following stroke. Although most respondents knew about CIMT, improved guidance and knowledge of CIMT are required to remediate knowledge gaps. This may assist in improving the feasibility of CIMT and thus promote its clinical application, given the prevalence of UE impairment in stroke patients managed by therapists.

#### INTRODUCTION

Most stroke survivors have upper extremity (UE) impairment early after stroke<sup>1</sup>. The prevalence of upper extremity impairment is approximately 50–80% in the acute phase and 40–50% in the chronic phase<sup>2</sup>. Impairment of the UE can cause significant difficulties for patients recovering from stroke as it affects all areas of occupation. In clinical practice, occupational therapists and physiotherapists are expected to manage UE impairment after stroke and carry out treatment approaches that will effectively rehabilitate the UE. Yet, the treatment approaches for managing these difficulties in South Africa have not been widely reviewed.

After a stroke, several approaches exist for UE motor function rehabilitation. Constraint-induced movement therapy (CIMT) is a commonly used rehabilitation approach to improve upper extremity function (e.g., hemiparesis) after a stroke. In CIMT, the less affected UE is restrained while the affected UE receives intensive training in unimanual skills and the fine motor skills of the affected UE improve significantly after intervention<sup>3</sup>. CIMT has been shown to improve motor function in chronic hemiparesis of stroke patients<sup>4</sup>. In chronic patients with mild to moderate hemiparesis, the CIMT rehabilitation approach has been

used for improving the motor recovery of the affected UE<sup>4,5</sup>. Following a stroke, the patient starts to compensate due to difficulty using the affected limb, relying increasingly on the unaffected limb, and this compensation will result in learned non-use<sup>6</sup>. Although CIMT is regarded as the most effective approach to facilitating UE recovery following stroke, it has also not been used frequently for neurological rehabilitation by therapists<sup>5</sup>.

In South Africa, the absolute number of persons affected by stroke has increased yearly since 1990, along with the number of disabled stroke survivors7. The use of the CIMT treatment approach could be valuable in treating UE impairment; however, its application within the South African context is not well documented. Knowledge and perception of the use of CIMT for stroke rehabilitation are reported to directly affect the therapist-patient interaction, competence in carrying out the necessary intervention, and preferred therapy approach when providing treatment<sup>6</sup>. The study investigated the knowledge and perceptions of South African occupational therapists and physiotherapists on the utilisation of CIMT for UE rehabilitation in stroke patients. The main hypothesis examined in this study was that there would be no significant difference in the knowledge and perception of South African occupational therapists and physiotherapists in the utilisation of CIMT for UE stroke rehabilitation. The outcome of this enquiry may be useful for knowledge translation by South African health professional associations to influence clinical practice, and in informing curricula inclusions at an undergraduate level at institutions.

#### LITERATURE REVIEW

CIMT is suitable for stroke patients with mild to moderate arm and hand function impairment. It encourages increased use of the affected arm in daily life8. CIMT indicate improvements in the patient's ability to complete daily activities with their affected extremity following CIMT treatment<sup>9</sup>. Therefore, in patients with residual arm function but still with severe functional impairments (i.e., moderate paresis), therapy with CIMT should be strongly considered10. The process of gain in motor function of the affected UE after the introduction of the CIMT during rehabilitation is said to be linked with the increase in activation of motor cortices of the undamaged hemisphere during affected hand movement; patients show a shift in motor cortical laterality toward the ipsilateral hemisphere in association with improved motor function of the affected limb resulting in improved motor function of the affected UE in patients with chronic stroke<sup>4, 5</sup>.

## Practice of constraint-induced movement therapy

The principal foundation of CIMT practice is the (a) use of restraint, (b) repetitive, structured, practice intensive therapy in the more affected arm, and (c) application of a package of behavioural techniques that transfers gains

from the clinical setting to the real world". A restraint is worn over the unaffected arm to prevent movement, to ensure that the stroke survivor uses the affected limb to carry out functional tasks. Mass practice is the intensive repetition of motor activity11. Methods and duration of CIMT delivery vary in the type of constraint worn, and in time frames ranging from 30 minutes to six hours a day, or more<sup>12</sup>. Prominent ranges in dosage variability found in the literature included: durations from five days<sup>13</sup>, to 70 days<sup>14</sup>, and one hour a day<sup>13</sup> to six hours a day<sup>15</sup>. This variation in dosage depends on the availability of the caregiver, level of tolerance and active participation of the patient. Shaping is a method in which motor tasks are gradually made more difficult. It is the progression of tasks given to a patient according to the patient's motor ability11. The tasks are usually functional and can include picking up a cup from the table, taking it to the mouth, drinking from it, writing letters, transferring objects from left to right on a table, brushing the teeth, and removing shoes, amongst others. Transfer package is the use of the hand in life situations, and problem-solving to overcome perceived barriers to using the other body extremities<sup>16</sup>.

## Barriers to constraint-induced movement therapy use

Factors that hinder the usage of CIMT are categorised into three broad groups as described by Fleet et al5. These barriers are therapist-related, institutional mediated, and patient-related barriers (including physical or cognitive challenges). Regarding institutional and patient barriers, findings have shown that a lack of resources can hinder CIMT use. Patient non-compliance and cognitive and physical characteristics may be the main barriers to implementing CIMT. Restraint and repetitive intensive training may affect the participant's motivation to use CIMT<sup>17,18</sup> and the high labour demand in the clinical setting may hinder the use of CIMT<sup>18</sup>. Therefore, increasing participants' motivation and decreasing the CIMT's human resources demand are required to successfully implement CIMT. The duration required for each CIMT session differs widely between studies, ranging from 30 minutes to six hours per day<sup>12-15, 17</sup>. This can pose a considerable hindrance to the utilization of the CIMT treatment approach.

#### **METHODS**

#### **Study Design**

The study used a descriptive cross-sectional study design with a self-administered online questionnaire that sought to assess and compare the knowledge and perception of CIMT by South African occupational therapists and physiotherapists.

#### **Study Setting**

The study used an online platform to access occupational

therapists and physiotherapists working in the public and private health care sectors of SA.

#### Recruitment, Selection and Sampling

Participants were recruited through a convenience sample after satisfying the selection criteria. Inclusion criteria required participants to be currently registered with the Health Professions Council of South Africa (HPCSA), participants holding recognised undergraduate qualifications in occupational therapy or physiotherapy, employed in South Africa, and currently practising occupational therapy or physiotherapy. Lastly, participants had to be engaged in providing interventions for patients with neurological impairments in clinical practice at the time of the study. Participants employed outside of South Africa and practising in other health professions were excluded.

Participants were sampled based on their field of practice in adult neurology. The sample size was determined using the Cohen effect size formula to compare the knowledge and perception of occupational therapists and physiotherapists about the use of CIMT as described by Sullivan19. Using an a-priori effect size of 0.6, at a power of 80% and a 95% confidence interval, each group needed to have a minimum sample size of 44 participants making a total of N=88 participants for the two groups. Assuming a 10% non-response rate, the desired sample size was 96 participants (48 subjects per group).

A series of initial qualifying questions were asked in the survey. Those who did not meet the eligibility for participation were immediately redirected to submit without being permitted to complete/progress on the survey. The qualifying questions included undergraduate qualification, and registration status with the HPCSA and if their experience in the field of stroke rehabilitation had been obtained in South Africa or internationally. Only participants who met all the predetermined criteria could continue to the next section of the survey.

#### **Research Instrument**

The research instrument was a questionnaire that was developed using Google Forms which is a survey administration application. The three-part questionnaire had section A that sought to elicit demographic data, presented in closed multiple-choice format. Section B consisted of twelve dichotomous questions on knowledge about CIMT and Section C had thirteen Likert scale questions on perception of CIMT use in clinical practice.

Intra-rater test-retest reliability involving 20 therapists was done for the developed questionnaire. This had an item-by-item kappa value of 1 for all 25 items correlated implying an excellent item by item internal consistency. The initial intraclass coefficient (ICC) for the research instrument was 0.619 with a 95% confidence interval of 0.426-0.771. The item-by-item Cronbach Alphas were used in improving the ICC by removing some redundant questions. This resulted in a new ICC of 0.768 with a 95% confidence interval of 0.65-0.86. An expert panel of occupational therapists and physiotherapists conducted

a face validity check on the questionnaire. This reduced threats of validity by improving the data collection tool and ensuring that it measured what it purports to measure.

#### **Data Collection**

An online survey format was used for data collection, and this was appropriate as it limited human to human contact as it is prescribed in this COVID era. It also allowed the researcher to collect data from therapists across a larger geographical area. This online survey was sent out via the Occupational Therapy Association of South Africa (OTASA) and the South African Society of Physiotherapy (SASP). Data collection aimed to gain insight into the knowledge and perceptions of participants.

#### **Data Analysis**

Since Google Survey was used as an online platform for data collection, responses were automatically uploaded into a secure Google spreadsheet. The data were transferred onto a spreadsheet using Microsoft Excel and were later analysed using SPSS 21 software (IBM, 2017). Data were collated, cleaned, and coded for descriptive analysis. Scoring of sections B and C of the questionnaire was done to generate knowledge and perception scores, respectively. In the knowledge section, every correct answer was scored one and any incorrect answer was scored zero. For the perception section, all the negative answers (strongly disagree/agreed, disagree/agreed and neutral) were scored zero while all positive answers were scored one; agree/disagree was scored one and strongly agree/ strongly disagreed was scored two. A test of normality was performed on the knowledge and perception scores using the Shapiro Wilk test with a p-value of 0.002 for perception score and <0.0001 for knowledge score, showing that the data were not normally distributed. Mann-Whitney U and Kruskal Wallis tests were used in making inferences on the association between components of knowledge, perception and demographic characteristics. The level of statistical significance was set at  $p \le 0.05$ .

#### **Ethical Considerations**

Ethical approval for the study was obtained from the Human and Social Science Research Ethics Committee (HSSREC) of the University of KwaZulu-Natal (HSS-REC/00002860/2021). Gatekeeper's permission was obtained from OTASA and SASP. Informed consent was obtained from individuals participating in the study. The participants were required to declare that they understood the research process, their rights as participants and voluntarily consent to participate.

#### **RESULTS**

A total of n=108 therapists responded to the study and provided consent. Of these 91.7%, (n=99) of respondents completed all three sections of the online questionnaire. Of these, 49.1% (n=53) practised as occupational therapists, and 50.9% (n=55) practised as physiotherapists. Respondents comprised of 30.6% (n=33) males and 69.4%

Table I: Demographic characteristics of the respondents (n=108)

		Occupational Therapists n (%)	Physiotherapists n (%)	Total n (%)
	Female		32 (29.6)	75 (69.4)
Gender	Male	10 (9.3)	23 (21.3)	33 (30.6)
	<29 years	23 (21.3)	25 (23.1)	48 (44.5)
	30 - 39 years	20 (18.5)	13 (12.0)	33 (30.6)
	40 - 49 years	3 (2.8)	12 (11.1)	15 (13.9)
Age	50 - 59 years	7 (6.5)	4 (3.7)	11 (10.2)
	> 60 years	0 (0.0)	1 (0.9)	1 (0.9)
	Other (Please specify)	0 (0.0)	1 (0.9)	1 (0.9)
	Sefako Makgatho University / MEDUNSA	2 (1.9)	8 (7.4)	10 (9.3)
	University of Cape Town	4 (3.7)	5 (4.6)	9 (8.3)
	University of the Free State	2 (1.9)	0 (0.00)	2 (1.9)
Jniversity (undergraduate legree)	University of KwaZulu- Natal/ University of Durban Westville	17 (15.7)	16 (14.8)	33 (30.6)
	University of Pretoria	6 (5.6)	8 (7.4)	14 (13.0)
	University of Stellenbosch	9 (8.3)	7 (6.5)	16 (14.8)
	University of the Western Cape	5 (4.6)	3 (2.8)	8 (7.4)
	University of the Witwatersrand	8 (7.4)	7 (6.5)	15 (13.9)
	PhD	0	3 (2.8)	3 (2.8)
Qualification	Masters	11 (10.2)	8 (7.4)	19 (17.6)
	Bachelors	42 (38.9)	44 (40.7)	86 (79.6)
	Community service therapist	2 (1.9)	1 (0.9)	3 (2.8)
IPCSA registration	Independent practitioner	51 (47.2)	54 (50)	105 (97.2)
Duration of practice	< 2 years	6 (5.6)	1 (0.9)	7 (6.5)
	Between 2 - 4 years	11 (10.2)	11 (10.2)	22 (20.4)
	Between 4 - 10 years	17 (15.7)	18 (16.7)	35 (32.4)
	>10 years	19 (17.6)	25 (23.1)	44 (40.7)
	Eastern Cape	5 (4.6)	2 (1.9)	7 (6.5)
	Free State	3 (2.8)	2 (1.9)	5 (4.6)
	Gauteng	13 (12.0)	9 (16.4)	22 (20.3)
	KwaZulu-Natal	16 (14.8)	15 (13.9)	31 (28.7)
Province	Limpopo	2 (1.9)	3 (2.8)	5 (4.6)
	Mpumalanga	3 (2.8)	3 (2.8)	6 (5.6)
	Northwest	0 (0.0)	7 (6.4))	7 (6.4)
	Northern Cape	1 (0.9)	3 (2.8)	4 (3.7)
	Western Cape	10 (9.3)	11 (10.2)	21 (19.4)
	Private/Public	0 (0.0)	2 (1.9)	2 (1.9)
	Private only	27 (25.0)	22 (20.4)	49 (45.4)
ractice	Public only	26 (24.1)	29 (26.9)	55 (50.9)
	Academia	0 (0.0)	2 (1.9)	2 (1.9)
	Both in-patient and out-patient	32 (29.6)	42 (38.9)	74 (68.5)
Status of Patients	Out-patient only	18 (16.7)	13 (12.0)	31 (28.7)
	In-patient only	3 (2.8)	0 (0.0)	3 (2.8)
	<5 years	23 (21.3)	19 (17.6)	42 (38.9)
Years of experience in	5 – 10 years	17 (15.7)	14 (13.0)	31(28.7)
stroke rehabilitation	>10 years	13 (12.0)	22 (20.4)	35 (32.4)

Table II: Comparison of CIMT knowledge score across demographic and work-related variables (n=99)

Variable	N	Median	Interquartile range	p-value	
Professional group				a0.164	
Occupational Therapist	47	10.0	8-10		
Physiotherapist	52	9.0	8-10		
Gender				a0.210	
Male	33	9.0	8-10		
Female	66	9.0	8-10		
Qualification				b0.136	
PhD	3	10.0	-		
Masters	14	9.5	9-10		
Bachelors	82	9.0	8-10		
Years of experience				b0.161	
<5 years	42	9.0	8-10		
5 – 10 years	28	9.0	8-10		
>5 years	29	10.0	9-10		
Duration of practice					
<2 years	7	8.0	7-9	b0.318	
Between 2 – 4 years	22	9.0	7-10.25		
Between 4 – 10 years	34	9.5	8-10		
>10 years	36	8.0	8-10		
Setting of practice				b0.347	
Both	2	8.0	-		
Private	40	9.0	8-10		
Public	55	9.0	8-10		
Academia	2	10.0	-		
Status of patients treated	1			b0.126	
Both in-patient and out- patient	69	9.0	8-10		
Out-patient only	27	9.0	8-10		
In-patient only	3	11.0	10-11		
Do you routinely manage patients	stroke			a0.037*	
No	6	8.0	7.5-9		
Yes	93	9.0	8-10		

<sup>\*=</sup>Significant at p≤0.05 a=Mann-Whitney test, b=Kruskal Wallis test

(n=75) females who represented all provinces. A total of 79.6% (n=86) respondents reported a bachelor's degree as their highest level of education, 17.6% (n=19) had a master's degree, and 2.8% (n=3) reported they had a PhD. While all respondents had experience practising in stroke rehabilitation, 38.9% (n=42) reported having less than five years of experience. Most respondents (68.5%; n=74) reported working primarily with both in-patient and out-patients. Other demographic characteristics of the respondents are detailed in Table I, above.

#### Therapists' Knowledge of Constraint-Induced Movement Therapy

The knowledge score ranged from 5 to 12, with a median knowledge score and its interquartile range being 9.0 (8-10). Statistical hypothesis testing was conducted (Table II, above) between the knowledge components to determine the statistical difference ( $p \le 0.05$ ) and the association between selected variables elicited in section A of the questionnaire. The knowledge of occupational therapists and physiotherapists of CIMT was not significantly different as presented in Table II, above (p-value = 0.164).

Therapists involved in managing stroke patients in clinical practice had a significantly higher CIMT knowledge score when compared to therapists that do not routinely manage stroke patients with CIMT (p = 0.037).

A total of 84.8% (n=84) respondents were aware of the CIMT as a treatment technique for UE impairment and 98% (n=97) respondents agreed that it can be used in stroke rehabilitation. Furthermore, 15.2% (n=15) of respondents reported being unaware of CIMT as a treatment technique for UE impairment. A total of 66.7% (n=66) respondents reported that CIMT does not involve constraining the affected arm, and 78.8% (n=78) respondents reported that CIMT is delivered one to seven days for about six hours a day. The majority of respondents (88.9%; n=88) reported intensive graded practice of the affected UE to enhance specific use as one of the components of CIMT. The majority (77.8%; n=77) of respondents indicated that CIMT gains could not be transferred from the clinical setting to allow for functions and 90.9% (n=90) described the aim of CIMT as to improve and increase the use of the more affected UE while restricting the use of the unaffected UE hence improving the functioning of the affected UE. Most respondents (98.0%, n=97) believed CIMT to be an efficacious treatment technique in stroke rehabilitation (see Tables III and IV on pages 56 and 57).

The CIMT perception scores ranged from 0 to 19, with a median and interquartile range of 9.0 (7-12). Statistical hypothesis testing was conducted (Table V page 59) between perception components to determine the statistical

difference (p  $\leq$  0.05) and the association between selected variables elicited in section A of the questionnaire. Therapists with higher qualifications had higher CIMT perception scores (p = 0.050) on the use of CIMT in the management of UE impairment during stroke rehabilitation thus implying that therapists with higher qualifications perceive CIMT as a valuable treatment modality. There was no significant difference between the perception of occupational therapists and physiotherapist on the use of CIMT (p=0.930 see Table V, page 59).

Table III Response distribution on knowledge of CIMT (n = 99) (the correct response is highlighted)

99) (the correct respons	I	T
Knowledge of CIMT	Yes	No
	f (%)	f (%)
Are you aware of constraint-induced movement therapy (CIMT) as a treatment technique for upper extremity impairment	84 (84.8)*	15 (15.2)
CIMT is a behavioural approach to neurorehabilitation based on learned non- use	77 (77.8)*	22 (22.2)
CIMT does not involve constraining affected limb	33 (33.3)	66 (66.7)*
One component of CIMT is intensive graded practice of the affected limb to enhance specific use	88 (88.9)*	11 (11.1)
In CIMT gains obtained cannot be transferred into clinical setting to allow functionality	22 (22.2)	77 (77.8)*
CIMT improves and increases the use of the more affected upper extremity while restricting the use of the unaffected arm	90 (90.9)*	9 (9.1)
Can CIMT be used in stroke rehabilitation	97 (98.0)*	2 (2)
The minimum motor inclusion criteria into CIMT exclude minimal AROM for wrist extension, thumb abduction and finger extension	29 (29.3)	70 (70.7)*
CIMT uses forms of restraining and is delivered 1-7 days, for about 6 hours a day	78 (78.8)*	21 (21.2)
Clinical setting and forms of constraint used cannot affect motivation of the patient to engage in CIMT	40 (40.9)*	59 (59.5)
Shaping in CIMT is a significant part of therapy	76 (76.8)*	23 (23.2)
Does your level of knowledge and experience impact on how CIMT is delivered?	92 (92.9)*	7 (7.1)

<sup>\*=</sup>Correct option

#### **DISCUSSION**

This study was designed to assess and compare the knowledge and perception of occupational therapists and physiotherapists on the use of CIMT for managing UE impairment after stroke in South Africa. Occupational therapists and physiotherapists have a fundamental role in treating UE impairment in stroke rehabilitation. Occupational therapists use CIMT to improve the performance of occupations, such as activities of daily living and

increased spontaneous use of the affected arm during dressing, bathing, and feeding<sup>20</sup>. In occupational therapy, CIMT has been shown to elicit changes in UE function through improvements in components of performance skills practised repetitively<sup>21</sup> including improved hand function of the affected arm in reach, grasp, release, push, pull, sustained grasp, and bilateral use during play<sup>22</sup>. Physiotherapists use CIMT to improve gait and mobilityrelated functions. The outcome of this study reveals that the knowledge and perception of occupational therapists and physiotherapists in SA about CIMT were not significantly different. Though no published study known to the authors had examined the difference in knowledge and perception about CIMT among these two-rehabilitation professionals, it is expected that occupational therapists should be more knowledgeable and practically oriented about the use of CIMT in UE impairments of stroke survivors. This assumption is premised on the fact that the model of the practice of occupational therapists focuses more on the restoration of precision activities function than physiotherapists that focus more on gross movement restoration. Hence, occupational therapists may be more attentive to implementing a transfer treatment package alongside shaping activities as it is entrenched in the CIMT protocol.

Knowledge is a crucial requirement for using CIMT in stroke patients. Knowledge is a modifying factor in perception and practical behaviours<sup>23</sup>. The level of knowledge about CIMT demonstrated by occupational therapists and physiotherapists will reveal the competency of therapists to use the treatment technique in treating UE impairment successfully. More than half of the respondents reported being knowledgeable about CIMT as a treatment technique used in stroke rehabilitation. They indicated that CIMT improves the potential motor capability of patients following stroke, it appears that some therapists were not well informed on the utility of CIMT while some do not use it at all despite the benefits associated with its use. The non-usage of CIMT by these therapists may be related to their lack of knowledge and other factors that influence their practice.

Most respondents stated that CIMT requires additional specialised training to ensure that therapists are competent and effective when delivering stroke intervention using this treatment technique for UE impairment. There are specific components of CIMT that are necessary for efficacious intervention<sup>16,24</sup>. These regimens are better learnt with specific training for clinicians interested in delivering CIMT for stroke survivors. The modified protocol of CIMT appears to be much more accepted in clinical practice and therapists are expected to receive further training to enable the standardised usage of the revised protocol. Most respondents reported having clinical experience of more than ten years, this may explain the reason why most of them had good knowledge of CIMT and its components as they may have come across this intervention during their years of training and clinical practice. Therapists who have only some knowledge of CIMT (i.e., minimal or moderate knowledge) would need

Table IV Response distribution on Perception of CIMT (n = 99)

Perception of CIMT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	f (%)	f (%)	f (%)	f (%)	f (%)
CIMT is an efficacious treatment approach in stroke rehabilitation	17(1)	45(45.5)	32(32.3)	4(4)	1(1)
CIMT should be used as the primary treatment approach when indicated	8(8.1)	34(34.3	36(36.4)	20(20.2)	1(1)
CIMT should be delivered independently by a therapist in a clinical practice	1(1)	24(24.2)	45(45.5)	27(27.3)	2(2)
CIMT should be delivered by a team in a clinical practice	13(13.4)	45(45.5)	26(36.4)	4(4)	1(1)
The type of restraint used in CIMT can impact the results of therapy	20(20.2)	56(56.6)	19(19.2)	3(3)	1(1)
Key components of CIMT are a guide to how intervention should be delivered.	14(14.1)	55(55.6)	27(27.3)	3(3)	O(O)
CIMT reveals the potential motor capability	20(20.7)	56(56.6)	21(21.2)	1(1)	1(1)
Physical training can overcome the learned non-use of the affected upper extremity post-stroke	14(14.1)	49(49.5)	31(31.3)	4(4)	1(1)
The level of knowledge of the therapist can be a barrier to CIMT use	31(31.3)	54(54.5)	12(12.1)	2(2)	0(0)
Lack of resources in clinical practice can be a barrier to delivering CIMT	22(22.2)	45(45.5)	16(16.2)	15(15.2)	1(1)
The type of setting and number of therapists working with stroke patients can hinder the implementation of CIMT	19(19.2)	47(47.5)	22(22.2)	10(10.1)	1(1)
The time duration required when implementing CIMT is a factor resulting in low use of this treatment approach	16(16.2)	57(57.8)	20(20.2)	5(5.1)	1(1)
CIMT requires additional specific training to allow therapists to be competent and effective when delivering intervention using this treatment approach	11(11.1)	52(52.5)	24(24.2)	12(12.1)	O(O)

further training to allow them to implement CIMT in clinical practice competently.

While CIMT is identified as an effective technique, 92.9% of respondents agreed that the level of knowledge and experience impacts the therapist's competency to successfully use CIMT as a treatment technique in a clinical setting. To assess respondents' knowledge about CIMT, they were asked if shaping is a significant component of CIMT. The majority were able to identify shaping as substantial in CIMT. Shaping is considered one of the core components of treatment, and, consequently, a critical part of any CIMT protocol<sup>20,24,25</sup>. This ability to identify CIMT fundamental components reveals a positive knowledge of the CIMT protocol among respondents<sup>24</sup>. The results obtained from our sample of therapists reinforce prior observations that increasing therapists' knowledge of CIMT can contribute to more frequent use in clinical practice. This is aligned with Christie and colleagues<sup>20</sup>, who reported that a range of strategies are needed for improving therapists' knowledge and skills to increase the frequency of CIMT delivery in clinical practice. Inferential analysis reveals that therapists practising stroke rehabilitation had significantly better knowledge than those not routinely involved in stroke rehabilitation. This is a plausible outcome as it is clear that the concept of CIMT stemmed from neurological rehabilitation<sup>25,26</sup>.

A similar analysis reveals that therapists with higher educational qualifications had a significantly better perception of CIMT. Therefore, the level of qualification and duration of working with stroke patients impact the knowledge and perception of occupational therapists and physiotherapists on CIMT as a treatment technique for UE impairment. Fleet et al5 reported similar findings among a population of Canadian occupational therapists and physiotherapists, hence the most accessible means of promoting the effective application of CIMT is through improved education.

The CIMT technique encourages the use of the affected UE therefore, it allows patients to be meaningfully engaged in basic activities of daily living and improve their occupational performance. CIMT has beneficial effects on motor function, arm-hand activities, and self-reported daily arm-hand functioning. Findings from the study showed that less than half of the respondents had a negative perception about using CIMT for UE management hence these respondents would not be eager to use CIMT in stroke rehabilitation. It was noted that restrictions and barriers to using CIMT mainly were a result of the negative perception of some therapists. They suggested that CIMT should not be considered a

Table V: Comparison between CIMT Perception scores and selected variables (n=99)

Variable	N	Median	Interquartile range	p-value
Professional group			ª0.930	
Occupational Therapist	47	9.0	7-11	
Physiotherapist	52	9.0	7-12	
Gender				ª0.268
Male	33	9.0	2.5-11.5	
Female	66	9.0	7-12	
Qualification				<sup>6</sup> 0.050*
PhD	3	11.0	10-11	
Masters	14	11.5	8-12	
Bachelors	82	9.0	7-11	
Years of experience				<sup>b</sup> 0.462
<5 years	42	9.0	6.75-12	
5 – 10 years	28	9.0	7-10.75	
>5 years	29	10.0	8-11.5	
Duration of practice				<sup>6</sup> 0.551
<2 years	7	7.0	6-9	
Between 2 – 4 years	22	9.0	3-13	
Between 4 – 10 years	34	9.0	7-11	
>10 years	36	9.5	7-11.75	
Setting of practice				<sup>6</sup> 0.172
Both	2	10.5	9-10.5	
Private	40	10.0	7.25-12	
Public	55	9.0	6-11	
Academia	2	12.0	11-12	
Status of patients tre	ated			₀0.183
Both in-patient and out-patient	69	9.0	7-11	
Out-patient only	27	10.0	7.75-12	
In-patient only	3	13.0	8-13	
Do you routinely mar stroke patients	nage			ª0.971
No	6	9.5	5.25-12	
Yes	93	9.0	7-11.5	

primary treatment technique for UE impairment in stroke patients. Still, in practical terms, stroke rehabilitation is usually composed of different intervention models. Based on our findings, the divergence between the knowledge and perception of the therapist about CIMT suggests that there are also several barriers to implementation and use of CIMT in clinical practice such as lack of specific knowledge, time duration<sup>6</sup> required to implement CIMT, number of therapists working with stroke patients, type of setting and lack of resources in clinical practice5,20,24,25. Therapists also reported type of restraints used to be a

barrier preventing CIMT use clinically<sup>24</sup>.

#### Limitations

Information gathered from the survey was restricted to closed-ended multiple-choice questions which may have been ambiguous to the respondent. Participants were not provided with an opportunity to share their experiences using CIMT. As a result, only knowledge and perceptions were assessed with no in-depth information regarding CIMT. A mixed-method research design may be more appropriate for comparing the knowledge and perception of the two professionals regarding their usage of CIMT.

#### **CONCLUSION**

The importance of occupational therapists and physiotherapists providing intervention for UE impairment using CIMT in stroke rehabilitation within the South African context was assessed and compared in this study. The outcomes from the study suggest that therapist's knowledge and perception on the use of CIMT was not different and a higher level of education / working specifically with stroke patients have better knowledge and perception of CIMT. Our findings regarding knowledge and perception about CIMT among practising therapists in our sample highlight the need for continuing professional education since most respondents indicated that additional training is required for therapists to successfully use CIMT intervention in stroke patients. Therapists' perceptions of CIMT can inform recommendations for UE intervention following stroke. Furthermore, these results can guide future research, which should focus on balancing the clinical feasibility of CIMT and its effectiveness in treating UE impairment in stroke patients.

#### **Author Contributions**

Velisiwe Zodwa Mbuyisa completed the study towards a postgraduate degree and was responsible for drafting the manuscript. Michael Opeoluwa Ogunlana, Nonjabulo Ndaba and Pragashnie Govender supervised the study and assisted in the critical revision of the manuscript. All authors approved the final version.

#### Conflict of Interest (COI) Statement

The authors declare no conflict of interest.

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#### **RESEARCH ARTICLE**

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#### Enablers and inhibitors to quality of life as experienced by substance abusers discharged from a rehabilitation centre in Gauteng, South Africa

#### ABSTRACT

**Introduction:** The impact of substance-related and addictive disorders is a serious health problem affecting society. Occupational therapy intervention for people with substance-related disorders is ultimately directed at enhancing the quality of life. This article aims to present participants' experiences regarding their quality of life on their journey to sobriety.

**Methods:** A qualitative study, where an exploration of participants' perceptions and description thereof was used to gain insight into participants' experiences of their quality of life after discharge from a rehabilitation centre. Individual, semi-structured interviews were used to collect data from a purposive sample of 20 participants. The interviews were based on the Schedule for the Evaluation of Individual Quality of Life: A Direct Weighting Procedure for Quality-of-Life Domains (SEIQoL – DW). Data collected were analysed using thematic content analysis.

**Findings:** Two themes, namely (1) "enablers of quality of life", and (2) "quality of life inhibitors", emerged from the interviews. The participants described the enablers of quality of life as employment, education, support, parenting and leisure; while emotions experienced, family breakdown, harmful behaviours and socioeconomic status were described as the inhibitors of quality of life.

**Conclusions:** Engagement in occupations is important for the substance user to enhance their quality of life. Occupation-based occupational therapy intervention is therefore crucial in enhancing quality of life, particularly in the life of a substance user whose lifelong journey to sobriety is challenged daily by the barriers they encounter.

#### **INTRODUCTION**

"Drug/alcohol use refers to the general use of drugs/alcohol and usually starts on an experimental basis" Drug/alcohol abuse resulting from experimentation can cause individuals to become addicted despite the harmful and dangerous effects. Repeated substance use over time causes intense activation of the brain reward system, resulting in the neglect of normal activities. According to the DSM-52:483, "The essential feature of a substance use disorder is a cluster of cognitive, behavioural, and physiological symptoms indicating that the individual continues using the substance despite significant substance-related problems". With the continued use of substances, quality of life is negatively impacted, resulting in reduced life satisfaction and wellbeing<sup>3</sup>. Quality of life is defined as a client's dynamic appraisal of life satisfaction (perceptions of progress toward identified goals), self-concept (the composite of beliefs and feelings about themselves), health and functioning (including health status, self-care capabilities), and socio-economic factors (vocation, education, income)<sup>4</sup>.

Occupations are pertinent to the client's health status, identity, and competence, influencing the quality-of-life experienced<sup>4</sup>. Occupations are central to health and wellbeing as they provide identity, meaning and structure to peoples' lives<sup>5</sup>. In occupational therapy, occupations are understood as the activities one does in everyday life. It is through occupational performance that the client is able to function in their context. Occupations contribute to a well-balanced lifestyle that enhances the qual-

ity of life<sup>5</sup>. Furthermore, occupations are reported to include daily activities that enable people to sustain themselves, contribute to the lives of their families and participate in society<sup>6</sup>. Crowe<sup>7</sup> reports that young people in South Africa who persistently abuse substances find themselves experiencing an array of challenges in occupational engagement that include academic difficulties, health-related problems, poor peer relationships and ultimately, falling foul of the law. The challenges not only end with them but also extend to their family members, the community, and society. The implication of these challenges poses difficulties for young persons recently discharged from a rehabilitation unit, to change their behaviour, and adopt productive lifestyles through engagement in meaningful occupations<sup>7</sup>. A study by Denis<sup>8</sup> on alcohol-dependent patients in Pennsylvania (US) indicated that substance use had a significantly negative impact on the quality of life in education, employment, and social participation. He further found a higher impact on participants' mental functions than physical functions, ultimately negatively affecting their quality of life.

The primary outcome of occupational therapy intervention is to assist clients who are using substances to maintain a lifestyle without using drugs and improve their quality of life!. Furthermore, occupational therapy intervention with substance-related disorders is directed at changing the behaviour and lifestyle of the individual as occupational therapists have a holistic focus on skills in occupational engagement?

The intervention, therefore, assists the client in gaining insight into their condition and behaviour by equipping the client with relevant coping strategies and skills to improve their occupational performance in their life roles'. Occupational therapy intervention facilitates personal change by enabling the clients to identify the problems and consequences, realise their need for help, and learn to be constructive in how they live with this challenge of substance use¹. Ribeiro et al¹o reaffirm that occupational therapy aims to improve clients' lives by facilitating the ability to acquire the required occupational performance skills that are essential to a balanced lifestyle to cope with life effectively.

Therefore, occupational therapists play a vital role in the enhancement of the quality of life of their clients<sup>11</sup>. The intervention is therefore important in changing the habits and routines of clients' lifestyles to maintain and restore roles they lost because of substance use<sup>12</sup>. Ryan and Boland<sup>13</sup> support the understanding that occupational therapy is well-positioned to treat substance users and is most effective and supportive when going beyond teaching of skill to prioritise occupational engagement and client-centered practice.

Twinley<sup>14:302</sup> states, "It is possible to explore the dark side of a person's occupations and gain an understanding of the underlying and associated values, interests, motivations, skills, abilities, capacities, roles, meanings and satisfactions attributed to this engagement". Following this observation, it is evident that since substance use is an occupation of choice, it is also shaped or perpetuated by the contexts that these individuals find themselves in<sup>14</sup>. Thandi and Browne<sup>15</sup> in their

study on social contextual factors on substance abuse in British Columbia (Canada) report on the social and sociopolitical factors, including health and social inequities, stigma and discrimination as perpetuating factors to substance abuse use. Additionally, Amaro et al<sup>16</sup> affirm that societal and contextual influences on substance use are numerous and widespread. Their study findings report that societal stressors play a role in creating vulnerability to the use of substances<sup>16</sup>. These stressors range from socioeconomic and political stressors to psychosocial factors, which include disproportionately distributed population groups in communities<sup>16</sup>. Furthermore, Sibanda and Batisai<sup>17</sup> conducted a study at a SANCA rehabilitation center in Gauteng (SA) and identified structural unemployment, poverty, fractured families and communities as contributing to the perpetuation of engagement in negative occupations as a survival strategy. Regardless of the satisfaction, it may bring to the individuals, occupations associated with substance use are not the sort that would be encouraged by the occupational therapist as they result in the deterioration of quality of life, negatively affecting life roles and occupations. This position is supported by the fact that quality of life and wellbeing from an occupational therapy perspective is understood in terms of engagement in those constructive activities that can improve the overall health of an individual1. Hammel<sup>18</sup> states that numerous qualitative studies in occupational therapy suggest that filling one's time with personally meaningful occupations restores the sense of value, purpose and quality in one's life.

Stoffel and Moyers<sup>19</sup> emphasise the need to dedicate money and time to support research on the specific role occupational therapists play in treating people with substance use disorders. Gutman<sup>20</sup> is of a similar opinion and emphasises a need for research to effectively treat substance use disorders in occupational therapy. The adverse effects of substance dependence on the quality of life underline the need to focus on enhancing the quality of life.

The significant cognitive, behavioral and psychological problems clients with substance dependence experience negatively affect meaningful engagement in the occupational environments and diminish the experience of quality of life<sup>8</sup>. Furthermore, their quality of life is affected when they reintegrate into their society and find that they are unable to fulfil the roles they had before their admissions. Individuals who define their quality of life by their roles and occupations find themselves in positions where they either have lost the roles or are deprived of meaningful/adequate engagement in occupations<sup>8</sup>. With the quality of life, being apparent when one lives well and feels good, problems arising from substance use can consequently affect life satisfaction<sup>3</sup>.

This article is based on a study that was conducted on the quality of life of substance abusers at a rehabilitation centre in Gauteng, South Africa. The purpose of the study was to describe the experiences of participants regarding their quality of life on their journey to sobriety. Some studies focus on how occupational therapists can support people with substance use disorders<sup>21</sup> and the interventions used in the field<sup>22</sup>.

However, there are limited studies on the experiences of substance abusers on their quality of life after discharge. This study will provide insights that will inform the development of occupational therapy interventions that enhance quality of life. While expanding on the existing body of knowledge regarding substance use disorders in occupational therapy, the study will furthermore aid in the development of rehabilitation programmes, strategies and policies used in the field.

#### **Literature Review**

Substance use is a global concern and is rapid in its growth. Epidemiological studies of substance-related disorders are immense and provide data that is fast growing nationally and throughout the world<sup>23,16</sup>. The World Drug Report for 2018 released by United Nations Office on Drugs and Crime (UNODC) states that the use of substances is rapidly increasing globally. The report highlighted, for example, that the estimated global annual prevalence of drug use between 2006 and 2016 grew from 4.9% - 5.6% for ages between 15 and 64 years<sup>24</sup>. Furthermore, the UNODC statistics demonstrated that the prevalence of cannabis use among clients in Europe in 2016 showed the highest prevalence at 13.9%, with the United States of America at 11.6%, Africa at 6.6%, and Asia at the lowest at 2.7%. The statistics for all these regions have increased compared to 2016. The coronavirus disease 2019 (COVID-19) pandemic has put an enormous strain on mental health. Czeisler et al $^{25}$  reports that 40.9% of respondents reported at least one mental or behavioural health condition, which included symptoms of anxiety disorder, depressive disorder, trauma and stressor-related disorders related to the pandemic having started and significantly increased substance use to cope with stress and/or emotions related to COVID-19. Furthermore, they state that 1 in 5 people over the age of 12 used illicit drugs as a coping mechanism during the hard lockdown periods<sup>25</sup>.

South Africa's National Drug Master Plan (NDMP) 2019-2024 aims to have a South Africa "free of substance abuse" 26. The methods proposed to achieve this aim are reducing supply and demand of drugs for non-medical use. This is achieved by increasing harm reduction treatment, which entails the development of programmes that are directed at reducing social, economic, and health-related harm that results from substance use, controlling drugs for medical use, and preventing new drugs from entering the market. An integrated approach, including demand reduction, supply reduction, and harm reduction, will advance the realisation of this goal 26. The NDMP 2019 – 2024 further states that substance use destroys communities, families and, even more concerning, the developing youth of the country 26.

Moreover, a strong relationship is reported to exist between substance use and poverty, crime, reduced productivity, unemployment, dysfunctional family life, escalation of chronic diseases and premature death. This, therefore, emphasises that the quality of life of a substance user may be significantly impacted in almost all occupations. A survey done by the Central Drug Authority (CDA) of South Africa from 2019 - 2020 contains alarming findings, including the fact that the youth were addicted to drugs and alcohol by the age of 12, which in South Africa is pre-high school age.

Drugs such as 'nyaope', a narcotic substance typically comprising heroin, marijuana and other substances smoked as a recreational drug in some parts of South Africa and cannabis have been commonly used. They are readily available in the local communities of South Africa, a situation that undermines the goal of the NDMP<sup>27</sup>. According to Census 2011, approximately 2 million of the 57 million South Africans were classified as substance users<sup>28</sup>. The COVID-19 pandemic has also exacerbated the mental health challenges in South Africa; the Human Sciences Research Council<sup>29</sup> reported that 33% of South Africans were depressed, 45% experiencing anxiety symptoms and 29% experienced severe loneliness. This, therefore, led to the predisposition to substance use disorders. Naidu<sup>30</sup> further reported that COVID-19 might lead to mental health challenges such as post-traumatic stress disorder, mood disorders, anxiety disorders and substance use disorders. Substance use disorders result in a maladaptive pattern of use leading to significant impairment in occupations and perpetuating occupational risks.

Occupations are multi-layered because there are positive and negative occupations<sup>14</sup>. Good occupations may provide a productive, meaningful life, whereas harmful occupations offer a false sense of meaning as they limit the ability of one to grow and thrive<sup>5</sup>. Occupations include what people do daily by themselves and collectively (core occupations). These occupations structure the habits and routines that promote health<sup>31</sup>. Occupational risks (occupational imbalance, alienation and deprivation) may be evident when there is a loss of harmony between lifestyle and environment<sup>32</sup>. The result of these risk factors are the unending results of stress and can manifest as boredom, anxiety and depression which perpetuate health risk behaviors such as substance use<sup>33</sup>. According to Crowe<sup>7</sup>, the youth of South Africa who falls prey to substance use encounter an array of challenges resulting in bad occupations that predispose them to academic difficulties, health-related problems, and poor relationships - all of which may lead to youths finding themselves in the South African Juvenile Justice System. Given that drugs are readily available in South Africa, it is challenging for a diagnosed substance user to refrain from using substances and maintain sobriety. Additionally, families of youths who use drugs are adversely impacted by substance use behaviour<sup>7</sup>.

A study done in a South African community by Cloete and Ramugondo<sup>34</sup> showed how alcohol consumption in pregnant women was not merely just "substance use", but also an occupation that provided meaning for some of these women. Cloete and Ramugondo<sup>34</sup> further stated that one's environment and historical context shape occupations such as these. Although viewed by society as harming the wellbeing of an individual, individuals who partake in these activities seem to derive some satisfaction from them. Wilcock<sup>35</sup> further states that a decline in quality-of-life experience is caused by occupational imbalance, occupational deprivation and occupational alienation. Occupational imbalance describes the experience of compromised health and quality of life due to being under-occupied. Occupational deprivation is a state of prolonged preclusion from engagement in oc-

<sup>&</sup>lt;sup>1</sup> Nyaope is mixture of low-grade heroin, cannabis products, antiretroviral drugs and other materials added as bulking agents.

cupations of necessity or meaning due to factors outside of an individual due to societal factors. Occupational alienation refers to engagement in occupations that do not satisfy personal needs related to meaning and purpose causing a significant decline in the experience of quality of life. Without engagement in purposeful occupations, abstinence and sobriety are not adequate predictors of quality of life for a substance user<sup>35</sup>. Therefore, it is of paramount importance that people with substance-related disorders are exposed to occupational therapy programmes to re-establish balance and participation in meaningful activity and ultimately enhance their quality of life<sup>1</sup>.

Occupational therapy interventions are well-positioned in supporting people with substance use disorders; however, there is limited literature on the outcomes of these interventions on the quality of life<sup>11,14</sup>. A few studies attest to the complexity of quality of life and the difficulty in reaching a consensus in defining the concept<sup>36</sup>. The understanding of quality of life from available literature encompassed different perspectives related to life satisfaction, self-concept, health and functioning and socio-economic factors. These factors are identified as concepts of interest in occupational therapy practice.

#### **METHODS**

This study's methodology was guided by the relevant domains of the Consolidated Criteria for Reporting Qualitative Research (COREQ), which are essential in reporting qualitative data<sup>37.</sup>

#### Study Design

An explorative descriptive design embedded in the qualitative paradigm was used in this study<sup>38,39</sup>. This research design allowed for exploration and description of the participants' quality of life<sup>40</sup>. Furthermore, the design is flexible and allowed the researcher the opportunity to describe this broad subject of substance use and quality of life<sup>38</sup>. This study aimed to explore the participants' post-discharge perceptions regarding enablers and inhibitors of their quality of life and to describe the influence of substance dependence on their quality of life prior to the rehabilitation.

#### **Study Setting**

The study was based at a 200-bed rehabilitation facility located in Gauteng, South Africa. The clients at the centre are voluntary in-patients aged 19 - 56. The centre operates under the auspices of the Department of Social Development. The centre runs a 6-week programme using a multidisciplinary team approach, including an occupational therapist, psychologist, social worker, and nurses.

#### **Participants**

The occupational therapist employed at the centre assisted with the recruitment of participants who met the inclusion criteria. The key inclusion criteria were that the participants be aged 18 years and above and be outpatients within the six weeks follow-up period and have participated in the occupational therapy programme during their admission as stipulated by the centre. Additional demographic char-

acteristics considered were gender, educational level, occupation, and marital status.

Purposive sampling, specifically the heterogeneous type, was used in this study to select participants<sup>41</sup>. Data were collected from 20 participants who consented to participate in the study and met the inclusion criteria. Participants were aged between 19 and 56, with a majority (60%) being male and 75%, single, 10% were in the educational process whilst an equal percentage of 45% were employed and unemployed. The participants used a variety of substances with 'nyaope' being the most common.

#### **Data Collection**

The researcher used one-to-one in-depth interviews, which entailed demographics in section A, Section B developed from the Schedule for the Evaluation of Individual Quality of Life (SEIQoL): A Direct Weighting Procedure for Quality of Life Domains (SEIQoL-DW) to collect the data<sup>42</sup> and Section C, based on intervention received by participants. The SEIQoL-DW was developed to establish the quality of life of a population or patient group and its usefulness was established in some studies<sup>43</sup>. Section B (Quality of Life) was explained to the participants as per the definition of quality of life used in the study. Based on the SEIQoL, it was possible to explore the factors related to the quality of life of substance users. The interview guide allowed the researcher to probe and follow-up on responses that required clarification. Each participant was given a pseudonym and the interviews were audio-recorded to enable the researcher to transcribe verbatim. Data collected from the participants comprised socio-demographic data, and factors enhancing and inhibiting quality of life. Due to the detailed information required from the participants, each participant was interviewed until data saturation was reached.

#### Data Analysis

The thematic content analysis method described by Burnard, Gill, Stewart, Treasure and Chadwick<sup>44</sup> was used to analyse data. This method of analysis enabled the researcher to analyse the transcripts to understand the data. Units of meaning were gathered from the transcripts; these units of meaning were then put into categories. The researcher further combined categories where similarities were shared and then the theme was developed (e.g. Enablers to quality of life). Each participant was given a pseudonym to keep their identity confidential. This was done following the order of transcription, the first letter of the pseudonym and page number on which the transcript appears to give, for example, TIK3 where T stands for a transcript, for the first transcript analysed, K for the first letter of the pseudonym and 3 for the page number the unit of meaning was quoted from. The data analysis was subjected to peer review in which the methodology employed, and analysis procedures were subjected to scrutiny by experts in the field<sup>45</sup>. This process aided the researcher in ensuring trustworthiness. Trustworthiness was further ensured by confirmability by having audit trails that gave a record of how the study was conducted from its inception, through data collection, field notes, audiotapes, supervisor feedback and analysis, and concluding on the

**Table I: Demographic Profile of Participants** 

Participant	Gender	Age	Marital status	Educational level	Employment status
1	Female	36	Widow	Matric	Unemployed
2	Male	25	Single	Matric	Unemployed
3	Female	26	Single	Matric	Unemployed
4	Female	25	Single	Grade 10	Unemployed
5	Female	29	Single	Grade 10	Employed
6	Female	19	Single	Grade 10	Unemployed
7	Female	27	Single	Grade 11	Employed
8	Male	32	Single	Matric	Employed
9	Female	56	Divorced	Grade 11	Unemployed
10	Male	31	Single	Grade 11	Employed
11	Male	23	Single	Grade 10	Unemployed
12	Male	31	Single	Matric	Employed
13	Male	35	Married	Matric	Employed
14	Female	25	Single	Matric	Unemployed
15	Male	32	Single	Matric	Unemployed
16	Male	43	Divorced	Grade 11	Employed
17	Male	28	Single	Grade 11	Unemployed
18	Male	38	Married	Matric	Employed
19	Male	33	Single	Matric	Employed
20	Male	30	Single	Grade 11	Unemployed

Table II: Themes – Enablers and Inhibitors

Theme 1	Sub-theme	Category			
	Employment and Education	Financial security Status in life Social standing			
to quality of life Support: Family Intervention Spirituality		Family support Community support Activity participation Connection with a higher power			
	Parenting	Importance of the parenting role			
	Leisure	Opportunity to learn activities for relaxation			
Theme 2	Sub-theme	Category			
	Emotional experiences	Stress impacting on emotions Grief Anxiety Shame Failure Anger Regret			
Inhibitors to quality of life	Family breakdown	Loss of trust Poor relationship Poor parenting Poor communication			
Behaviours influencing the quality of life		Avolition Drug dependency Manipulation Experimentation			
	Socio-economic circumstances	Unemployment Poor financial use			

findings<sup>46, 47</sup>. To further ensure trustworthiness, the researcher was noted her thoughts and wrote them alongside the responses. Noting these thoughts limited bias and ensured reflexivity and trustworthiness <sup>48</sup>.

#### **Ethical Considerations**

The Research and Ethics Committee at Sefako Makgatho Health Sciences University in Gauteng, South Africa approved the study (SMUREC/H/92/2015). Permission to conduct the study was also granted by the rehabilitation center where data were collected, and the Department of Social Development. Participants were given consent forms to read through and sign before commencing the interview and were allowed to seek clarity regarding issues pertaining to the study. They were made aware that they could withdraw from the study at any point. By so doing, the researcher ensured that participation was voluntary and informed. The researcher maintained respect and sensitivity towards the participants throughout the data collection.

#### **FINDINGS**

#### **Description of participants**

The demographic profile of the participants considered aspects like age, gender, the highest level of education, occupation, and marital status. Adult males (60%) and females (40%) with ages ranging between 19 and 56 participated in the study (See Table I adjacent). The popular substance of use was 'nyaope', followed by cannabis and other substances (KAT, rock, heroin, alcohol, nicotine and crystal meth).

#### **Themes**

Two themes emerged from the study and are illustrated in (Table II adjacent): (1) Enablers to quality of life; (2) Inhibitors to quality of life.

#### Theme 1: Enablers to Quality of Life

This theme shed light on the factors related to participants' quality of life; in essence, it describes the participants' perceptions of those factors which enabled their quality of life. The participants provided insights about their life satisfaction and self-concept as they shared their experiences about the occupations, they were involved in that brought about quality of life.

Employment and education were cited as occupations that brought a great quality of life for the participants as these two provided the participants with a sense of financial security. Financial security or the ability to make money came out strongly from the participants:

"It is work; it helps feed me and my family" (T5 G4).

"Financial security will help at home. (It gives) some sort of stability." (T7 L3)

The ability to provide for loved ones brought a sense of fulfilment and life satisfaction to those who were employed. Employment and education delivered the means to provide financially for loved ones and gave participants the improved life status that many of them aspired to. These two occupations thus furthermore improved the social standing of participants. People in their communities respected them because they were educated or had a job. They were not a burden to their family or society.

"...a job e ka thusa (it can help) 'cause I need money for a better life". (T17 J4)

"I really want to further my studies, because I want to make something of my life and be somebody." (TI K3)

The second category that emerged from this theme was support – family support, intervention received and spirituality. These three factors determined a sense of self-concept for the participants. Family for the participants played a vital role in recovery by keeping them grounded and giving them a sense of belonging and worth, as evidenced by the responses below:

"...family is what I grew up with, family, we are a family we stick together, cover each other. Weekends and during the week we're together, I would go from one to the other, I was surrounded by family." (T11 D7)

"... what makes me feel great is when my mother gives me support so that I can find a job." (T2 E2)

The participants identified the intervention at the rehabilitation centre, community support groups and the enhancement of activity participation as key. The participants saw the vital role of community intervention when discharged from the Centre. Activity participation, which is also critical in community occupational therapy, was reported as part of what brings about a quality of life:

"Because ja, it's just this challenge of support groups outside. Ja, it's a major thing really, and I think more people wouldn't be on drugs if there were things like that on the outside." (T7 L13)

"And there must be activities when you get out here, there must be where we can go to do some activities to learn something there, because we wasted a lot of time doing drugs and doing nothing". (T10 S11)

Spirituality is a form of support that the participants noted as an occupation that brought connectedness to a higher power. Participants drew strength and peace from the higher power and felt that there was a sense of resolution and change that could be found in that connectedness:

"Finding inner peace with God 'cause there are people coming in here [Centre] speaking to us about God" (TI K7). "...also going to church, so it [substance use behaviour] wants a person to go to churches to change." (T4 P8)

The third category in this theme was parenting. The majority of the participants that were interviewed were parents. They found meaning and purpose in this role because it required responsibility to their children. They realised that substance use made them unable to perform this role effectively, yet this role brought so much meaning to them.

"I want to be a good mother to my children like I used to be 'cause that is important' (TI K3).

"I neglected my child as a parent, and stopped giving him motherly love, I need to stop and be a good mother to my child, 'cause he needs me." (T6 B3).

Leisure participation was the last category of this theme. Leisure and recreation were reported as enhancing the quality of life of these participants because they were able to find themselves relaxed and learning something new, a skill that brought meaning.

"I would say gardening, I love gardening. It helps to keep my mind off stuff". (T9 A2)

"And there must be activities when you get out here, there must be where we can go to do some activities, to learn something there." (T10 S11)

It is therefore evident in this theme that participants drew on roles and occupations as what brought meaning into their lives. This is what brought about quality of life for the participants.

#### Theme 2: Inhibitors to Quality of Life

Participants reported on factors that hindered them from attaining optimal quality of life before admission in this theme. This brought to the researcher's attention how substance dependence affected the participants' quality of life. It was vital for the researcher to explore this with the participants, as it would aid them to find quality of life.

The first category of this theme was that of emotions, and from the data, the researcher established that the emotions were all negative. These emotions hindered the participants from experiencing quality of life, thus impacted negatively on their emotional wellbeing. Some of these emotions were stress-related, resulting in grief, anxiety, shame, failure, anger and regret. These emotions came at different times of the participants' dependence journey. Some experienced the emotions before commencing substances, meaning that the experienced emotion led them to use substances as relief or "cry out." For some of the participants, the emotions came after exposure to drug dependence:

"...in 2010 after finishing my matric I did not have money

to study further, it stressed me and that is when I started using nyaope." (T3 M4)

"I tried my best and I even failed in that [parenting role] (eyes watery, as if about to cry) so I lost a lot of contact with my children." (TI K4)

The second category was that of family breakdown. The family systems of the participants broke down because of their substance dependence. The participants shared how the loss of trust toward them from their family affected them. This lack of trust further led to poor relationships with their family members and in some cases, led to ineffective communication or estrangement. The self-worth they once derived from their family had also been lost due to negative behaviours emanating from substance dependence. Participants also cited poor parenting and poor communication due to substance dependence as they could no longer fulfil the parenting role and communicate effectively.

"My parents don't trust me anymore; even my sisters don't trust me anymore because of this drug". (T12 T6)

"It [substance] has affected me because I'm irritable then next I don't want to speak to them [family], the next I'm high and it's killing my mother to see me like that, but I think I'm fine and sometimes I don't even want to be with them [family] and just kept going for months on end. And it's [substance use] just debilitated the whole relationship." (T7 L6)

The third category of this theme was that of behaviours that influenced quality of life negatively, namely avolition of drug dependence, manipulation, and experimentation. Participants recognised these behaviours as having inhibited them from achieving quality of life. Concerning avolition, a key factor in occupational therapy, participants lacked the drive and energy to participate in their occupations as they were fully consumed by the "new-found" occupation of drug dependency. Participants found themselves having to use substances to cope with the demands of their occupations. The participants also manipulated their family, friends and colleagues for them to pursue their substance dependence. For many of them, experimentation was the behaviour that caused the start of the substance dependence journey.

"It [substance use] did affect me a lot, yoh! 'Cause where I used to work, I was working as a government employee, it means I was helping the community about these drugs. So I was not able to finish up my contract. I ended up leaving my work in the middle". (T5 G5)

"It has affected me a lot, because you can't do something else if you don't have the drug in yet, so I felt I need the drug every day to help me in life.". (TT K5)

Socio-economic circumstances posed a barrier to the participants in their recovery towards sobriety. The poor socio-economic circumstances that the participants found

themselves in inhibited their experience of a quality of life. Unemployment and poor finances were robust features in this category. The lack of money or a way of making money precipitated and perpetuated the participants' drug use. Emanating from this also was the behaviour itself of substance use, because when the participants found employment, their income was directed at buying and using more drugs. The quotes below attest to this:

"Uhm, not having a job I get bored and have nothing to do and there is no support group and finances." (T2 E5)

"Yes, I would be able to make 300% profit, but I did not see progress because of my addiction". (T8 Q4)

#### DISCUSSION

The participants' responses were mainly around their occupations and experiences of quality of life. Participants described their family relations as critical to their quality of life. They reported that their family members' opinions and perceptions of them defined their quality of life. The family included the immediate family they lived with, and for some, it was the family they had estranged themselves from because of their substance use behaviour. As De Maeyer et al<sup>49</sup> highlighted, family support and good family structure tend to influence the quality of life for participants significantly. Navabi et al<sup>50</sup> further report in their study that erosion of quality of life does happen to the individual using substances and the entire family unit. For this reason, their study found that the quality of life of the family was a strong determinant of the individual's quality of life and vice versa. The same finding applied to this study.

Employment was also a factor that came out strongly from the participants, as they indicated that with employment came the financial advantage that maintained their lifestyle and that of their family; hence, it brought about quality of life for them. Schnohr et al<sup>51</sup> conducted a study which showed a relationship between educational attainment, employment and substance use. They found that individuals with low or no educational attainment and unemployed showed lower quality of life. Regarding the education factor, it was mainly because the level of education allows them the opportunities to better their lives and seek better employment prospects<sup>51</sup>. It is evident in this current study that jobless participants with low educational qualifications had an inhibited quality of life.

Participants also perceived family support, involvement in support groups and spirituality to enhance their quality of life. Participants felt a sense of calm and hope regarding their spiritual affiliation. Heinz et al<sup>52</sup> conducted groups that discussed the influence of spirituality on substance use behaviour. In their study, they reported that most participants agreed that making spirituality a part of formal treatment assisted in their recovery<sup>52</sup>. The NA and AA groups use a 12-step programme that holds spirituality in high regard53. In this study, participants identified support groups (Narcotics Anonymous, South African National Council on Alcoholism)<sup>53</sup> as an essential part of their recovery upon discharge. One limitation that they mentioned was that their population was deeply spiritual. Spirituality, however, does not neces-

sarily have to do with the connection to a higher power only; spirituality is also an integral part of an individual's identity and well-being54. The Occupational Therapy Practice Framework recognises that spirituality can influence the clients' ability to cope, rehabilitate, connect with others and ultimately enhance quality of life<sup>54</sup> given that it reduces distress and enhances health and recovery. Jones et al<sup>55</sup> reported that occupational therapists play a vital role in addressing the interferences in wellbeing and quality of life by facilitating the spiritual coping strategies for clients to be restored and their sense of meaning and purpose gained. "Therefore, spirituality is considered as one of the significant elements of the holistic approach that promotes the health, quality of life and wellbeing of individuals, groups and communities in the South African context"<sup>56</sup> (p.16).

Concerning leisure participation, the participants viewed it as a means of learning a new skill and using their time more wisely. Chen and Chippendale<sup>57</sup> report that leisure should be viewed as an end goal of intervention in the occupational therapy practice, as this will enhance the health and wellbeing of clients. Furthermore, Mayasich and Tyce<sup>58</sup> also report on the importance of leisure as an occupation that enhances health and quality of life. This current study argues that occupation is vital to the substance user in enhancing the experience of quality of life.

The participants identified the inhibitors of quality of life as related to negative emotions that resulted from their substance use behaviour. Fooladi et al<sup>59</sup> reported in their study how an unhealthy emotional status exacerbated substance use behaviour and reduced quality of life. The negative emotions reported by participants in this current study made them experience a lack of control, leading them to use substances to numb the negative feelings they had.

The behaviours that arose from substance use behaviour inhibited the participants from experiencing a quality of life. Avolition, which was indicated by participants, reduced quality of life significantly. While dependent on a drug, the participants had neither drive nor purpose to participate in the various occupations and this caused a reduction in functioning. A study done by McLellan et al<sup>60</sup> reported that drug dependence is mainly a social problem that produces functional problems, influencing an individual's day-to-day functioning. In another study by Denis<sup>8</sup>, substance dependence impacted quality of life since the results showed that mental functions were impacted negatively, causing a barrier to the experience of quality of life.

Through the misuse of financial resources, participants experienced a reduction in their quality of life. The participants reported this as money wrongfully used to sponsor their addiction at the expense of their financial responsibilities in everyday life. Participants who lost their jobs found that lack of income drove them to substance use, leading to the inability to support themselves and their families, ultimately leading to a reduced quality of life experience.

It was therefore evident in the study that the factors that determined quality of life for the participants were their occupations (e.g., employment and education, social and leisure participation), and support (family support, intervention, spirituality). Occupational therapy intervention can contrib-

ute to enhancing the quality of life among substance users where family support and support groups aim to improve life satisfaction, self-concept, motivation and insight as well as to re-establish the roles of the participants to have quality of life after being discharged from the Center. Furthermore, the barriers to quality-of-life stem from the emotional status of the participants, their family dynamics (social interactions) and behaviours. It is therefore recommended that occupational therapy address the emotional wellbeing and motivation of substance users.

The limitations of the study dwell in the management and analysis of data, which was large in volume, and therefore time-consuming for the researcher. Another limitation was the challenge the researcher encountered in finding literature on quality of life in occupational therapy. Occupational therapy practice should focus on addressing the contextual factors leading to substance use to establish a holistic, context-specific and client-centred approach.

#### CONCLUSION

Literature has shown that substance use indeed affects an individual's life in many different ways. This study brought to the surface the participants' experience of the enablers and inhibitors of quality of life. Furthermore, it demonstrated the understanding that substance use inhibits quality of life because of the negative emotions that individuals with substance use disorders encounter. The participants also reported family breakdown, negative behaviours and poor socio-economic status as inhibitors of their quality of life in the occupations they found themselves in. The participants also shared the enablers of their quality of life, which included employment and education, which afforded them the ability to provide for their loved ones and maintain a good socio-economic status. Leisure participation enhanced quality of life as it provided a sense of relaxation and meaning to the individuals. Support in terms of family, intervention (support groups and occupational therapy intervention) and spirituality enhanced their quality of life because it provided satisfaction and wellness.

Therefore, the study found that participants described enablers and inhibitors to their quality of life, which influenced engagement in their occupations and experience of independence. The occupations (activities of daily living, instrumental activities of daily living, education, work, leisure, social participation, play and rest and sleep) in the field of occupational therapy form part of the occupational therapy domain. Therefore, the occupational therapist's role is of great importance when it comes to the rehabilitation of persons with substance use disorders.

Quality of life is also what occupational therapy strives toward for their clients. As such, the skills of occupational therapists are important for the full recovery of the client to sobriety. Therefore, the occupational therapist needs to provide a holistic approach to the individual's treatment programme. The intervention programme focusing on the enablers of quality of life will ensure quality of life is addressed in therapy. Therefore, engagement in occupation is as important as the engagement itself, therefore when these occupations are not engaged in, an individual will be deprived

of quality of life, which may lead to ill health.

Recommendations can therefore be made for more effective programmes in the treatment centers. These programmes should use an inter-professional collaboration that is impactful in holistically addressing the client's needs. Effective outpatient programs are essential for clients to be exposed to various concepts like prevention strategies, psychoeducation for the caregivers/family, and the critical acquisition of life skills. Aftercare programmes are essential in establishing successful reintegration into society and further assist in relapse prevention.

#### **Author contributions**

Marusa L Lefine and Ramadimetja A Lesunyane conceptualised and operationalised the research project. They collected and analysed the data and wrote the journal article.

#### **Conflicts of interests**

The authors have no conflicts of interests to declare

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# Occupational enablement through the Crosstrainer programme: Experiences of early childhood development practitioners

#### **ABSTRACT**

**Introduction:** In rural South Africa, inadequately trained Early Childhood Development practitioners and inequity of access have been placed as top priorities to address. Enabling occupation is the primary goal and core competency of occupational therapists and supporting the services of ECD practitioners may address these problems. The Crosstrainer Programme aims to do this by training and equipping ECD practitioners. ECD practitioners were therefore approached to reflect on the occupational enablement through the Crosstrainer Programme.

**Method:** Demographic questionnaires and semi-structured interviews were utilised. The data were analysed through the cyclical process of coding.

**Results:** Three major themes emerged from the data analysis, namely The Great Imbalance, Enabling Occupation, and Disabling Occupation. The participants expressed the difficulty of fulfilling the need for their services in their communities. The CTP relieves these difficulties and enables the work of ECD practitioners through increased knowledge, confidence, creative alternatives to resources, and guidance in managing their time, incorporating all six enablement foundations. The CTP disables their occupation of work through the language barrier, unclear scaling of the activities, and insufficient involvement. **Conclusions:** The CTP enables the occupation of the ECD practitioners and the children. Through translating the programme, adding more activities, and increasing involvement and mentoring, enablement through the CTP will improve.

#### INTRODUCTION

Currently, in South Africa, it is recognised that rural areas are deprived of essential Early Childhood Development (ECD) services<sup>1</sup>. The South African ECD sector has been experiencing inequity of access to good quality early learning programmes, which creates a distinct disadvantage and school-readiness gap for children from poorer communities or low-level income families<sup>2-3</sup>. Consequently, quality early learning opportunities for all South African children have become a top priority<sup>2</sup>.

Therefore, the National Integrated Early Childhood Development Policy, a relatively new policy in South Africa approved by the Cabinet in December 2015, mandates the provision of ECD services as a right of all children without discrimination. The long-term goal aims to provide a comprehensive, developmental stage-appropriate ECD package providing necessary services to reach the Constitutional rights of South African children and their holistic development<sup>2,4</sup>. However, many children and ECD practitioners in rural areas may still have difficulties to access such opportunities<sup>3,5</sup>. Consequently, it is critical for different departments to collaborate in addressing this inequity<sup>1-3</sup>, predominantly from the private and non-profit sectors, until such time as the governmental policy has been fully implemented<sup>1,4</sup>.

Being a change agent is attributed as a central role and proficiency of occupational therapists6. Occupational therapy recognises a broader global and social responsibility towards the issues of inequity and poverty, as it has the potential to benefit both the wider society and the individual7. Becoming involved in the ECD change is therefore imperative for South African occupational therapists.

Moreover, the programmes utilised have to be of good quality<sup>1</sup>. This is reached through increased training of and support to ECD practitioners<sup>1-2</sup>. In South Africa, an ECD practitioner is defined as someone trained formally or informally to provide early learning services and childhood development in an ECD centre to children from birth to school-going age8. However, South African ECD practitioners, especially in rural or low-socio economic areas, have been deemed inadequately trained<sup>1</sup>. Therefore, the training of these practitioners has been established as an essential component towards an improved ECD sector<sup>1</sup>.

The need for more, trained ECD practitioners enthused the Crossroads Educational Foundation, a Non-Profit Organisation (NPO), to invest in Early Childhood Development in South Africa9. Consequently, the organisation developed and established the Crosstrainer Programme (CTP) in order to train and equip ECD practitioners. The CTP is an ECD centre-based programme providing early learning stimulation for children from three to six years of age in rural African, especially South African, areas9. It consists of a systematic guide (set of books) with daily, age specific, zero to low-cost activities, which were derived from basic occupational therapy knowledge to ensure that all the critical stages of ECD are covered and a foundation for future learning accordingly secured<sup>10</sup>. The books are designed for ECD practitioners in the rural setup to simply follow, implement and adapt where necessary. It aims to empower the practitioners to provide the essential early learning services and childhood development in their ECD centres for the children and ultimately address the issue of inequity and access<sup>3,9</sup>.

For occupational therapists, a social responsibility towards the issues of inequity and poverty is recognised, as occupational therapy has the potential to benefit the wider society as well as the individual7. And occupational therapy enablement is not only limited to individuals with impairments but aims toward health, well-being, and justice for individuals and the human population through occupation<sup>6,11-12</sup>. Therefore, becoming involved in the change of the South African ECD sector, is also the responsibility of occupational therapists. This central role of the occupational therapist within the community has evolved to become a core rather than subordinate focus and greater emphasis is placed on prevention, public health promotion and community development in the South African health care context<sup>13</sup>. Even within the community, occupational therapists focus on occupation as the core domain of concern. Being a change agent for the ECD sector and specifically these ECD practitioners include focussing on their occupation and the enablement thereof

Human occupation is considered the core domain of concern in occupational therapy<sup>11-12</sup>. In occupational therapy, occupation is an ever-evolving term and has further been refined to much more than a career or activity in which people engage. Occupation is essential to all people as humans are born as occupational beings. It also possesses potential therapeutic value 12,14,15. It refers to every activity or everything humans engage in their daily living and is essential to promote health and well-being which in turn also describe who a person is and how one feels about oneself16.

Enabling occupation is the core competency and primary goal of occupational therapists<sup>11-12</sup>. Any person, thing, or environment can essentially enable or disable occupation. In occupational therapy, enablement encompasses more than providing opportunities, simplifying, or assisting. Occupational therapy enablement goes beyond the enablement of everyday life12. This enablement aims toward health, wellbeing, and justice for individuals and the human population through occupation<sup>6,11-12</sup>. Therefore, occupational enablement for the ECD practitioners relates to more than occupation as a career, but as a daily activity they partake in as an individual, directly involving their immediate communities.

In the context of occupational therapy, there are six foundations of occupational enablement, which were coined and defined by Townsend and Polatajko in their publication of 'Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Well-being, & Justice through Occupation'12. Each foundation is described briefly in Table I on page 75:

Human occupation and the enablement thereof are best investigated within occupational therapy enablement because it forces critical reflection and accounts for multiple perspectives, inequities of power, and diversity<sup>12</sup>. Therefore, these six foundations as seen in Table I (page 75) were used to describe the enablement of the ECD practitioners' occupations, as derived from their experiences incorporating the CTP. Within the South African ECD sector, enabling the occupation of the ECD practitioners through training, mentoring, and providing support will play a major role in transforming the ECD sector. Additionally, these strategies will support the efforts of the South African government and other organisations towards this improvement. The CTP could be a possible instrument towards providing such training and support. Allowing the ECD practitioners to reflect on their experiences of the CTP and the occupational enablement thereof could give more understanding on this, given the reflections are appropriately disseminated.

#### RESEARCH METHODOLOGY

The purpose of the research is to describe the experiences of the ECD practitioners regarding the occupational enablement through the CTP. No prior research has been done on the perceptions of the ECD practitioners concerning the CTP nor the enablement thereof. Therefore, this study was aimed at obtaining rich, descriptive data by collaborating and generating knowledge with a sample of ECD practitioners using the CTP.

#### Research paradigm

The constructivist paradigm was used, which allowed the researcher to generate knowledge together with the participants. 'Truth' is therefore constructed by the personal experiences of the participants and then transposed by the researcher. A certain sense of subjectivity and the personal voice of the researcher are evident in this paradigm and should not be ignored or denied<sup>17,18</sup>.

#### Study design

A Descriptive Qualitative research design was utilised with supportive quantitative demographic data to gain rich, descriptive data.

Table I: Townsend & Polatajko's Six Occupational Enablement Foundations

Enablement foundation	Description
Choice, risk & responsibility	This is regarded as a right of clients and a prerequisite for enablement. It is the therapist or service collaborating with the client/person to allow them to make choices, take risks and share the responsibility within their occupations, activities and their therapy intervention programmes <sup>12,13</sup> .
Client participation	An essential feature of enabling occupation that promotes the involvement of the client in each process towards enablement. Clients are therefore included and entitled to participate in the decisions regarding any intervention towards enabling occupation <sup>11-12</sup> . It is further necessary to facilitate the knowledge and skills necessary to participate in decision-making and problem solving <sup>13</sup> .
Visions of possibility	A result from the realisation of improvement. Possibilities of improvement inspire people to engage and perform, beyond their previous expectations. This includes engaging in occupations and participating in their communities or society. In turn, these possibilities are anticipated to prompt the client to making new choices, taking greater risks and more responsibility that were previously unthinkable. Eventually, visions of possibility challenge reality and embrace new opportunities and prospects. The perception that change is impossible is therefore refuted <sup>12</sup> .
Change	This refers to change directed at enabling the occupations in various clients, whether superficial and undetectable or radical. Change is often influenced by vision of possibilities and also brings upon new perspectives on life. Consequently, clients' identities as individuals, family members, and representatives of groups, communities, organisations and populations are ultimately transformed <sup>12</sup> .
Justice	As an occupational enablement foundation includes recognising inequity, welcoming diversity, and advocating a belonging to society, embracing a holistic view on people's environments and occupations <sup>11-12</sup> .
Power-sharing	Emphasises a commitment to client-centred collaboration. Clients should know that they share power with their therapist. They should be given opportunities and resources, which allow them to make choices about their occupations and occupational therapy. Power-sharing involves mutual respect which in due time encourages clients to freely develop and live out their talents and capabilities <sup>11-12</sup> . Though generated from an occupational therapy discipline, these enablement foundations may be applied to a wider scope <sup>13</sup> .

#### **Unit of analysis**

The study population included ECD practitioners situated in the Mafikeng Rural area who have received training in the CTP. The total population of ECD practitioners trained in the CTP in the Rural Mahikeng Area is 37. Non-probability, purposive (judgmental) sampling<sup>18</sup> was used to approach all the ECD practitioners who met the following eligibility criteria:

- The ECD practitioner had to have been trained in the CTP.
- ECD practitioners from the same training dates, therefore excluding any variations in the CTP training.
- The ECD practitioner had to have had at least six months' experience in practice with the CTP to promote integrated perceptions within the discussion. This was to ensure that the practitioner had had ample time to engage with the CTP and would therefore be able to have reached opinions and experiences to bring across in the interviews.
- ECD practitioners of all cultural groups within the specific population were included in the study.
- ECD practitioners who comfortably spoke and understood English and/or Setswana were included. The service of a translator was offered to any participant who may have preferred to conduct the session in Setswana.
   ECD practitioners were excluded from this study if any of

Nine ECD practitioners met the inclusion criteria and completed the interview, questionnaire, and member checking processes. No data saturation point was reached <sup>20</sup>. Pseud-

onyms were allotted to the final nine participants.

Table II (page 76) presents a general description of the participants as obtained from the questionnaires.

As Table II (page 76) reveals, all the participants were female with the median age of 43. Only three of them graduated high school, of which two completed tertiary qualifications, specifically diplomas. Five had completed some ECD level training, of which only two completed all five levels. Four participants had ten years or less experience and the remaining five had more than ten years of experience as ECD practitioners.

These ECD practitioners were distributed over eight ECD centres as two participants were from the same ECD centre. Table III (page 76) presents a general setup of the ECD centres, as described by the ECD practitioners

From Table III, it can be deducted that their ECD centres varied in building types, number of classes, availability of resources and equipment, yet marginally similar environments. Therefore, these ECD centres were concurrent with the description of typical rural South African ECD centres<sup>3,9</sup>.

#### Data collection and management

#### Data were collected through two methods:

A **questionnaire** presented in English and Setswana was completed by the participant right before the interview commenced. The questionnaire aimed at collecting demographic information in order to describe the participants' context in detail. Most of the information generated from

the above criteria was not met.

Table II: General description of the ECD practitioners

Pseudonym	Age	Gender	Schooling (Highest grade passed)	Tertiary qual.	ECD level training	Duration as ECD practitioner
Anna	60	Female	Grade 9/Std 7	None	None	6-10 years
Betty	43	Female	Grade 11/Std 9	None	None	6-10 years
Cathy	37	Female	Grade 11/Std 9	None	Level 5	11-15 years
Dora	41	Female	Grade 11/Std 9	Diploma	Levels 1-5	More than 15 yr.
Edith	52	Female	Grade 12/Std 10	None	Level 5	11-15 years
Frieda	52	Female	Grade 8/Std 6	None	Level 4	More than 15 yr.
Grace	42	Female	Grade 12/Std 10	None	Levels 1-5	11-15 years
Hester	55	Female	Grade 12/Std 10	Diploma	None	6-10 years
Irene	41	Female	Grade 9/Std 7	None	None	0-5 years

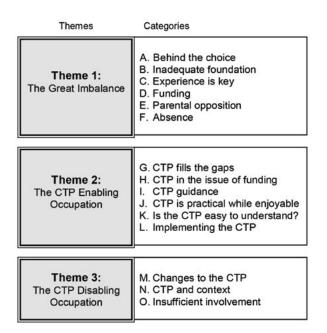


Figure 1: Layout of the themes and categories

the questionnaire was used to describe the population in the previous section.

**Semi-structured interviews** were held with each participant. During these interviews, the experiences from the participants were elicited by having face-to-face discussions. An interview protocol<sup>21</sup> was formulated to guide the structure of the interview, whilst allowing for a semi-structured interview process. The interviews were recorded with the help of two voice recordings to capture both the English and translated questions and answers. These were copied to an external hard drive after each day of interviews to ensure safe storing. Data from the transcriptions were coded and analysed with the help of one co-coder. Side notes were taken during the interviews for personal use to assist with referring to specific moments in the interview<sup>21</sup>. These were filed for safekeeping.

The process of member checking (participant review or validation) occurred once all the statements were summarised and presented during a brief follow-up interview

with each of the nine participants, which was recorded and transcribed. Consensus was reached with each participant during this process<sup>21</sup>.

### Data analysis

The data received from the interviews were analysed using a flexible, yet widely used process namely, thematic analysis<sup>22</sup>. The process of coding was done manually by two of the authors. As coding is a cyclical process rather than linear<sup>22</sup>, two coding cycles were employed, allowing for coding, recoding, and comparing. For the first cycle of coding, a Descriptive coding<sup>22</sup> method was used to create an inventory of the data, from which patterns and reoccurring topics were created. As this method does not necessarily allow for much insight into the participants' thoughts, a second coding cycle was conducted using Pattern Coding 22. This was used to cluster similar codes into pattern codes, which formed valuable codes for recognising emergent categories and themes.

The demographic information obtained by the questionnaire was analysed by the University of the Free State Department of Biostatistics to calculate descriptive statistics for continuous data. Frequencies and percentages were calculated for categorical data.

### **Trustworthiness**

In this study, multiple strategies were used to ensure trustworthiness. The translator of the documents and interviews holds a BA Education and Setswana degree, has over 15 years of experience in ECD and is qualified as a registered nurse. External reviewing by an external critical reader <sup>21</sup> and the involvement from the Education and Research Committee of the School of Allied Health Professions of the University of the Free State. Furthermore, member checking, prolonged engagement with the participants, using a thick description and keeping an audit trail further increased trustworthiness in this study <sup>21</sup>.

### **Ethics**

Ethical approval was received from the Health Sciences Research Ethics Committee of the University of the Free State (HSREC 67/2017, dated 19 June 2017). Informed consent was received from the participating ECD practitioners and

Table III: General setup of the ECD centres

ECD	Duilding ton	Number of	Equipment	Running water <sup>f</sup>
centre	Building type	classesd	available	
1	Shack/makoekoea	2	No	Yes
2	Concrete building <sup>b</sup>	4	No	No
3	Shack/makoekoe	2	Yes	Yes
4	Church building <sup>c</sup>	4	Yes	Yes
5	Concrete building	2	No	Yes
6	Church building	1	No	No
7	Shack/makoekoe	2	Yes	Yes
8	Concrete building	3	No	Yes
a. b. c. d. e.	Shack/makoekoe: informal build Concrete building: well-structure Church building: typically on ch Classes: children grouped acco Equipment available: basic equ	ed buildings made of concre urch properties or even part rding to their age, each gro	ete t of the church building itself up with their own ECD pract	itioner
f.	Running water: when there is no running water, they have to fetch water at a central water point			

their ECD centre principal. Participants were allotted pseudonyms and all their information has been kept confidential.

### **FINDINGS**

Three major themes emerged from the cyclical process as discussed in the data analysis section. These were formulated as the Great Imbalance, the CTP Enabling Occupation, and the CTP Disabling Occupation.

Each theme and category from Figure 1 (page 76) will be briefly discussed below with quotes from some of the participants.

### THEME 1: THE GREAT IMBALANCE

The Great Imbalance summarises the difficulties experienced by the ECD practitioners during the process. This theme is aimed at portraying the imbalance between the ECD practitioners' love and passion for children and the difficulties they experience in their occupation of work.

**Category A:** Behind the choice of becoming ECD practitioners for the majority was the love and passion they have for children. They noticed a need in their communities for children to be cared for, kept safe and educated and felt the urge to take responsibility. It is due to their love and passion that they endeavoured to becoming and growing as ECD practitioners but they face many hindrances in doing so.

"My favourite part of being a practitioner is because I love children; I have a long heart [laughs]." (Cathy)

"I cannot live without kids; that's my life. So being a practitioner is a call. I am not here by mistake... I've never used ECD as business; I use it as my life." (Dora)

"...the kids need someone to look after them. So, to us, we are just going to look after these kids... but it started from that love." (Anna)

**Category B:** One of the hindrances mentioned by the majority of participants was having an *inadequate foundation* as ECD practitioners. They explained that they felt they had a lack of knowledge and felt unqualified to be ECD practitioners due to their background.

"I never dreamed that I would be a teacher because of my background, you know, less qualified." (Anna)

**Category C:** Additionally, they explained that *experience is key* and that often only after years of experience do they feel confident enough in being ECD practitioners.

"Right now, nothing is difficult 'cause what I'm doing it's what I've already done before." (Cathy)

**Category D:** The barrier of *funding* posed another issue disabling their occupations, their biggest challenge being the parents not paying the fees for the children to attend their ECD centres. This causes stress for the ECD practitioners, as they are dependent on the monthly fees to buy materials, equipment, and food for the children.

"Because I'm working with the parents in the rural area and then the payments starve." (Grace)

"Sometimes they bring the children, they don't bring the money for the school fees. That's the challenge." (Edith)

Category E: On top of slacking on payments, parental opposition was also mentioned as a frustration for the ECD practitioners as some participants explained that they often experience high expectations from parents whilst not receiving their monthly payments. This often results in the wanting to guit, but their love for the children motivates them to press on regardless.

"...most of the time parents are difficult... You can find other that are on the same page as you...what would make me say 'ai, ai, I'll quit this crèche'. But on the other side, I feel for other children who their parents don't have that difficulties." (Cathy)

Category F: The absence of the children results in low progress of their development. Many children had a poor attendance at the ECD centre due to various reasons and consequently a low understanding of the work.

It is difficult when I am teaching and a child stays away from school. The child falls behind and stays behind through the year, which reflects badly on me. (Paraphrased by translator - Frieda)

This theme shows how the ECD practitioners constantly need to overcome barriers to live out their passion and to take responsibility for the needs of the children. The following two themes are aimed at portraying how the CTP may enable or disable their occupations as experienced by the ECD practitioners. The findings will be discussed briefly for each theme.

### THEME 2: THE CTP ENABLING OCCUPATION

This theme looks at how the ECD practitioners found the CTP enabled their occupation. Many of the hindrances discussed in the previous theme were actually addressed in some way by the CTP.

Category G: It was found that the CTP fills the gaps mentioned in the previous theme by giving them more knowledge, fuelling their growth as ECD practitioners and consequently boosting their confidence. Some participants also mentioned that they received positive feedback from the parents since implementing the CTP in their ECD centres.

"So 2015, after using these books [CTP], there was light now and I started realising, seeing my way forward." (Irene)

"Since I met the CTP I am brave enough to do the things that I never thought I would do, the things I never thought I knew how to do." (Dora)

**Category H:** The participants expressed that the CTP has helped regarding the issue of funding in two ways. Firstly, that the CTP modified the way they thought about equipment and activities by guiding them to make their own or improvise with what they have. Secondly, that the CTP was in most instances the only equipment they needed, as they only have to implement the daily activities from the lesson

plans using the supportive materials in the books.

"Yes, it has given me different ideas..." (Edith)

She said, before she started with the CTP she had to get a lot of things. But since she started with CTP, she's got everything. Everything is just compact (Indirectly translated - Hester)

Category I: Additionally, the guidance given by the CTP assisted the ECD practitioners through directing their lesson plans and time management, in turn lightening their workload.

"I helped me about how to plan, lesson plan." (Grace) "It leads me, gives me direction where to go." (Dora)

Category J: Some participants also mentioned how the CTP is practical while enjoyable.

"It helps me a lot with activities... we read there, then we do the practical...and it's enjoyable."(Edith)

Category K: According to the ECD practitioners the CTP was easily understood, as the CTP was easy for them to implement and easy enough for the children to understand the content.

"...it [CTP] gets easily into children." (Cathy)

Category L: Simply implementing the CTP also positively affected them to taking more responsibility and even taking initiative to add to the CTP activities.

"So it pushed my responsibility that I have to focus on my work." (Grace)

From these categories, it can be seen that the CTP enables their occupations especially by bringing solutions to what they would generally find hindering them.

### THEME 3: THE CTP DISABLING OCCUPATION

In constructing this theme, disabling factors were derived by the changes the participants wanted to see in the CTP as well as other problems they brought up during the interviews. The three categories that emerged were:

Category M: Some mentioned changes to the CTP they would like to see, which included translating the CTP to Setswana (as it is only available in English at this point) and adding more pictures for them to use. However, it is important to note that the majority of participants explicitly said the CTP did not need to change in any way.

"No, now I just think that if the books can be... some of it must also Setswana. I think it's easier." (Anna)

"In most cases, almost every day I'm teaching the themes. Sometimes it becomes more difficult when I don't have

material. Then, at least, if I can have some picture or get something, it can make it very simple." (Dora)

"No, according to my observation, I don't think should change." (Grace)

**Category N:** This further stirred the question of the CTP and context. The fact that the books are only available in English is a disabling factor as most children's home language is Setswana in that area and the primary schools expect ECD centres to teach the children in Setswana (main language in the area). As a solution, they opt to translate the lessons themselves.

"...because if you keep teaching them English, to them at the end of the day is hard at school." (Anna)

"I translate it in Setswana for them and they understand." (Edith)

Two participants mentioned that they found the demand on the ability of the children too high and that they had to adapt some of the lessons for the children.

**Category O:** Lastly, the participants expressed that they feel the *insufficient involvement* from the CTP hindered their occupation. This was evident as some explained their need for more regular monitoring, more assistance with administration and more opportunities for other ECD practitioners to be trained as well.

"I just think this CTP can make like more time for us; they can workshop us again... all teachers must go there..." (Betty)

"...it doesn't mean I'm stuck if you don't come. It's just; I get strength when someone comes...even if you can just call." (Dora)

"...Yes, even if you can just phone." (Anna)

It is clear that the language and the limited involvement from the CTP are the major disabling factors in this theme.

### DISCUSSION

### THE GREAT IMBALANCE

It was apparent throughout this theme that the participants truly chose to become ECD practitioners due to having a love for children, calling it a passion, not only a career choice. Moreover, they recognised a need in their communities for a safe place for children to grow and develop and that their ECD centres provided that safe place. This correlates with findings from other studies<sup>23-25</sup> and links with the occupational enablement foundation of justice, advocating a belonging and participating in society<sup>12</sup>.

However, the participants shared significant inequities they experience as they endeavoured in doing what they are passionate about, being ECD practitioners, becoming competent, and belonging in their communities. They felt hindered

by their inadequate training, limited experience, personal background, financial barriers, parental opposition, and low attendances. Therefore, when considering the enablement or disablement of their occupation, it needed to be in light of these hindrances.

### THE CTP ENABLING OCCUPATION

Enabling occupation refers to providing the necessary opportunities and means for individuals, groups and communities to shape their own lives and enable their occupation<sup>12</sup>. The CTP uniquely enables the occupation of work in a few ways and according to the ECD practitioners, the CTP brought solution to most hindrances mentioned in the first theme. The enablers are discussed in light of the six occupational enablement foundations as previously defined.

The CTP encouraged the ECD practitioners to make their own choices, take new risks or transcend existing risks, and to take responsibility in their ECD centre and the lessons12. The ECD practitioners are encouraged to adapt the CTP activities to suit their context and means. Implementing the CTP resulted in them being drawn in to be actively involved and taking more responsibility. This was increased even more as they were given necessary skills to participate, which in turn promoted more participation from the ECD practitioners<sup>12,13</sup>.

Visions of possibility<sup>12</sup> increased by the CTP through availing knowledge, boosting their confidence, fuelling their growth as practitioners, and modifying their thinking on the equipment that is necessary for activities. Since the CTP, they have believed themselves to be capable of doing previously unthinkable tasks, mastering their skills, and embracing new opportunities. These necessary changes<sup>12</sup> enabled their occupation.

The CTP strengthens their belonging in society as ECD practitioners by increasing their knowledge and confidence, alleviating the issue of funding, and guidance. Providing guidance through directing lesson plans and time management and in turn lightening their workload, a unique but contextually specific way of pursuing justice<sup>12</sup>. Power-sharing was evident throughout the interviews as they shared that they were able to implement, adapt and change where necessary and therefore collaborate with the CTP in the process of teaching the children<sup>12</sup>. Although they enjoyed much autonomy in practice, it is in light of their minimal resources and limited assistance from the government that qualifies this collaborative approach as enablement. Furthermore, in another study it was found that following a generic ECD curriculum would achieve very little if anything at all<sup>23</sup>.

Therefore, the CTP contributed through all the enablement foundations to the enablement of their occupation as ECD practitioner.

### THE CTP DISABLING OCCUPATION

Just as anything or anyone could potentially enable occupation, this much is true towards disabling occupation12. To disable also refers to preventing, restricting or even discouraging a person from doing something26. The term disabling occupation was also coined and defined by Townsend and Polatajko<sup>12</sup>.

From the findings it can be seen that the CTP hindered the

occupation of the ECD practitioners in two ways.

The first is regarding the alignment of their context, particularly concerning three aspects: not having the CTP in their main teaching language, the level of difficulty of some of the activities, and the need for more visual aids or pictures in the lessons. Although the minority of participants mentioned these aspects, it is still important to note as a disabling factor.

The second disabling factor was their experience of insufficient involvement from the CTP, specifically regarding these three aspects: minimal monitoring, the need for more administrative help, and seldom opportunities for training. The participants expressed that they need more regular monitoring, administrative assistance and opportunities for training from the CTP. This correlates with other South African programmes and organisations <sup>27, 28</sup> also involved in training ECD practitioners, as they practise a higher level of involvement through more regular follow-ups, administrative aid, and regular training.

It was also found from numerous other studies and ECD programmes that increased levels of monitoring positively affects the fidelity of the ECD practitioners and therefore the efficacy of the programme<sup>23,27,28</sup>.

### Limitations of this study

Three limitations occurred in this study, which could otherwise have potentially added additional information and depth to the study. The first is that the culture of the participants was not explicitly considered during the research process, limiting contextual description. The second was that during the conduction of the interviews, the participants preferred to speak English instead of their home language, which may not have rendered the potential depth of discussion in some cases. The third is not taking field notes, which could have contributed to a thick description.

### Recommendations

Further research is recommended on the CTP, occupational enablement, and the South African ECD practitioners. This could include conducting a similar study on a wider population in South Africa, a comparative study on the occupational enablement from different ECD programmes, a study on the occupational enablement of the CTP on the occupation of the children, a study using PAR (participatory action research) towards developing a tailor-made programme for each ECD centre.

Based on the findings and the experiences of the ECD practitioners, I would like to render a few recommendations that could improve the CTP: adding more pictures in the CTP books, increasing administrative assistance, training opportunities and monitoring, and translating the CTP to the main educational languages of South Africa.

### CONCLUSION

The ECD practitioners painted a picture of the great imbalance as they want to fill a need in their communities because of their passion for children, but are hindered by feelings of inadequacy, the reality of their backgrounds, finances, and cooperation from the parents of the children. The participants mentioned how the CTP has given them more

knowledge, confidence, creative alternatives to resources, and guidance in managing their time.

The CTP mainly disables their occupation by not having the programme available in their main teaching languages, by feeling unsure on how to scale lessons, and insufficient involvement from the CTP. These can simply be bettered by investing in translating the programme, adding more options to the activities, and increasing the level of involvement.

In conclusion, upon implementing these necessary changes, the CTP is a valuable programme towards the occupational enablement of South African ECD practitioners and the children in their centres.

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Adeleigh Homan conceptualised and completed the research for a master's level postgraduate degree in occupational therapy. Santie van Vuuren and Danette de Villiers were supervisors and contributed with the conceptualisation, supervised the data gathering and analysis, drafting, revision and completion of the article.

### **Conflict of interest**

During the time of conducting the study, the corresponding author was appointed by Crossroads Educational Foundation to investigate the efficacy of the Crosstrainer Programme. This was not to prove the value of the CTP, but to discover both the value and the limitations of the programme.

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# Brazilian occupational apartheid: historical legacy and prospects for occupational therapists

### **ABSTRACT**

**Background:** Since the colonization of Brazil in 1500, systemic, institutional, and relational racism has produced inequalities for its black and indigenous people. This legacy perpetuates white supremacy and intensifies social inequalities.

**Purpose:** This Opinion Piece aims to raise reflexivity on racism in Brazil and its impacts on the occupations of black people within the context of occupational apartheid.

**Key issues:** We start exploring social justice and occupational justice concepts to map a methodological path for the theoretically informed discussion. Then, we discuss the concept of collective occupations as a possibility for intervention in the face of racial inequalities and introduce some occupational therapy practices to exemplify strategies to tackle the identified challenges.

**Implications:** We conclude by showing that the field of ethnic-racial relations is still only minimally explored in Brazilian occupational therapy. We also point out some possibilities for further studies in the area.

### INTRODUCTION

This piece reflects on the body of ethno-racial studies in Brazil, considering the impact of racism in different occupational areas for black communities. Racism can occur on at least three levels and actions, namely: systemic racism, that which structures society and creates unequal conditions in various spheres of social life; institutional racism that occurs within organizations and institutions and that offers unequal possibilities in the access and enjoyment of products and services; and, finally, relational racism that happens in the context of interpersonal relationships and refers to values and beliefs internalized by each person¹. With an understanding that racism is a problem that affects the black and indigenous Brazilian population and produces inequalities and daily deprivations in life, we reflect on occupational justice and racism in the Brazilian context through the experiences of occupational therapists working with the black population.

In the first part of the text, we present a historical-social overview on how racism was instituted in Brazil by the Portuguese invasion and the enslavement of black Africans. We highlight the myth of racial democracy and veiled racism. We then discuss aspects of the concepts of social justice and occupational justice, considering how these concepts have been incorporated into Brazilian occupational therapy. In the third part, we approach the concept of occupational apartheid, linking the processes of racially informed exclusion in Brazil to their impact on the occupations of black people. We then present occupational therapists experiences with black populations to demonstrate opportunities for action in the face of racial inequalities. Finally, we recommend an antiracist plan, for the future, identifying perspectives for occupational therapists to be actively involved.

### **Racism in Brazil**

Directly influenced by a mythological/ontological perspective of a superior race, the central countries of Europe inaugurated the theft of lands beyond the Atlantic, aiming to expand their civilization ideals and fortify their space of power<sup>2</sup>. Ways of understanding and organizing society are initiated through excluding previous power structures, aiming at the hegemony of the colonial nations<sup>3</sup>. Colonialism was consolidated in

a system of ideological, political, and economic domination of natural resources and enslaved labour, subjugating indigenous and black populations, and strengthening white supremacy<sup>4</sup>. Ideological discourses of social functioning were (and still are) produced in forged societies, implying patterns of civil normality that are aligned with the white male European, bourgeois, hetero-cisnormative, Christian, urban, and ableist profiles <sup>3,4</sup>.

Achille Mbembe<sup>5</sup> reflects on the mechanisms of colonial power, which operate for the deprivation of humanity of nonwhites in everyday relationships, reducing them to indignation and death. As well, the access to opportunities for these racial groups is denied, on the grounds that they are incapable and inferior. Mbembe<sup>5</sup> defines this process as necropolitics. In the case of the Brazilian State, several forms of control, values, rules of sociability and policies are instituted to legitimize conditions of subordination and/or massive elimination of blacks as a legacy of the colonial paradigm. The social norms are upheld and disguised by meritocratic perspectives which govern a kind of "naturalized inferiorisation" of people of colour. Brazilian racism organizes social relations, reinforcing a system of focus on the wealthy, determining social classes, and racializing everyday life. As a result of this social-historical development, the servile characteristics of subaltern classes are imposed upon, become naturalized<sup>6</sup>. Dependent on a strong hierarchical and classificatory model of social organization arising from the Iberian region, racism in Brazil presents itself as a fundamental pillar for the construction of a progressive nation. This organization model mirrors and is aimed at the example of prosperity and well-being of the great metropolises, conveyed by a rigid hierarchy of races<sup>4,7</sup>.

According to Campos<sup>8</sup>, the concepts around racism in the social sciences originate from different theoretical frameworks based on ideologies, principles, and structures that attempt to understand the phenomenon in its entirety. The proponents of these frameworks do not always build on, or consult with, each other, resulting in a fragmented body of scholarly work. However, even with these differences, Campos highlights that "each racism can only be understood from its own history" (Guimarães apud Campos<sup>8:2</sup>, original in Portuguese).

To understand this phenomenon in the Brazilian context, we turn to Lélia Gonzalez, a Brazilian scholar who suggests the term "Brazilian-style racism" to explain racist practices in the country and differentiate it from other nations<sup>4</sup>. Racism in Brazil comes from a colonization strategy through which the colonialists encouraged and justified the internalization of racism, naturalizing it to guarantee the perception of the superiority of the colonizer over the colonized<sup>4</sup>. As proof of the success of this tactic of oppression, Brazilian racism presents itself in two ways: open, which would be the guarantee of racial purity through the explicit segregation of non-white groups; and disguised or by denial, characteristic of Latin American colonies, in which theories of miscegenation are encouraged to achieve ethnic cleansing through whitening<sup>4</sup>. Racism by denial is the most sophisticated and perverse way

of keeping non-white peoples in a subordinate position, as it guarantees alienation through the naturalization of the whites as a dominant group and the non-whites as inferior. It also guarantees the confusion of national identity and subjectivities with the desire to 'whiten', in which the blacks begin to deny their own ethnic identity<sup>4</sup>.

From the country's desire to achieve Eurocentric modernity in the mid-19<sup>th</sup> century, miscegenation became a problem for the state, which, through scientific, naturalist, positivist and evolutionist postulates, would distinguish terms of 'black' and 'indigenous' as differing elements<sup>7</sup>. At the turn of the 19<sup>th</sup> to the 20<sup>th</sup> century, when ideas of non-white people as belonging to Brazilian society took place, miscegenation became strengthened as an affirmation of national identification in the fusion of the three races, although always keeping the whites in a superior position<sup>7</sup>.

These excluding and dichotomous configurations around ethnic-racial elements cement the constitution of Brazilian society. In summary, the denial of racism in Brazil was and still is a political project of institution and control of national identity, aiming at a progressive ideology of modernity. Based on supposed racial equality denunciations of oppression motivated by race and the struggle for black protagonists are concealed through the eugenic precept that all citizens enjoy the same rights, while the granting of social privileges falls truly only to whites<sup>4,6</sup>. According to Florestan Fernandes<sup>9</sup>, an important Brazilian sociologist, after the abolishment of slavery, the black population was left to fend for themselves, without remedial public policies, income sources, housing support, education, and any other resources for attainment of basic human rights.

Concerning social and political participation, even after the abolishment of slavery, in 1888, blacks were denied the right to vote. Although the Brazilian Constitution of 1824 did not prevent black people from voting, there were strict rules about who could vote: voters should be male, free from slavery, landowners, and have financial assets<sup>10</sup>. Eventually, in 1881, the so-called Saraiva Law determined that people who did not have high financial assets could also vote, but only if they were literate and professionally well established<sup>10</sup>. Later, as a result of extreme social unrest and black movements' advocacy, the Constitution of 1981 determined that anyone could vote, except the homeless and illiterate individuals<sup>10</sup>. It must be noted that even 'free' black people were mostly without a home or land, and were prohibited from obtaining basic education 9-11. On the contrary, white men, mostly immigrants, were able to vote. Civil rights were only granted to black individuals more than 180 years after the abolition of slavery, through the Constitution of 1988, the current Brazilian Constitution. Also, for the first half of the 20<sup>th</sup> century, the Brazilian government encouraged and financed European immigration to occupy workplaces to avoid benefiting Brazilian-born black people9. Simultaneously, controlling policies were created by the legal system based on eugenic theories, mainly spread by physicians, which stated that black people were born with mental disorders prone to criminal activiy<sup>12</sup>.

Although 'apartheid' has not been an explicit state policy in Brazil, there were many laws and policies that promoted marginalization, alienation, and the violation of the dignity of black people. Consequently, black areas were built around the large industrial urban centres, in order to somehow protect blacks from constant harassment<sup>11</sup>. Black culture, religious rites, music, dance, and other black expressions were limited to these marginalized territories<sup>11</sup>. Brazilian black people were forced to settle in precarious territories without work, education, and housing, where violence, extreme poverty and hunger constituted everyday life.

Currently, the Brazilian Institute of Geography and Statistics (IBGE) is responsible for carrying out a sociodemographic census of the Brazilian population. In 2019, IBGE identified racial inequalities in several fields: educational levels, access to health, housing, basic sanitation, work and income, political rights, safety, exposure to violence, and high children and young adult mortality, among others. In relation to the distribution of income in 2018, 15.4% of the white population and 32.9% of the black population of Brazil earned less than U\$5.50/day. Conversely, 3.2% of white people received less than U\$1.90/day, compared to 8.8% of the black population13. Illiteracy rates were three times higher among black people than among white people and white men and women made up more that 75% of the elected political representatives13.

In addition, black people constituted 66% of the unemployed and displaced – with black women in the majority. At least 44% of the black homes lack one of the three basic elements of sanitation: garbage collection, sewage treatment, or clean water supply. The rate of intentional homicide is 2.7 times higher in the black population<sup>13</sup>. In 2020, the consequences of the Covid-19 pandemic evidenced further racial inequalities. For example, due to limited access to health services, the deathrate and vaccination rates among the black population have been three times greater and smaller respectively as compared to their white counterparts. Not surprisingly, black people face more unemployment: of the total of 8.9 million unemployed people, 6.4 million (or 72%) are black men and women<sup>14</sup>.

Obviously, Brazilian black people still suffer from inequity, exclusion, and marginalization. These examples expose how racial inequalities affect several fields and impact on occupational choices, occupational engagement, and occupational opportunities for the black population<sup>15</sup>.

### The impact of a history of racism on social and occupational justice

since 1970, occupational therapists in Brazil have incorporated theoretical frameworks from the Human and Social Sciences16 in their day-to-day practice. The growing global social inequalities in the 20<sup>th</sup> century have brought these questions to the occupational therapy fields of intervention and knowledge<sup>17</sup> and have prompted the adoption of critical-reflexive perspectives to identify actions that could enact full citizenship and fight inequities16. Thus, revisiting concepts in/for Brazilian occupational therapy has become an important task in view of the complexity of social vulnerabilities that have arisen in the globalized world<sup>17</sup>.

Since the military rule in Brazil from the 1960s to the 1990, 'social justice', 'full citizenship' and 'human rights' are concepts that are receiving attention in especially the community, social and cultural practical contexts, and are guiding critical perspectives on the actions required from occupational therapists<sup>17</sup>. The articulation of these concepts in Brazil has sparked the analysis of the social problems experienced in the daily lives and occupations of people and groups in the face of social disparities which arise from the power dynamics produced by capitalism<sup>17,18</sup>. As a result, professional practices and the construction of knowledge by some groups are aimed at promoting justice and social rights for the inclusion and social participation of people and communities that experience vulnerability on a daily basis<sup>18</sup>. It is understood then that social justice is related to the processes of social inequalities, which may manifest themselves in different areas of occupational life, and vary in range, depending on the sum of vulnerabilities and support networks<sup>18</sup>.

In the international context, Townsend and Wilcock<sup>19</sup> theorized about occupational justice, which advocates for the fair distribution of resources and rights that will allow all human beings to perform their meaningful occupations, ensuring that everyone can, in a fair way, explore their occupational potential equitably and satisfactorily, favouring personal and collective well-being for all<sup>19</sup>. Likewise, according to the World Federation of Occupational Therapists, access to occupations is a fundamental right and people must enjoy guarantees that allow them to engage in occupations that provide both individual and collective well-being<sup>20,21</sup>.

Occupational justice and injustice therefore constitute opposite poles, occupational justice being the full, equitable distribution of resources and opportunities, while occupational injustice constitutes the inequality of this distribution, privileging certain groups to the detriment of others<sup>22</sup>.

Townsend & Marval<sup>21</sup> argue that a population living in extreme poverty is one of the groups most affected by occupational injustices, as there are few public, social, financial and educational policies that guarantee their development. Although we agree with this statement, we intend, in the next sections, to position ourselves critically from an ethnic-racial standpoint. We understand that an ethnic-racial perspective - before placing poverty at the centre of the problem - reiterates the impact of colonization, exploitation, and enslavement of people and communities, for which we must emphasize the historical trauma and the legacy of pain and outrage these processes inflicted.

The five forms of occupational injustice that can be used as a framework for understanding the impact of a history of racism on occupational participation in Brazil are: (1) occupational deprivation; (2) occupational imbalance; (3) occupational alienation; (4) occupational marginalization and (5) occupational apartheid<sup>20</sup>. In this article, we will be focusing on 'occupational apartheid' as the lens through which we approach our analysis, since, again, we consider racial inequality in Brazil a central element in the production of our pervasive social disparities.

### From social justice to occupational apartheid

Debates around the concept of social justice emphasize full citizenship and human, social and universal rights. However, the concept of social justice has been linked to liberal ideals that perceive social justice as opportunities allied to individual freedoms<sup>23</sup>. Bailliard, Carroll and Peak<sup>24</sup> problematize that the main theories around the concept of occupational justice and social justice advocate neutrality, in reference to socio-political issues, as well as universality, neglecting the differences between people.

"Yet claims of impartiality are impossible, as we cannot separate ourselves from the biases of our embodied sociocultural experiences or our respective intentions. In the United States, dominant institutional structures in education and government, deluded by the possibility of impartiality, canonized the perspective and experiences of the privileged dominant group (i.e., white Anglo-Saxon Protestants) to be positioned as universal, thus denying the possibility of difference" 24:4-5.

From an epistemic perspective that articulates the so-called 'Global South', occupational justice can be situated from the discussions held in Latin America and occupational therapists from the South. According to Guajardo Córdoba<sup>25</sup>, processes of exploitation, enslavement, and genocide of natives and blacks that took place in the global South bequeathed us a past of injustices that remain in operation, albeit with new characteristics. Even with the emancipation of the Americas and part of Africa through independence movements, many countries still suffer the impacts of colonization, including land disputes, religious rights, language restrictions, and so on<sup>25, 26</sup>. Therefore, authors from Latin American, African and Asian countries have advocated for an anti-racist, anti-hetero cisgender patriarchal and anticolonial occupational therapy, which considers the plurality of knowledges, as well as assuring a leading role for groups whose voices have long been silenced and whose places of speech are still denied 25-28.

Beagan et al.<sup>29</sup> point out that in occupational therapy, the scholarly work on occupations in relation to colonial oppression is incipient, especially considering race. Commonly, occupations are conceptualized based on Northern-Western perspectives, resulting in the marginalization and invisibility of non-white groups<sup>29,30</sup>. According to Lee<sup>28</sup>, the perspectives on occupation are based on western epistemologies around the world. In colonized countries, it is common for occupational participation and engagement to be measured by these perspectives. Thus, participation in traditional occupations, original occupational, traditional culture, does not fit into standardizer protocols and procedures<sup>28</sup>. In Brazil, African-Brazilian and indigenous occupations and culture are usually considerer inferior and not sufficient as valid, normative, and satisfying cultural forms of occupation<sup>4,12,15,26,28</sup>.

In their research, Beagan et al.<sup>29</sup> interviewed black occupational therapists who talked about their experience around racism. The authors found that facing racism is a naturalized phenomenon inside professional practices (i.e., racial violence from patients, colleagues, and managers;

exclusion from social events; loneliness etc.). From this, the authors inferred that black occupational therapists exhibited distinct strategies to fight against systemic racism: "Coping, surviving, is often all that is possible; sometimes people find the energy to resist, collectively and/or individually- and there are usually costs, particularly in terms of stereotyping and scapegoating." <sup>29.7</sup>. In their study, guite unique within the field, the authors identified contradictory perspectives: Some participants absolved others from blame, for example, suggesting that if you just respond the right way, you can end the racist comments and innuendos. Some suggested racism signalled ignorance: "I am not blaming them... they lack the awareness"29:7. Not surprisingly, the black therapists also reported avoidance or withdrawal to preserve themselves29. Thus, although still developing, recent literature suggests that occupational therapists, especially white professionals31, must develop skills to identify and analyse the impact of racism on human occupations and the underpinnings of collective engagement in the coping and resistance dynamics <sup>29</sup>.

Hammell<sup>32</sup>, one of the critics of the concept of occupational justice, reiterates her privileged place as a white, cisgender, heterosexual woman, as well as an Anglo-Canadian dual citizen, to reflect on the notions of justice that have been produced in the Global North. The author understands that human beings must have the right to carry out their occupations, regardless of race/ethnicity, social class, religion, gender, and sexuality, among other aspects. The denial of these rights is configured as occupational injustice. However, Hammell shows that the fortuitous division of types of injustice brings us other problems; after all, since we run the risk of segregating and/or leaving out different oppressions that happen simultaneously and structurally in society. For Hammell, the focus should be on the negative impacts of injustice on health and well-being, rather than on their typification. However, the author suggests that the only scholarly construct that makes sense to maintain is occupational apartheid, which has a well-rounded definition and can help us understand very well-marked processes of ethnic-racial exclusion in societies<sup>32</sup>.

Originally defined by Frank Kronenberg and Nick Pollard<sup>33</sup>, occupational apartheid is systematic, political, social, cultural, and economic segregation that impacts health and the occupations of people and collectives, and it occurs:

"...by restricting or denying access to dignified and meaningful participation in the occupations of daily living, based on race, colour, disability, origin, age, gender, sexual orientation, religion, political beliefs, social status, or other characteristics" 33:67.

The concept of occupational apartheid in Brazil has been adopted to discuss the processes of inequalities directed to racialized groups, such as, for example, urban black youth, *quilombola*<sup>1</sup> populations, native peoples and traditional

<sup>1</sup>Quilombolas are people who live in Quilombos. Quilombos is a black community, which was formed by ex-slaves. In Brazil, commonly those communities are located in rural fields which are protect by public policies. communities, among others<sup>34-36</sup>, understanding that in the context of colonial subalternity, these groups face limitations in their occupations that do not satisfy their very basic needs. Ambrosiol5 emphasizes that even in contexts where precarious conditions of class and geographic location are similar for different groups, identity marks such as race, gender and sexuality are promoters of inequality between people.

Apartheid, a word that means "racial segregation of any kind", was instituted in the 17<sup>th</sup> century in South Africa by a white European colonizing minority. In the United States and South Africa, laws that legitimized racial separatism made this segregation official. Thus, black people were not considered citizens, did not have the right to vote, interracial marriage was prohibited, and white and non-white people could not frequent the same places. This racial hierarchy prevented non-white people from enjoying their rights<sup>37</sup>. Despite worldwide demonstrations against apartheid, both the associations of occupational therapists in South Africa and the United States, as well as the WFOT, for years remained silent and adopted supposed neutrality regarding the marginalization of black people<sup>38</sup>.

Although there were no official apartheid laws in Brazil, scholars of ethno-racial relations point to state policies that legally promoted racial segregation<sup>12,39</sup>. From opening policies for European salaried labour to legislation inscribed in the Brazilian penal code, there were explicit strategies of whitening the population, racial control and open black genocide<sup>39</sup>. It is worth remembering, for example, the figure of Nina Rodrigues, a Brazilian doctor, white and oligarch, who played a large role in the consolidation of segregationist policies. His propositions concealed explicit apartheid and fostered the creation of the myth of racial democracy, which would mark the passage from an imperial state to a republican state with liberal bases under the sign of individual equality<sup>12</sup>.

"Anticipating this problem, it bets on the strategy of establishing social control in practice, in everyday life, through a punitive system, which will often take place at the hands of the authorities who manage daily life: medical authorities, police authorities, judicial authorities. This is the focus of Nina Rodrigues' thinking" [2:138] (original in Portuguese)

"Apparently, there was not, at least not in a massive and institutionalized way in all fields of social life, a proper apartheid regime, as it was being established in Anglo-Saxon colonization societies, but we had a scientific legitimation for the maintenance of a citizenship exclusionary" 12:139 (original in Portuguese).

The newly crafted Federal Constitution<sup>40</sup> provides that all Brazilians are equal before the law. However, in the Brazilian context this equality is still non-existent. This is evident in the current scenario of the coronavirus pandemic, which records disparities in the mortality and morbidity of whites and blacks<sup>41</sup>. The existence of places frequented only by white people and others where only black people are allowed; as well as groups protected by the police while black persons are victims of constant harassment and murder. These are

but a few examples of processes that can be understood as a Brazilian style apartheid, according to Lélia Gonzalez<sup>4</sup>. It seems that it might not be an apartheid regulated by law, like in the South African and American contexts. Still, it can be described as disguised apartheid tolerated in many social practices in Brazili<sup>39</sup>. Based on this reading of Brazilian historical, social, and political processes, although we cannot configure a Brazilian apartheid instituted by legislation, the impacts of covert separation, which affect the majority of the Brazilian black population, are clear.

### Collective occupations as a means toward occupational justice

We have already noted that social justice and occupational justice concepts stem from liberal and universalist ideals<sup>23,24</sup>. Contrarily, authors have proposed interventions based on the idea of collective occupations, seeking to confront occupational apartheid. For Ramungondo & Kronenberg<sup>42</sup>, collective occupations are:

"Occupations carried out by individuals, groups, communities and/or societies in everyday contexts; these may reflect an intention of social cohesion or dysfunction and/or advancement or aversion to a common good. Collective occupations can have consequences that benefit some populations and not others." 42:10

Ramungondo and Kronenberg<sup>42</sup> argue that collective occupations can represent a continuum between relations of oppression and freedom, especially within minority groups. According to the authors, it is important to understand that occupations are social constructs and, therefore, represent forms of organization of societies reflecting dynamics of power and privilege of certain groups, to the detriment of others<sup>42</sup>.

In the historical-social-cultural constitution of black Brazilian occupations, the processes of enslavement are central in the production of inequalities, indignant experiences, and genocide<sup>43</sup>. The slave period, which lasted for almost 300 years in Brazil, represents more than half of the history of the presence of black people in the country. From this perspective, as a subordinated group, the black population is constituted through the restriction of significant occupations, notably collective ones, to serve and meet the impositions of the white group. As we mentioned earlier, based on IBGE's<sup>14</sup> census data, Brazilian racial inequality is easily identifiable within several social indicators such as unemployment, mortality, incarceration, school dropout, salary disparities, access to basic sanitation, human right violations, and food insecurity among others. As Galvaan<sup>44</sup> would emphasize, the situated nature of occupational choice is undoubtedly linked to the social environment and its discursive practices, which must be considered when it comes to occupational justice and its underpinnings.

Considering that the occupational demands of black people in Brazil vary considerably – educational, work and income, mobility, housing, health, food security, religious and cultural freedom, among others, there is a vast field for the work of occupational therapists. Thus, collective actions can

offer an expanded approach that understands and problematizes the limitations that occupational injustices cause in social life. Conversely, it is necessary to look beyond the clinical settings, the traditional dichotomy between health and illness, and to pay attention to the context and environment in which the persons live<sup>25,32,42,45</sup>.

Brazilian occupational therapists' practices are mostly colour and ethnically "neutral" to date. This is due to many factors, especially the lack of cultural safety awareness within educational programs and the pervasive disguising measures that render racist exchanges invisible, as explained earlier<sup>14</sup>. We must then concede that occupational therapy interventions with black populations based on community and collective perspectives, mindful of the ethnic-racial identities, are still incipient in Brazil, even though the black population represent the majority of the Brazilian demographics. Nevertheless, in the next section we offer some recent examples, which show encouraging actions, despite the adverse conditions. Below, we will present some examples of interventions based on collective occupations.

## Examples of interventions based on collective occupations by occupational therapists to facilitate occupational justice

In the context of affirmative actions, Andrade et al.46 propose an occupational therapy intervention with a group of black undergraduate students to offer better conditions for academic performance. Through collective activities, the authors applied artistic and cultural resources to rescue, value and empower black students in the university context, in the face of oppression caused by racist strategies imposed by white supremacy<sup>46</sup>. Ambrosio et al.<sup>34</sup> presented an occupational therapeutic process carried out in an institution that cared for adolescents and young people with intellectual disabilities based on collective artistic and cultural experiments of Afro-Brazilian matrices. Faced with the racism experienced in the institution daily life, the authors designed a set of activities to promote ethnic-cultural valorisation through essentially Afro-Brazilian cultural collective occupations, such as dances, hair braiding, tying turbans, etc. The authors attest that collective experimentation impacted young socialization, promoting relationships based on respect in the face of racial diversities. The experience also produced institutional impacts on providing care by mostly white professionals to a predominantly black group

Silva<sup>36</sup> described the work in a quilombola community in the interior of the State of Bahia, which had gone through a process of eviction after flooding caused by the construction of dams. The context was very controversial, as the community was not involved nor consulted in the relocation measures. For Silva, activities to recover memories and honoured traditions of the community could be achieved through collective action to face the situation of homelessness and lack of support<sup>36</sup>. When discussing the black diasporas in Brazil and understanding the processes of collective displacement of black groups for the formation of quilombos, the author points out strategies of resistance displayed in collective and community occupations.

We can also cite works by occupational therapists who propose appreciating black Brazilian cultures through collective artistic and cultural activities, especially self-expression through Hip hops<sup>47</sup>. Hip Hop, as a black cultural expression, has been claimed as an advocacy strategy, a denunciation of oppressive situations, but also as an expression of the body and a reminder of people's struggles and survival accomplishments<sup>47</sup>. Pereira et al.<sup>28</sup> describe similar processes in the study developed within a female prison system, with selfdeclared black and brown women. Collective activities and iconographic resources favoured empowerment, increased occupational repertoire, remembrance of life stories, engagement in meaningful occupations, and the construction of personal and collective identities. Although not complete, these examples can offer great insights on the opportunities for work in this field.

### Inclusive social engagement from an ethnical racial standpoint

Racism has produced inequalities in Brazil since its constitution as a country. Here, black people continue to be kept on subaltern spaces, and their occupations' precariousness is evident. Occupational apartheid provides us with tools to make racial oppressions visible and to reveal the structures of domination imposed by colonial, patriarchal, heterosexual, and ableist systems that privilege certain groups over others. As action strategies for occupational therapy, collective occupations can be used help marginalize black people understand their collective story as a people. Collective interventions are powerful tools for the transformation of individual logics in favour of the collectivization of resistance processes.

The field of occupations for black people, as well as the regimes of control and deprivation of black occupations are still little explored but, in view of the proposed discussions, there is no doubt that these are urgent themes for overcoming the historical discriminatory and racist legacy of Brazilian occupational therapy.

### Step-by-step guide to occupational therapy intervention in collective occupations:

- Identify perspectives, epistemologies, worldviews that guide perceptions about life, everyday life, and occupation.
- Recognize ethno-knowledge about care, health, and well-being.
- Recognize traditional occupations as an essential occupation to promote belonging, sociability, and social participation.
- Recognize, confront and address social structures of exclusion using government strategies and legal resources to ensure access to dignified community living conditions.
- Ensure community and representative participation in political decisions, such as participatory planning strategies.
- Promote actions to preserve and enhance collective memories, ancestry, and cultural diversity.

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### COMMENTARY

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# Doing a scoping review with undergraduate occupational therapy students in the time of the COVID-19 pandemic

### INTRODUCTION

In South Africa, the COVID-19 pandemic manifested in March 2020, bringing with it severe disruption and posing unique challenges to healthcare and the education of health practitioners<sup>1</sup>. In their operational guidance for the COVID-19 circular of June 2020<sup>2</sup> the World Health Organisation (WHO) acknowledged the challenges brough about by the pandemic and specifically note the effect thereof on rehabilitation<sup>3</sup>. The negative impacts on rehabilitation at healthcare facilities included a decrease in patient numbers, termination of 'non-essential' and group services, and staff availability being affected by infection and isolation policies. These factors had a knock-on effect on the training of undergraduate students in occupational therapy. Without access to clinical settings, students lost exposure to both the contexts within which they were being trained to practice in and the realities of the service users they would be seeing. Research activities were similarly disrupted. Research exposure and experience is imbedded in the undergraduate program and the successful completion of a research project a prerequisite for graduating as an occupational therapist from Stellenbosch University (SU). To expose final year graduates to the theory and practice of research, data collection for projects is usually done in groups within clinical settings, thus affording them insight into the generation of evidence-based practice. With the pandemic disrupting the training of occupational therapy students and jeopardizing completion of their studies within normal timeframes, innovative initiatives were needed to address the research component of the undergraduate training programme without putting quality education and integrity of education facilities at risk.

This commentary describes such an initiative. A supervised scoping review, that focused on how persons with disabilities in South Africa accessed rehabilitation services in public healthcare facilities, was undertaken with a group of five final year occupational therapy students. The reasoning was that the framework of a scoping review would introduce students to multiple examples of research methodology as well as the rigours of evidence synthesis. A discussed concern was that conducting a scoping review would be too time-consuming and difficult for undergraduate students. To address this concern, structure, and supervision with practical demonstrations, were prioritised. The educational objective was to expose the students to the realities of service users as described in published peer-reviewed primary research.

### METHOD

During the week of 29 March to 1 April 2021, a group of five undergraduate final year occupational therapy students from Stellenbosch University (SU) and their two supervisors did a scoping review with the question: How do persons with disabilities access public healthcare rehabilitation services in South Africa? The Joanna Briggs Institute user manual, resources and website were used throughout<sup>4</sup>. Mendeley Reference Manager<sup>5</sup>, a free, open-source, web and desktop reference-management application, was used to import, remove duplicates, organise, and export articles. Rayyan<sup>6</sup>, a free web-tool designed to help researchers working on knowledge-synthesis projects, was used to screen articles and Taguette<sup>7</sup>, a free open-source tool for qualitative research, was used for qualitative evidence. Continuous supervision and interaction between students and supervisors took place daily and virtually on Microsoft Teams<sup>8</sup> and a WhatsApp group<sup>9</sup>.

There were six phases to the review. Each phase started with an online tutorial. This was followed by a team discussion in which planning, and task allocation took place. The students were expected to work either individually or in groups and supervisor advice

Table I: Anonymous critical reflections by student participants

Matters of reflection	Students' responses	
What did I learn about how persons with disabilities access rehabilitation in the public healthcare sector in South Africa?	Persons with disability's access to rehabilitation in the public healthcare sector in South Africa, is an in-depth problem without an easy solution. Surface problems such as lack of transportation and/or limited finances, can be traced back to deep socio-economic problems that need governmental and social structural changes.  Furthermore, there are existing policies within South Africa which provide plans for equal access to public rehabilitation, but these have not been put into practice.	
What did I learn about research, scoping reviews, and evidence synthesis?	There is a systematic and strategic method in which one can source and analyse literature related to one's topic of interest. This method of literature review provides a thorough overview of what is known and yet to be known about the subject at hand.  Furthermore, each step within the research process holds the same importance and makes a difference to the integrated picture drawn at the end, it is also a continuous process which needs to be constantly updated as new evidence arises to provide an overview of available research evidence. We now understand better how evidence for evidence-based practice comes about.	
If this is done with other occupational therapy students: What aspects of the project should remain the same?	It is very difficult and confusing at first but the way in which our supervisor structured tutorial sessions and demonstrated how to use the online tools available for research was extremely helpful. Doing a scoping review provoked interest for future involvement in research, this should continue to be implemented in future. It is exciting to think our work will be published in a journal.	
If this is done with other occupational therapy students: What should change.	Due to COVID-19 and important safety regulations, in-person meetings were not possible throughout this project. This did limit our ability to discuss, plan, and share ideas with each other. Whenever possible, in-person meetings are preferable.	
Any other thoughts?	This project was extremely educational and informative in terms of how the scoping review procedure is implemented and carried out. It provided a platform for us students to consider engaging in future research and scoping review projects. However, it would be more beneficial for students themselves to be involved in real research and data collection processes.	

could be accessed when needed.

- Phase one comprised planning and preparation for the review. This included a tutorial on what a scoping reviewing is, review question formulation, eligibility criteria development and creation of extraction templates. The learning objective in this phase was to make clear to students why they were conducting a scoping review and what it entailed.
- In phase two, students were taught how to develop a search string, how to identify key words using Boolean terms and how to negotiate different data bases. Using Google Scholar and SU library databases, they ran the searches and downloaded full texts of sources into Mendeley.
- Phase three saw students selecting the sources of evidence for their scoping review and populating a PRISMA flow diagram. The learning objective was to understand the reason and rigour of blinded and systematic selection of articles and learn to use a PRISMA flow diagram in the scoping review process. Inclusion and exclusion criteria were confirmed by the group and students took part in Title and Abstract Screening and Full Text Screening using Rayyan.
- Data charting and extraction were done in phase four.
   Two self-developed data-extraction templates were used by the students. During the tutorial, the supervisor used one of the articles to illustrate how to find and extract data. Following this, each student received a certain section of the articles for individual extraction, collaborating when necessary.
- In phase five, students used Excel and Taguette, to summarize, analyse and synthesize the evidence they captured. This phase concluded with a group session

- attended by the supervisors and during which results were discussed and themes agreed on.
- Phase six saw students co-authored their scoping review and compiled it into a journal article. The article was submitted to a journal and the students experienced the process associated with having an article published in a scientific peer reviewed journal. They were also tasked to critically reflect on their learning experience while doing the scoping review and make suggestions to improve similar teaching initiatives in future.

The first author drew up a table with open-ended questions for students to reflect on, and a section for additional thoughts (See Table I, above). The table allowed the student co-authors to reflect on and capture their individual experiences. Their responses were checked with all participants and summarised during an online group session.

### **RESULTS**

Students' reflections on their learning experience are summarised and shown in Table I (above).

### DISCUSSION

Not disregarding or denying the adverse impact that a global pandemic such as COVID-19 brings, the authors would like to reiterate the opinion that it also offers a unique opportunity for change and opportunities for the implementation of innovative and creative initiatives. This report shows that exposing undergraduate students to the rigour and process of a scoping review is beneficial as they are exposed to a large variety of research methodologies, outcomes, and diverse points of view. Reporting their findings in an article format focussed students' attention on the most important components of research and guides them to write suc-

cinctly. It was also realised that conducting a scoping review is more cost and time effective than real time field work research whilst accomplishing a similar level of exposure to the world of research. Despite popular opinion that a scoping review is too difficult for undergraduate students, this exercise illustrates that, given a well-structured process, multiple tutorials, real-time demonstrations and supervisors' consistent availability, undergraduates can do research at this level. The scoping review was submitted to the Disability, CBR and Inclusive Development journal on 10 June 2022 where it was vetted, reviewed, revised and accepted for publication in October 202210.

### Limitations

The reason for doing the scoping review was to use it as an educational and learning tool. There were no data trails, and the group did not consider or address potential biases. The knowledge claim of this commentary is based on reflections by five students. More in-depth research with a wider range of data capturing is recommended. The students and supervisor only met in group sessions. Individual meetings with the supervisor and each student should have been done. This would have ensured inclusion of verbatim words and made the critical reflection more specific. It would have summarized the student's personal experiences and perspective more comprehensively to give the reader an in-depth understanding.

### CONCLUSION

Students' reflections show that they gained insight into research, perceiving the activity of doing a scoping review as a largely positive experience and expressed interest to engage in future research. The prospect of their work being published, motivated them. However, they reported that they would still prefer to have done research that required face-to-face interaction and exposure to clinical settings within various contexts. Educators of occupational therapists could consider doing a scoping review with undergraduate students is as a possible future education strategy. However further research and empirical evidence would be needed to support such strategies and the possibility of exploring a hybrid approach in future is suggested.

### Author contributions, conflicts of interest, bias and ethical declarations

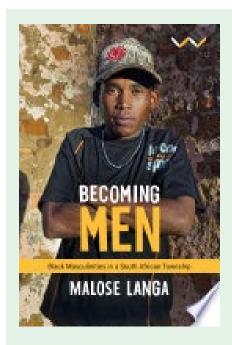
The authors declare no bias affecting their interpretation and results of the review. No ethical clearance was sought or obtained. The review and journal article contributed towards the Bachelor of Occupational Therapy degree for Bianca Salie, Jancke van Wyk, Jessica Daniel, Lize-Mari Kersop and Michaela Naidoo, who are co-authors. They took part in the commentary and scoping review as part of their curriculum; reflections were anonymous, volunteered and did not affect the marking of their scoping review.

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### **BOOK REVIEW**



**TITLE:** Becoming Men. Black Masculinities in a South African Township

**AUTHOR:** Malose Langa

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# Becoming Men. Black Masculinities in a South African Township by Malose Langa

### Information on the author

Dr Malose Langa is an associate professor in the Department of Psychology at the University of the Witwatersrand (Wits), Johannesburg. He lectures undergraduate students from various disciplines and as such is known by occupational therapists who graduate from Wits. Dr Malose also works at the Centre for the Study of Violence and Reconciliation (CSVR). His research and publications included his work with juvenile offenders, ex-combatants and causes of violent crime in South Africa. His well-known report Smoke that Calls which investigates causes of violent protests post 1994 and how these protests are linked to hegemonic masculinities and power struggles. His research interests include risk-taking behaviours amongst youth, the trauma of collective violence and the psychology of men (masculinity) in postapartheid South Africa. His PhD was focused on exploring masculinity amongst adolescent boys in Alexandra Township, South Africa. Which is the subjectmatter of this book.

### The Review

Malose Langa, the author studied a group of male participants (in Alexandra township, collegially called Alex) for 10 years from when they were teenagers to when they became young adults. The book focuses on unpacking the complexities and adversities that had an impact on the participants' masculinity and eventually who they became in society. Overall, each participant's life turned out differently, despite all being brought up in a similar harsh environment. Participants' experiences range from those who were killed, jailed, had a qualification, being in a stable relationship, having a job to some *making it* and moving out of Alex. The layout of the book is easy to follow and understand. It is admirable how the author could repackage his PhD into an easy-to-read book. Photographs are used to elicit participants' authentic contextual stories and to further unpack sensitive issues, such as sexual preferences or orientation.

In Chapter 1 Malose sets the scene by giving an overview of the book, and what inspired him to do his PhD. A longitudinal research approach was used. The participants (started at n=32 and decreased to n=12) were teenagers in high school when the research started and young adults (some were working) when the research ended. Focusing on what makes a man a man, Malose contextualises the complexities of masculinity, to Alex township. He highlights the ineffectiveness of initiatives meant to assist adolescent boys, in Chapter 2 as they don't align to the society (and the environments) they live in. Historic issues such as patriarchal practices play a negative role and make it challenging for alternative hegemonic masculinity to be popular and accepted in society.

In Chapter 3, Malose gives background and an overview of Alexandra Township. When, how and why Alex was established and how it changed over the years. He highlights how the current complexities of Alex emanate from its past. Under the South African Apartheid Group Areas Act, Alex was a hub for black South Africans to provide labour to the, then designated whites-only suburb of Santon, which todate is still one of most affluent suburbs of South Africa.

Malose unpacks issues his participants faced that are associated with present mothers, and absent fathers in *Chapter 4*. The emotional difficulties expressed by the boys ranged from longing for a present father, to suicidal thoughts. One participant relates having considered performing rituals to carry his late father's name so that he can align with his heritage and be accepted by his late father's ancestors.

Malose also highlights the value of a mother who instiled discipline, and was regarded as an important role player in assisting the boys to stay focused, and prevent them from going astray. And in *Chapter 5 and 6* he highlights the social complexities his participants face. At the top of the social hierarchy are those engaging in heroic risky behaviours (tsotsi masculinity). Being academically oriented is perceived as 'uncool' and associated with negative connotations such as being called derogatory words and classified as 'teacher's pets'. These result in some boys attempting to appear cool publicly (showing tsotsi behaviour) but studying in private to get better marks. Growing up in Alex there are weekly parties where alcohol is easily available. Sex is male-driven. Those who engage in it, especially with multiple partners, are perceived as 'cool' and respected, but those who do not are called names such as di bari (fools). On the masculinity hierarchy, Christians and gays, in that order, are at the bottom. In order to belong and not be embarrassed by their peers and friends, these boys (Christians and gays) would deny and lie when it comes to such subjects. To overcome such pressures some participants resorted to their faith and/or talking to an elderly person for advice. In Chapter 7 Malose unpacks the subject of homosexuality which is viewed as less masculine and being inferior. With maturity, one participant gained confidence and identified openly as gay despite homophobic experiences. Such homophobic experiences entailed e.g., lack of support structure, being judged from how they dress (colourful clothes) and being called derogatory words such as isitabani (gay).

In Chapter 8 Malose focuses on challenges faced by those becoming fathers at an early age, navigating studies and the world of work. Those who impregnated their girlfriends at a young age had to deal with issues such a paying for damages to the girlfriend's family. Later on, they deal with being young fathers and were observed reflecting on their childhood traumas resulting from their own absent fathers. Those who made it to university had to deal with challenges around funding (for e.g. accommodation, food and transport), though they were expected to perform and pass regardless. They deemed the varsity system as being unfair as expectations remained the same across all students irrespective of their background, social and economic standing. Despite their dire situation, some participants made it out of Alex (as was their aspiration), secured good jobs and led prosperous lives. To give back, they considered setting up support structures (e.g., a Non-Government Organisation) with an aim to help those in need in Alex.

Chapter 9 is a case study. One participant who initially followed the Christian faith, passed his matric but ended up in prison when he was forced to take a gap year due to lack of funding to further his education. He succumbed to peer pressure and engaged in criminal activities. In prison, he regains his faith and uses the oppertunity to study law, enroling in an LLB degree. The author sums up the book in Chapter 10. He raises findings that are contrary to traditional beliefs and popular assumptions about masculinities that may emerge from communities similar to Alex. The author opens up on how this research touched him personally e.g. he his father was also absent (unknown), a subject he never

spoke about with his colleagues before. Malose concludes making recommendations aimed at assisting in building better communities that support not only present mothers but fathers, boys and girls. With an intention to publicly celebrate and promote non-risk-taking, non-violent and non-sexist behaviour in society.

This book is highly recommended reading and has significant relevance to occupational therapy in South Africa. Like any non-white community in South Africa, the community of Alex was and still is disadvantaged, especially economically and socially. Post-apartheid in 1994, such communities started having access to basic services e.g., to health professionals like occupational therapists. Despite almost 30 years of democracy in South Africa, Alex is still a high-density, low-income township that is economically and socially disadvantaged. There are however many projects and institutions working to address this. One of these is the occupational therapy services offered at Alex Clinic through by Wits University's 4th year Occupational students during their community placement block.

According to Ned et.al.1 the majority of occupational therapists are females (95%), white and privileged. Although occupational therapists or the Occupational Therapy Profession is not mentioned, the book is relevant to the South African occupational therapy community in this sense:

- Awareness, continued awareness, learning and understanding of those communities that patients return to post-discharge from occupational therapy intervention at a tertiary hospital is crucial. A better understanding of patients' realities and living conditions will enhance occupational therapists' planning and therapy outcomes that are not only sustainable, but faciliates patients' community reintegration.
- In line with recommendations made by Birioukova and Barker2 in their publication titled The male occupational therapist: Demographics, issues and recommendations., the Occupational Therapy Association of South Africa (OTASA), as part of their transformation agenda, could take into account issues raised in this book should they consider recruiting and making the profession appealing to males.

### General personal views of the reviewer

As a black male, from rural Bushbuckridge, with family living in Alex, I can relate to many of the issues faced by the participants in this book. Things that I can relate to are a need to perform rituals (which may be perceived as psychoses by a less insightfull and knowledgable professional), peer pressure, university challenges (e.g., financially related). Also, as a male (minority) in the occupational therapy profession and coming from a disadvantaged past, I have experienced challenges in the profession relating to its feminine Western culture and practices, feelings of isolation, and being 'misunderstood'.

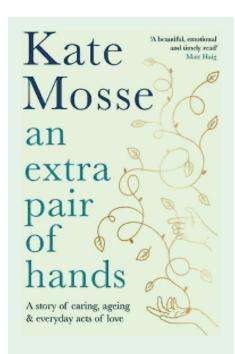
I know of two cases in Alex where two young male friends hanged themselves, a month apart. Their tragic stories were related to mental health issues which started when their parents passed on, followed by substance abuse and finally leading to them taking their own lives. On the other hand, I

am aware of Alex success stories such as that of Israel Matseke Zulu who turned around his life after imprisonment and is currently a successful actor and poet. His story aligns with that of the participants in this book in that he grew up in Alex, in a one-roomed house, had an absent father, succumbed to peer pressure (tsotsi behavour) and engaged in criminal activities which landed him in prison. Today is he widely known for his roles in movies such as Amandla, Beyond the River, Hard to Get and Avenged and before that as GP in the SABC1 drama series Gaz'lam. His life story, and the fact that there are books such as Becoming Men being written and read in South Africa acts as a beacon of hope for the future of young people in what might often be perceived to be a hopeless situation.

Although not the main focus, the book also highlights (directly and indirectly) important inequality issues. Issues such as mental health, gender-based violence, homophobia, substance abuse, poverty and educational access and appropriateness (related to the *fees must fall movement* in South Africa), and housing (related to the land reform and distribution in South Africa). I found some chapters especially educational and enlightening, specifically around the issue of homophobia. A relevant topic that locally, in South Africa, we have platforms that were created (from government to individual) to sensitise and raise awareness such as MacG's YouTube based Podcast and Chill (Queer way of life with Bujy Bikwa).

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**TITLE:** An Extra Pair of Hands. A Story of Caring, Aging and Everyday Acts of Love

**AUTHOR:** Kate Mosse

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## An Extra Pair of Hands. A Story of Caring, Aging and Everyday Acts of Love by Kate Mosse

### Information on the author

Kate Mosse is an internationally bestselling novelist, playwright, and non-fiction author with sales of more than eight million copies in 38 languages. Renowned for bringing unheard and under-heard histories to life, she is a champion of women's creativity. Kate is the Founder Director of the Women's Prize for Fiction, the Founder of the global 'Woman in History' campaign and a Visiting Professor of Contemporary Fiction and Creative Writing at the University of Chichester. Kate lives in West Sussex with her husband and mother-in-law.

### The Review

In this book, Kate Mosse shares her personal story of finding herself as a caregiver in middle age: first, helping her mother look after her father who was suffering from Parkinson's, followed by supporting her mother in widowhood, and finally as "an extra pair of hands" for her 90-year-old mother-in-law who stays with them.

Kate states that all too often, old age is presented as a problem to be solved, when it should be a cause for celebration that many women and men are living enjoyable, contented, valued and beloved lives well into their eighties and nineties. However, the consequences of people living to this age, are firstly, the issue of quality of life and living well with dignity, secondly, who does the caring, and thirdly when caring for someone whose mental functions are impaired, such as from dementia or Alzheimer's, the care burden is exponentially more demanding.

Kate elaborates on the demands of being a caregiver. She had paid caregivers in to help with more intimate and physically demanding aspects of getting her loved one up in the morning and going to bed at night and still felt the demands of care giving. She explains the routine, endless repetition of things such as conversations, medication, meals, laundry, personal hygiene. It is about always having someone else's needs at the forefront of your mind, and about having a parallel life running alongside your own, about thinking for two (or more) instead of one. How food and eating can be a battlefield. The constant dialogue about it, the struggle to summon up interest in food and loss of appetites. How caregivers worry that the person they're caring for is eating too little or too little of the 'right' thing. The indignity of no longer being able to feed oneself. Kate suggests that learning to be tolerant and patient around the person being cared for is not only a requirement, but an act of kindness. Any impatience a caregiver might feel is tenfold worse for the person who, possibly against the characteristics of a lifetime, is having to ask for help with menial tasks.

Many caregivers that Kate spoke to when she was writing the book, admitted how they had often wished that the constant low-level pressure of caring would go away. How they felt guilty about feeling impatient, not compassionate, at yet another call for help. Guilty about the misunderstandings, how they felt bad at not wanting to be in a sickroom that smelt of defeat, doing all those unpleasant and intimate tasks that must be done over and again. Caregivers also report that they feel lonely or socially isolated and suffered with their own mental and physical health. Often caregivers are elderly themselves. Kate stresses the importance that caregivers be kind to themselves too, and how they should accept that sometimes they feel snappy or ill, resentful, and become frustrated. Kate points out that coping with and preparing for grief (once the person cared for has passed on) is a key part of being a caregiver. After the initial sense of freedom from living one's daily life to another person's rhythm, it is not uncommon for caregivers to feel purposeless.

Giving insight into the experiences and realities of caregiving this book is recom-

mended reading for occupational therapists. A reminder that the only thing caregiver can do is to take one day at a time. Enjoy the good days, muddle through the bad days, and never take anything for granted. An Extra Pair of Hands is an easy-read-story of Kate's journey of caring for her 3 older adult loved ones. Occupational therapists often work with both caregivers and those that need caring and in rehabilitation caregivers are often part of the team. The insights from this book will be of value.