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## Primary to secondary school transition of learners with traumatic brain injuries in the Cape metropolitan area: A learner perspective

**ABSTRACT****Aim:** This study explores the lived experiences of adolescent learners with Traumatic Brain Injuries (TBI) from a low to middle-income context when they transition from primary to secondary school. An understanding of the insider perspective of this school transition process sought to illuminate the factors that facilitate or hinder learners' primary to secondary school transition.**Method:** An interpretive phenomenological research design was used. Four participants were purposively selected. The data collection method included semi-structured face to face interviews. Data were analysed inductively using Burnard's Framework. Four themes emanated from the data including: changes in functioning; personal resources; enabling external support structures and gaps in support structures.**Results:** For learners with TBI, there are factors that facilitate a positive primary to secondary school transition including them drawing on personal resources and the support that they receive from enabling external support structures. Barriers to the school transition following a TBI, include the changes in physical, mental, and social functions that impact on adolescents' ability to fulfil their learner role as well as gaps in the provision of support within the multi systems within the learners' environment.**Conclusion:** Members of the multidisciplinary team, should adopt a learner-centred approach for interventions that seeks to prepare and support learners with TBI for their primary to secondary school transition. Planning the primary to secondary school transition should seek to prepare the learner, and those in the learner's context.**INTRODUCTION:**In the South African Western Cape province, violence and injury contributes to a high incidence of Traumatic Brain Injury (TBI)<sup>1</sup>. TBI may result in cognitive, physical, and social impairments and impacts on a person's functioning post-TBI<sup>2</sup>. Adolescents with TBI must adjust to impairments associated with the TBI and, in addition, adjust to the physical and cognitive changes linked to the developmental stage of adolescence<sup>3</sup>. This may affect adolescents' perception of how they view themselves in relation to others which may negatively impact on their sense of self and may ultimately hinder their participation in meaningful and developmentally appropriate occupations<sup>4</sup>.For an adolescent, one of the main occupations is that of learning, i.e., participation in school. School participation is often disrupted by the sudden onset of a TBI. If the impairments associated with the TBI persist, they may affect a learner's continued school participation<sup>5</sup>. Literature has shown that as the learner with a TBI transitions through the different schooling phases, the scholastic demands increase, and the impairments associated with the TBI may become more pronounced. This may in turn affect the ability of the learner to optimally perform at school<sup>5</sup>.

Within the South African context, there are policies and strategic guidelines that aim to respond to the needs of learners to ensure optimal school participation. The government implemented these policies to ensure that all learners have access to basic quality education especially learners who experience barriers to learning and development<sup>5</sup>. This strategic focus is highlighted in specific policies such as White Paper 6 special needs education: building an inclusive education and training system<sup>6</sup>. This policy highlights that all children and youth can and have the right to learn and that their participation within the school curriculum should be optimised by ensuring that barriers to learning are mitigated. It also emphasises the need for the review and organisation of learner support systems and teaching and learning methods within schools<sup>6</sup>. The policy on Screening, Identification, Assessment and Support (SIAS)<sup>7</sup> is one of the incremental ways set out to operationalise the main elements of an inclusive education system as outlined in White Paper 6 referred to above. This policy further provides a framework that seeks to standardise the procedures to identify, assess and provide additional support to learners, thus maximizing their participation and inclusion in school<sup>7</sup>. The two mentioned policies reflect the government's commitment to promote access to a quality education for all. However, these policies lack specific and practical guidelines on how to support learners who experience barriers to learning following the onset of a newly acquired disability, specifically as these learners navigate the various transitions throughout their school career<sup>8</sup>.

### **The value and meaning of participating in school**

In their role as learners<sup>9</sup>, school participation encompasses those activities completed within the school environment including academic, non-academic (e.g., self-help and breaks) and extracurricular tasks (e.g., sports and clubs)<sup>10</sup>. It is through doing in school that learners learn and master skills, learn coping strategies and adapt to limitations. School further provides opportunities for learners to experience role identity and performance competence<sup>11</sup>. Competence is linked to the learners' capacity to effectively interact and meet the demands of the situations or tasks within their environment. School participation provides purpose and structure to learners' lives<sup>12</sup>. This was supported by qualitative studies that focused on the role of school for learners following TBI within Australia and the USA. Learners highlighted the significant role school participation played in providing purpose and structure through the educational and vocational goals that they set for themselves. Learners further highlighted that socialization was a key component of their school experience and an essential part of their school identity. The social aspects of school were viewed as integral specifically when it allowed the learner to experience a sense of belonging, acceptance, and positive recognition<sup>5,13</sup>.

### **School transitions post TBI**

School transitions for learners with TBI include the following transitions: hospital-school (school re-entry post TBI); grade-grade; primary-secondary school and secondary-post secondary transition<sup>14,5</sup>. The onset of a TBI may hinder the learner's ability to optimally transition and participate in school. In Australia, Sharp, Bye, Llewellyn and Cusick<sup>13</sup> found that adolescents who had acquired a TBI found it challenging to fit in when transitioning from hospital to school. There were certain factors that facilitated their ability to make this transition, including education of the relevant teachers and peers regarding the learners' TBI and specific needs and open communication between key role players (e.g., parents, teachers, and the multidisciplinary team). The provision of accommodations including assessment (e.g., extra time to complete tests), instructional (e.g., peer work tasks) and environmental accommodations (e.g., preferential seating) were additional factors. Learners also felt that their preparation visit to the school during which they could engage with educators and their peers assisted with a positive school transition<sup>13</sup>.

Once they had returned to school, learners felt that barriers to school participation included the teachers' inadequate response to their specific needs. This was demonstrated by their ineffective use of teaching and learning strategies. Further barriers included the lack of consistency in applying accommodations, and negative reactions from peers. The degree to which learners were able to adjust to their personal losses (i.e., loss of abilities, friendships, and future goals) associated with the TBI also impacted on their school participation<sup>13</sup>.

Most research found has focused on the initial return to school post TBI and the transition from secondary to tertiary education thus indicating the paucity in research regarding an adolescent's transition from primary to secondary school post TBI. The existing body of literature on the effect TBI has on adolescents transitioning from primary school to secondary school has predominantly been conducted in high income contexts<sup>5</sup>. This has resulted in a paucity in research on the effect of TBI on adolescents transitioning from primary school to secondary school in middle to low-income contexts. The need for research of the phenomenon within middle to low-income contexts such as South Africa is essential given the differences in terms of the geographical area, culture, socioeconomic status, policy, and legislation. These contextual differences have an impact on the interventions and strategies put into place<sup>7,8</sup>. Existing research has previously focused on the outsider's perspective of learners who have sustained a TBI, focusing on experiences of those who provide support to the learner (e.g., care-giver, teacher, health care professional), with limited research on the lived experiences of the learner<sup>5,13,8</sup>. The lack of the insider perspective, may result in the provision of support services which may not specifically address the needs of the learner and this may have a negative effect on the learner's ability to transition effectively.

The aim of this study was to explore adolescent learners with TBI lived experiences of their primary to secondary school transition within the Cape Metropolitan area. It was anticipated that this would provide an increased understanding of the factors that hinder and/or facilitate the primary to secondary school transition of adolescent learners with traumatic brain injuries to highlight the specific support needs of these learners. This may assist occupational therapists to render services which are relevant and responsive and are thus in line with a learner-centred approach.

## METHODOLOGY

### Research design

A qualitative phenomenological perspective with the implementation of an interpretive design allowed for the voices of the learners to be heard and directed the descriptions of the learner's lived experiences transitioning from primary to secondary school post TBI. The interpretive paradigm allowed the researchers to convey meaning to the learners' experiences<sup>15,16</sup>.

### Participant recruitment, sampling, and ethics

Prior to the commencement of this study, ethical approval Ethics Clearance Number: U19/01/008 was obtained from the Undergraduate Research Ethics Committee (UREC), Stellenbosch University and the Western Cape Department of Education, South Africa. Gatekeepers including occupational therapists working at public health care facilities or in educational settings who specifically focused on rendering services to learners with neurological disorders living within the Cape Metropolitan area were phoned and emailed to inform them of the research and to ask if they had learners who met the selection criteria (See Table I below). When appropriate candidates were identified, permission to conduct the research was obtained from the heads of the various health facilities. Four research participants were purposively selected (see Table II above) for demographics of participants)

**Table I: Selection criteria for research participants**

The traumatic brain injury must have occurred whilst the learner was in primary school.
Learners must have lived in the Cape Metropolitan region.
Learners must have been able to speak one of the three predominant languages spoken in the Western Cape Province, i.e., English, Afrikaans, or isiXhosa.
Learners must have either attended ordinary schools or special needs schools.
Learners must have experienced the transition to secondary school for at least six months. This includes learners who have dropped out of secondary school, but they must have experienced at least 6 months in secondary school and should not have been out of school for more than two years.
Learners must have cognitive and language abilities that allowed them to participate in an interview. The researchers relied on the gatekeeper who assessed the learner to indicate if he/she had a baseline level of cognitive functioning needed to participate in an interview. This was confirmed by reviewing the learner's medical/school records.

**Table II: Demographic information of participants**

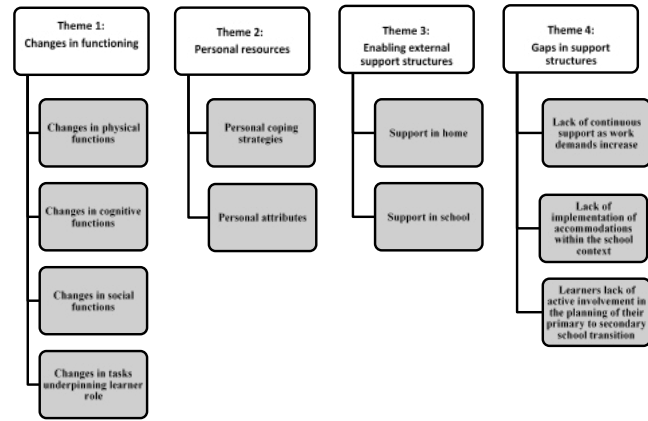
Pseudonym	Age	Gender	Grade TBI occurred	Grade currently in	Language	Socio-economic status
Kuyivo	14 years old	Male	13 years old	Grade 8	isiXhosa	Poor
Coffee	13 years old	Male	8 years old	Grade 8	English	Middle-class
Ashely	18 years old	Male	13 years old	Grade 11	English	Poor
Power	15 years old	Male	9 years old	Special needs /work skills class	isiXhosa	Poor

### Data collection

The researchers made telephonic contact with the primary caregivers of the potential participants to explain the research and to obtain verbal consent for their children to be approached regarding their participation in the study. Verbal assent was obtained from learners after explaining the research aim and research procedure. The researchers approached the principals of the schools the learners attended to inform them about the research and to gain approval for the research to be conducted on school premises. Learners were given written consent forms to give to their primary caregivers to complete and return prior to the commencement of the interviews. Written assent from the learners was obtained on the day of the first interview before the interview was conducted. It was ensured that the time scheduled was suitable for the learner and the teacher and that the interview was conducted in a private room to maintain the confidentiality of the learner. The focus of the study was reiterated, and the learners were given an opportunity to ask further questions before they gave written assent. One 60-minute or two 30-minute semi-structured face to face interviews were conducted depending on the learner's level of fatigue. The interview was conducted in the preferred language of the learner, i.e., Afrikaans, English or isiXhosa. The researchers were able to conduct the interviews in either English or Afrikaans and a translator was used when the learner preferred isiXhosa. The researcher asked the questions; the translator translated the question to the learner and then translated the answers back to the researchers in English to allow the researchers to transcribe them<sup>17</sup>. An interview guide with open-ended questions was used. The formulation of the questions was guided by the research objectives, literature on the research phenomenon, and were adapted from a questionnaire from a previous study that explored high school re-entry and school participation of adolescent learner's post TBI<sup>8</sup>. See Table III (page 29) for questions. All interviews were audio-recorded.

**Table III: Interview questions**

How long was it before you went back to primary school after your brain injury?  
Did you return to the same primary school that you were at before the injury? If no, why not?  
How did you experience primary school once you returned after the brain injury?  
Please tell us about how you first felt about moving from primary to secondary school.  
Was there a meeting to talk about this move from primary to secondary school? Who was part of this meeting?  
How would you say you were prepared for the move from primary to secondary school?  
Looking back do you think you were prepared enough for this move from primary to secondary school?  
Having the brain injury do you know if people at the secondary school were prepared for you coming to the school?  
What do you think could have been done more of or differently to help you feel more prepared for the move from primary to secondary school?  
When you started secondary school can you tell us how that went?  
What did the secondary school do to help you cope at school?  
Who helps you with your schoolwork at home?  
What do you think could be done differently or extra to help you do well at school?



**Figure 1: Themes and categories that emerged from the data**

as a result of their TBI they continue to experience impairments in their functioning, including physical endurance and vision:

“...Sometimes when I walk my legs get tired.” - (Power, Line 240)

“ ... I do have difficulty seeing.” - (Kuyivo, Line 44)

Learners also reported changes in cognitive functions such as impairments in their memory, comprehension, thought processes and concentration following the onset of the TBI:

“But short-term if you tell me about an hour ago then I would forget it.” - (Ashley, Line 253-254)

“... I can’t concentrate in class.” - (Coffee, Line 28 - 29)

“ ... after the accident I was slow, and I took my time to answer the question the teacher put on the board. The teacher would write the question on the board, and I would still be busy...” - (Power, Line 398 - 400)

Post TBI learners also reported changes in interpersonal interactions, which resulted in a loss of friends and limited their social interaction with their peers:

“...I had to stand and watch my friends play (soccer) and then I would just walk away because for me it was sad because I always used to play and up till today still I can’t. I just have to watch and look at them.” - (Ashley, Line 129-131)

“I only have one friend at school now.” - (Power, Line 544)

Learners further shared the changes they experienced in academic and extracurricular school activities once they transitioned from primary to secondary school and this impacted on their feelings of competence:

In the eventuality that the participants became distressed or anxious, the researchers intended to seek permission from the learner to refer them to the relevant gatekeeper for follow up support. This was not needed in the study.

### Data Analysis

Audio recordings were transcribed verbatim. The interviews that were conducted in isiXhosa made use of a translator that translated the interview from isiXhosa to English for the researcher to transcribe. Member checking took place where the translated transcription was translated back to the learner, in the language they had spoken during the interview, to ensure accurate transcription and thus upholding reliability<sup>17</sup>. Data was analysed using Burnard’s Framework<sup>18</sup>. This was an inductive process and included open coding with peer checking throughout. Similar codes were collapsed into categories and from these overarching themes emerged. Data management strategies included the use of password protected computers to store all data, the storing of audio recordings in a locked cabinet as well as the use of pseudonyms to de-identify the participants.

### Trustworthiness and Rigor

Trustworthiness with respect to credibility, transferability, dependability, and confirmability as identified by Krefting<sup>19</sup> was upheld through the implementation of investigator triangulation, member checking and reflexivity as well as provision of thick descriptions of the context and the learner.

### FINDINGS

Four overarching themes, depicted in Figure 1 (above), emerged from the data.

#### Theme One: Changes in functioning

This theme relates to changes the learners experienced post TBI, specifically focusing on the changes they experienced physically, cognitively, socially and with tasks underpinning their learner roles.

Physical changes are reflected by learners who state that

"I found that my marks were dropping, and my schoolwork became difficult." - (Power, Line 374 - 375)

"I was excited but also it was like I was like I couldn't do sports after. I was doing sports a lot in primary school. I used to run and play rugby and soccer also like in intervals, but I can't do any of that anymore." - (Ashley, Line 127-129)

"I love soccer and played good before the accident, but now I'm not good in soccer anymore." - (Kuyivo, Line 36 - 37)

### Theme Two: Personal Resources

Overall, this theme reflects learners' perspectives of their personal coping strategies as well as the personal attributes that helped them with the primary to secondary school transition and facilitated their participation in school.

Personal coping strategies that influenced the learners' capacity to transition from primary to secondary school and participate in school included taking active steps to improve their learning process and asking help from others. Some learners made use of preventative steps as a strategy to limit the impact of the residual impairments on their school transition and school participation.

Learners reflected that they take active steps, rather than maintain a passive role in their school transition process:

"... I raise my hand and ask a question." - (Power, Line 284)

"... so, I usually go to the psychologist at school or wherever and then I talk." - (Coffee, Line 19 - 20)

The use of preventative steps to assist with limiting the impact of memory impairments on the ability to complete academic related tasks is reflected by a learner:

"So, like on my phone also I will put the alarm on and a reminder and then I would like put the heading of the reminder like state everything that I have to do or like why did I put the reminder on." - (Ashley, Line 259-260)

Asking help from others was reflected by a learner who asked his peers for assistance to remind him about school related matters:

"I like tell my friends and so like just remind me about this and that..." - (Ashley, Line 258)

The personal attributes that learners reflected assisted them with their transition and participation in school included being internally motivated, having internal drive, and being hard working and being accepting of oneself.

"I just study harder when I don't do well, or I try to read through my work on my own without the help so, to see how far I can go without any guidance." - (Coffee, Line 19 - 20)

When a learner was asked what helped with the transition, he responded by saying that self-acceptance assisted with the adaptation:

"I just love myself for who I am." - (Coffee, Line 129)

### Theme Three: Enabling external support structures

Overall, this theme reflects learners' perspectives of the level of support they received from various support structures (e.g., family members and teachers) who helped them with the primary to secondary school transition and facilitated their participation in school.

Learners reflected that the support they received within their homes assisted with the school transition and ultimately facilitated their participation in school:

"My brother helps me with my homework." - (Kuyivo, Line 215)

"... I would ask my mommy to like to proofread it (notes for oral) and edit it for me." - (Ashley - Line 380)

"...my mother is always there for me and wouldn't expect anything back." - (Ashley, Line 226-227)

Learners further received support in the school environment. This included support from peers:

"Some of the friends help me with my work at school." - (Power, Line 292)

"... like to lend books but my friends and like people, just like every day I had to take books home so I could catch up." - (Ashley, Line 213-215)

Support in school further included accommodations made by teachers who allow the learners to ask questions about work they did not understand. Some teachers also provided extra academic and physical classroom adaptations to facilitate an optimal learning experience.

"They did help me (the teachers) and kinda helped like if they knew what happened and then they told me like after school if I didn't understand or so on I can come back and they will explain the work to me so I can write down notes and yeah they did that." - (Ashley, Line 116 - 118)

"(Teacher) helped me with the maths and maybe general subjects and (another teacher) helped me do sport and helped me exercise." - (Coffee, Line 294 - 295)

A learner also reflects on the different level of support he experienced from primary school educators as opposed to secondary school educators:

"... the teachers are also trying to help us. Helping us succeed in our school career. So last year (in primary

school) they wouldn't do that, they would say everyone on their own." - (Coffee, Line 411 - 413)

#### **Theme Four: Gaps in support structures**

Overall, this theme reflects on the learners' perspectives of the lack of continuous support as their school-related work demands increase; the lack of accommodations implemented to address their needs to overcome the barriers to learning and their lack of involvement in the planning and decisions with regard to the primary to secondary school transition.

Learners' share their experiences of the limited amount of support they received whilst their scholastic demands increased as they transitioned and progressed through secondary school. The learners identified the lack of support from educators and health professionals. They further alluded to the lack of focus on their mental functions in current support services.

"Physically, I think I was prepared, but not mentally cause obviously the workload was more so in like grade 8 I could still cope but in grade 9 it was difficult." - (Ashley, Line 211 - 212)

"Therapy? No, I don't get any therapy at school." - (Kuyivo - Line 69)

The lack of accommodation for the learners' specific needs within the schooling environment were shared by participants:

"We don't choose where to sit, the teachers give us alphabetical places to sit." - (Coffee - Line 475)

"No changes were made at the school to help with my walking." - (Power - Line 133)

"I wish I could be helped better at this school." - (Kuyivo - Line 283)

Learners shared their experiences of their lack of active involvement in the decisions and planning regarding their primary to secondary school transition.

"My parents chose it (the secondary school) for me." - (Power - Line 218)

"My mother chose the school for me; I prefer my old school because it was a technical school." - (Kuyivo - Line 52 - 53)

## **DISCUSSION**

The research sought to explore the insider perspective of the primary to secondary school transition post TBI. The findings revealed that there were certain factors that facilitated this transition whereas others that hindered it. These factors will be discussed in terms of the four overarching themes.

## **Theme One: Changes in Functioning**

According to literature, a TBI may result in physical, cognitive, and social changes<sup>14</sup>. Changes in physical abilities and skills resulted in some learners comparing themselves to their able-bodied peers (i.e., upward comparison). This impacted on the way they viewed themselves<sup>20</sup>. Changes in physical abilities and skills post TBI may therefore alter a learner's self-concept and lower their sense of self belief<sup>20,21</sup>.

Changes in mental function such as attention and concentration, memory, psychomotor function, higher-level cognition function and processing speed affected the learners' school participation. The learners reported that school related tasks now required more cognitive effort than before. These changes in mental function resulted in a negative change in some of the learners' academic performance, which led to a loss in self-belief as they compared their academic performance and standing pre and post TBI<sup>22,23</sup>. For these learners the decreased levels of competence they experienced in academic tasks, further decreased their self-confidence, and affected their sense of self belief.

Learners in this study also expressed changes in their social functions, due to the residual impairments of the TBI that specifically impacted on their ability to participate in extra-mural activities associated with the learner role. This change in social function impacted on the learners' sense of connectivity with their peers, a finding that is confirmed in previous studies<sup>24,25,26</sup>. For some, this resulted in the loss of friends. The impact on the social facet of the school experience has been reported by participants in studies by Sharp et al.<sup>13</sup> as well as Mealings and Douglas<sup>5</sup>. In this study, learners who did not experience positive relationships with their peers reported feeling isolated. This resulted in a change the way they viewed themselves prior to the injury, specifically in cases where learners reported that they were very sociable before the TBI. These learners did not experience a sense of belonging within their school community. These factors could result in learners experiencing school as negative and impact on their school transition as well as affect their confidence and motivation to continue to participate in school.

## **Theme Two: Personal Resources**

Literature has shown that learners with a TBI tend to implement certain coping strategies as they transition from one developmental phase to the next<sup>27</sup>. In this study, personal coping strategies refer to the cognitive-behavioural strategies learners used deal with challenging situations<sup>8</sup>. In this study, learners demonstrated a sense of agency through the use of coping strategies such as taking active steps, taking preventive steps and seeking assistance from others. This further reflected the learners' motivation and determination. The active steps the learners undertook are indicative of their assertiveness to achieve their goals. It included initiatives such as exercising preferential seating, asking questions to clarify learning material, speaking to the psychologist. Preventative steps (e.g., putting reminders on the phone) were taken to prevent residual impairments post TBI (e.g., changes

in memory) from impacting on the learners' ability to execute tasks linked with the various life roles they fulfil. Some learners took the initiative of seeking assistance from others. For example, asking peers to provide reminders about certain school related matters. Learners reflected that by demonstrating a sense of agency they were able to make the transition and participate in school following the onset of the TBI. This finding is supported by Boyden and Mann<sup>29</sup> who found that where adolescents were more actively taking control of their lives, they were more likely to make positive adaptations in response to stressful situations.

In this study, learners highlighted certain personal attributes that assisted them to adapt to their changes in functioning as well as the demands of the occupation and the occupational environment. These included the willingness to put in personal effort to achieve goals, intrinsic motivation, and determination. These findings were similarly found amongst students who re-entered secondary and post-secondary educational settings post TBI<sup>30,31,25</sup>.

For a learner to adapt to occupational and occupational environmental changes demands that a learner explicitly refer to the need for self-acceptance. This is supported by Klinger<sup>32</sup>, whose study highlighted that it was necessary for persons with TBI to adapt and accept the new identity (i.e., post injury self) before an individual is able to successfully integrate into their valued occupations.

### **Theme Three: Enabling External Support Structures**

Learners highlighted that their families - from whom they received ongoing support and acceptance - enabled them to make the school transition and adapt to the demands of their schooling. This is congruent with the findings of Mealings and Douglas<sup>5</sup> in which one of the major relationships highlighted as important in school transition and participation post TBI is that between the learner and the family. Shotton et al.<sup>20</sup> state that in their study, participants with brain injury reported family support was instrumental in increasing their capacity to cope and served as encouragement for them to achieve more.

For some learners the support and acceptance from their peers contributed to their positive school transition. Peers assisted learners by providing them with their class notes, which helped them catch up on lost work or to remain on par with academic demands. These findings are in alignment with other studies<sup>5,13</sup>. The supportive role of the learners' peer group in their adaptation process is also congruent with the developmental stage of adolescence (specifically middle adolescence) where the peer group plays a significant role in their development<sup>33</sup>. The positive influence of peers is further supported by Boyden and Mann<sup>29</sup> whose study findings indicate that interacting with their peers allows adolescents a platform where they are able to develop a sense of competency, develop relationships, empathise and experience a sense of belonging, which are important for building their self-esteem and resilience.

In this study, learners also commented on the positive

effect of the positive attitude of some of their teachers, this helped them feel accepted as part of the community at their school and assisted with their positive school transition. Teachers who seemed willing to work with learners following their changes in functioning post TBI and who were open to altering their teaching methods, helped these learners adapt to the increased workload. Similarly, in a study by Mealings and Douglas<sup>5</sup> it was found that positive teacher-learner relationships were associated with positive school experiences of learners post TBI, even in cases where learners' academic outcomes were not met, they still experienced school as being okay.

The above findings highlight the role of supportive relationships in enhancing the capacity of adolescents to overcome occupational challenges amid adversity. This is supported by van Breda and Theron<sup>34</sup> who stated that friends, primary caregivers, and teachers were the most prominent sources of support that fostered a sense of belonging and value amongst adolescents. This support assisted the adolescent to experience a positive transition and participate in valued occupations such as schooling.

### **Theme Four: Gaps in Support Structures**

For some learners, there appeared to be a decreased level of the school's commitment to inclusion which was reflected by the negative attitudes of some teachers. Participants in this study also attributed teachers' negative attitudes to their lack of understanding of the learner's support needs. The perceived lack of understanding and training regarding the learner's condition and support needs were supported in other studies<sup>35,36,37</sup>. Participant learners in a study by Vaidya<sup>37</sup> also reported that their teachers' lack of understanding of the effects of acquired brain injuries (including TBI), resulted in their needs not being adequately accommodated and, as such, resulted in five of the seven participants wanting to cease school attendance.

A school's decreased level of commitment to inclusion was also reflected by a schools' lack of adaptation of teaching and learning methods to suit the needs of the learners. This was reflected by the lack of implementation of reasonable accommodations in terms of instruction (e.g., graded return to school, adjustments in terms of workload, etc.), the environment (e.g., preferential seating, ramps, grab rails, etc.) and assessment (e.g., extra time, use of scribes, etc.)<sup>38</sup>. For some learners this resulted in them experiencing school as stressful, given the extra effort they needed to invest in school related activities which impacted on their school transition.

Learners reported a lack of mental preparation for the school transition resulting in decreased feelings of competence and confidence thus decreasing participation in school. Some participants referred to the lack of follow up support from members of the multidisciplinary team. Learners had difficulty with the transition given the increase in demands on their skills and abilities as they progressed from a primary to secondary school phase. The need for psychological support from the relevant health

professionals is vital given that learners are faced with an increase in workload in addition to the emotional conflict of having to replace their pre-injury self with a post injury concept that is both meaningful and satisfying<sup>39</sup>.

As learners were minors at the onset of the TBI, primary caregivers were involved in organising their children's school transition. Learners were, however, not consulted in terms of the choice of secondary school they would transition to. It is important that the adolescent's preference should also be factored in assessing the best fit for the adolescent as the findings in a study by Jacobs-Nzuzi Khuabi et al.<sup>8</sup> revealed that where adolescents did not feel that the school was a match in terms of supporting their career aspirations, they did not experience a sense of belonging and this impacted on their participation in school.

## CONCLUSION

The current study explored the lived experiences of primary to secondary school transition of learners post TBI. The study aimed to illuminate those factors that enable or hinder this school transition. Enablers included the learner drawing on personal resources, including personal coping strategies and personal attributes, as well as the role of enabling support structures. The main barriers included changes in function and fulfilment of the learner role post TBI; a lack of ongoing intervention by members of the multidisciplinary team; a lack of mental preparation of the learner; the lack of learner accommodations being implemented and the lack of active involvement of the learner in decisions regarding the primary to secondary school transition.

In order for these learners to receive support that is relevant and responsive, there is a need for ongoing interventions to equip learners with the necessary adaptive strategies to address the occupational limitations brought about by the learners' residual impairments post TBI. It is further recommended that, in addition to the academic related activities, a focus should be placed on interventions that aim to facilitate learners' engagement in the non-academic aspects given the sense of personal satisfaction, competence, and connectedness that learners have attributed to the engagement in these activities. Service providers, including occupational therapists should advocate for the applicable accommodations to be implemented in the learner's school environment. This should be underpinned by educating other key role players involved in the primary to secondary school transition including learners, parents, and teachers on the range of support that the adolescent is entitled to. A learner centred approach should be adopted for interventions, which seeks to include the adolescent in the planning and decision making with regards to the primary to secondary school transition. Planning the primary to secondary school transition should seek to prepare the learner, and those in the learner's context. Preparation of the learner should include the development of the learner's self-advocacy skills, i.e., capacitating them to navigate the applicable support structures.

## STUDY LIMITATIONS

The study's small sample and location within the Cape Metropole does not make these findings generalisable. However, the purpose of the study was to provide a deeper understanding of the phenomenon rather than to generalise the results. Future studies could be completed in other provinces within South Africa as well as in rural areas to further explore the learners' experiences of transitions between different school phases post TBI.

## AUTHOR CONTRIBUTIONS

Lee-Ann Jacobs-Nzuzi Khuabi conceptualised the project, supervised data collection and analysis and contributed to the write up of the article. Kauthar Ally, Salmah Khan, Marizaan Moolman, Asmaa Begum Mustapha, Misqah Parker were fourth year occupational therapy students at Stellenbosch University at the time of the research project's execution. They conceptualised the project, collected and analysed data and contributed to the write up of the article.

## CONFLICT OF INTEREST

The authors declare that there are no conflicts of interest.

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