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Simone Harris; Zipora Katz; Marcelle Smith; Andre Mochan; Aline Ferreira Correia

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Disparities in access to treatment in relation to quality of life in people diagnosed with Parkinson's disease in the South African healthcare setting

S Harris,[1] BA (Hons Psyc), MA (SPR); **Z Katz,**[2] MB BCh, FCN (SA); **M Smith,**[3] MB ChB, FCN (SA); **A Mochan,**[2] FCP (SA)Neurology, FRCP (London); **A Ferreira-Correia,**[1] MA ClinPsyc, PhD

[1] *Department of Psychology, School of Human and Community Development, Faculty of Humanities, University of the Witwatersrand, Johannesburg, South Africa*
[2] *Division of Neurology, Department of Neurosciences, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa*
[3] *Wits Donald Gordon Medical Centre and Mediclinic Sandton, Johannesburg, South Africa*

Corresponding author: *A Ferreira-Correia (Aline.FerreiraCorreia@wits.ac.za)*

Background. South Africa's divide between the public and private healthcare sectors has implications for healthcare access and quality of life (QoL) outcomes. This exploratory study aimed to identify the types of treatments used by people with Parkinson's disease (PWPD) in two different healthcare settings (public and private), and their perception of treatment satisfaction. Additionally, this study compared the QoL experienced between these healthcare settings, and investigated whether the number of treatments, internet access and income level were associated with QoL.
Methods. Cross-sectional questionnaires assessing demographic variables and QoL were administered to PWPD across two different healthcare settings in the city of Johannesburg (public n=42, private n=38).
Results. PWPD in the private healthcare setting had greater access to treatment options and better QoL outcomes than PWPD in the public healthcare group ($p \leq 0.05$), who relied almost exclusively on medication to treat PD symptoms. The QoL psychological domain was the lowest across both healthcare settings. No significant differences were observed in treatment satisfaction.
Conclusion. PWPD using the public healthcare setting had reduced access to PD treatments and poorer QoL than PWPD using private healthcare. The number of treatments, household income and internet access were strongly correlated with QoL outcomes.

Keywords: Parkinson's disease, quality of life, treatment access, household income, internet access, healthcare disparities

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Parkinson's disease (PD) is a progressive neurodegenerative illness caused by the loss of dopaminergic neurons in the substantia nigra pars compacta (SNpc).[1] Characteristic PD motor symptoms include bradykinesia, tremor, postural instability and rigidity, as well as non-motor symptoms such as sensory abnormalities, autonomic dysfunction, behavioural changes, fatigue, and sleep, mood and psychiatric disturbances.[2] Symptoms manifest differently in every person with PD (PWPD), and subsequently impact quality of life (QoL).[2] Motor symptoms are managed primarily by pharmacotherapy, specifically levodopa, which is focused on the restoration of dopamine activity in the striatum.[4] However, prolonged use of levodopa treatment can have adverse effects such as fluctuations in motor response, which impact on QoL.[5,6] While there are also medications available to treat non-motor symptoms, such as cognitive impairment, sleep disorders and depression, these treatments only provide symptomatic relief due to the incurable nature of PD.[2] Adjunct therapies such as deep brain stimulation (DBS) surgery,[6] physiotherapy,[7] occupational therapy (OT),[8] speech therapy,[9] bright light therapy (BLT),[10] psychiatric and psychological therapy,[11] nutritional and dietary interventions,[12] cannabidiol (CBD) therapy,[13] traditional healing therapy[6] and botulinum toxin therapy[14] have all been used to manage motor and non-motor PD symptoms with the aim of improving QoL of PWPD.

The World Health Organization WHO Quality of Life Group[15] defines QoL as 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'. In PD, QoL has been linked to the progression and severity of both motor and non-motor symptoms.[16] In South Africa (SA), QoL of PWPD is further threatened by exorbitant socioeconomic inequalities,[17] characterised by deep disparities in access to basic needs, employment, quality education and adequate healthcare, which are mainly suffered by black African citizens living in rural areas.[18] A striking divide in the quality of healthcare received exists between the minority of the population who can afford private health insurance, and the majority who cannot.[19] Those who cannot afford private medical aid face greater barriers to receiving appropriate diagnosis, holistic treatment and adequate management. These discrepancies are further aggravated by other socioeconomic stresses and the progressive nature of the disease's chronicity and growing disability, such as the costs of chronic medication, travelling and specialised care.[20] This significantly increases the economic burden for the patient, their family and society,[8] while negatively affecting the QoL of PWPD and their families.

Another variable linked to QoL in PD is access to information about the disease and its management, as reduced or lack of access to information has been associated with delayed, incorrect, or absent diagnoses,[21] which can potentially lead to poor management and accelerated decline. Communication technologies have enabled access to health education and services, and have the potential to redefine healthcare;[22] however, inequalities regarding internet

access can limit or preclude connections between patients and web-based education sites as well as other support structures, such as communities of peers and telehealth services.[23] Therefore, access to health-related information may be affected by the availability and capacity to use diverse communication technologies and the internet. With this background, our study aimed to (*i*) explore treatment access and QoL of PWPD who use public or private healthcare facilities; and (*ii*) investigate whether the number of treatments used by PWPD, internet access and income level are associated with QoL.

Methods

Data collection took place over 6 months (January 2022 - June 2022) in Johannesburg, SA, using purposive homogenous sampling.[24] A total of 80 adult participants diagnosed with PD by a neurologist were recruited. Participants were receiving neurological care for PD in the private (n=38) or public (n=42) healthcare sectors, namely Sandton Mediclinic and Chris Hani Baragwanath Academic Hospital, respectively. Treating neurologists from these services informed PWPD of the research, who then either voluntarily consented or declined to be interviewed by the principal investigator of the study. Exclusion criteria included a history of traumatic brain injury or stroke, as well as active alcohol or drug use.

A demographic questionnaire was used to collect sociodemographic information, treatment modalities and internet access. QoL was assessed using the WHO Quality of Life instrument (WHOQOL-BREF) containing 26 5-point Likert items. This is the abbreviated version of the original 100-item instrument (WHOQOL), which is recommended for studies on patient-reported QoL when time is restricted due to the burden of a disease or disability, which should be minimised.[15,25] These instruments were administered in one session of approximately 30 minutes. In the public healthcare setting, participants opted for face-to-face administrations of the questionnaires, while most participants in the private healthcare facility requested telephonic administrations of the questionnaires.

The Human Research Ethics Committee (Medical) of the University of the Witwatersrand granted ethical clearance for the study (ref. no. M210934). Volunteers received an information sheet with full disclosure of the research aims and their rights, as well as access to the results upon completion of the study. The researchers honoured the Declaration of Helsinki[26] and the Singapore Statement on Research Integrity.[27]

Data analysis

Data analysis was performed using SAS version 9.4 for Windows (Microsoft, USA), with a significance level of 5%. Descriptive statistics, including frequency, percentages, median and ranges, were used to summarise the data (overall and by group). The χ^2 test was used to assess the relationships between categorical variables and the healthcare sector, while Fisher's exact test was employed when the assumptions for the χ^2 test were not met. The relationship between continuous variables and healthcare sector was assessed by the independent samples t-test. If the data did not meet the assumptions for this test, the Wilcoxon rank sum test, a non-parametric alternative, was applied. The Kruskal-Wallis test was used to explore the association between QoL scores and the number of treatments, household income and internet access, as the data did not meet the assumptions for a one-way ANOVA. Analysis of the proposed model for QoL as a function of the number of treatments, income and internet access was not possible because all three independent variables were highly correlated (Cramer's V>0.50) and could not be included in the same model. Given the sample size of 80, with an effect size of d=0.7, only large effect sizes, if present, would be detectable.

Results

Table 1 presents a summary of the demographic data. Most (62.5%) participants were male, and the median age of all participants was 68 years. The large majority (92.1%) of PWPD in the private healthcare group were on a medical aid, whereas only one person in the public healthcare group had health insurance. The private (n=38) and public (n=42) healthcare sector groups were homogenous in terms of age, gender distribution, relationship status and employment, but they were significantly different in several demographic variables (p<0.05), i.e. home language, level of education, household income and access to medical aid and internet. Most participants in the public sector had <11 years of education, whereas the majority of the participants in the private sector had matric and above, with 44.74% having postgraduate education levels. Most (92%) participants in the private group earned >ZAR20 000 per month, as opposed to the majority (81%) of PWPD from the public group, who received monthly household incomes of ≤ZAR3 500. Income disparities were so wide, in fact, that 42% of PWPD in the private group had household incomes of >ZAR50 000 per month, more than the large majority of PWPD in the public group received in a year. As anticipated, the public healthcare sector group had significantly lower access to internet and medical aid, when compared with the private healthcare group.

The groups were similar in terms of the variables that characterised disease duration, such as time since diagnosis and duration of symptoms before the diagnosis. Most of the participants had been diagnosed in the past 10 years and had received a diagnosis a few months after experiencing their first symptoms (Table 1).

Table 2 summarises a variety of treatments reported by our participants. It is unsurprising that no significant differences (>0.99) were found between the private and public healthcare group in terms of the use of medication, as it was the primary therapy for PD-related symptoms of the majority of the sample (98.75%). Only five (11.9%) PWPD from the public hospital listed adjunct therapies (physiotherapy n=3 and speech therapy n=2), whereas the majority of PWPD in the private group were using a wider range of options to treat and manage PD symptoms, such as physiotherapy (n=20), DBS (n=12) and mental health services (n=6). No participant in the study received light therapy or traditional healing therapy to manage their symptoms. Notably, the groups were homogenous in terms of the use of medication as a primary treatment, and the low use of adjunct services, such speech therapy, OT and dietician. The main significant differences (p<0.05) between the private and public healthcare groups were their access to DBS, physiotherapy and mental health services, exposing a huge discrepancy in how symptoms are managed in both sectors.

Descriptive and comparative statistics (Wilcoxon rank sum test) revealed that the public healthcare sector group had significantly poorer QoL than the private health sector group across all domains (p≤0.05) (Table 3). This indicates that the functional capacity and state of health of PWPD in the public sector is low in comparison to those who can afford healthcare in the private sector.

To investigate this further, a Kruskal-Wallis test was used to examine whether the number of treatments, income level and internet access were associated with QoL. As shown in Table 4, individuals who received ≥2 types of treatment had significantly higher median total QoL scores, as well as higher median scores in the social and environment domains. However, no significant relationship was found between the physical and psychological QoL domains and the number

Table 1. Descriptive statistics and comparisons between the private and public healthcare sectors for demographic and disease duration variables (*N*=80)

Characteristic	Overall, *n* (%)*	Private healthcare sector, *n*=38, *n* (%)*	Public healthcare sector, *n*=42, *n* (%)*	*p*-value
Demographic variable				
Age (years), median (IQR), range	68 (56 - 73), 24 - 84	70 (60 - 75), 45 -84	64 (55 -72), 24 - 79	0.097
Male	50 (62.5)	22 (57.98)	28 (66.67)	0.49
Home language				**<0.0001**
English	29 (36.25)	27 (71.05)	2 (4.76)	
Zulu	12 (15)	2 (5.26)	10 (23.81)	
Sotho	12 (15)	0 (0)	12 (28.57)	
Afrikaans	9 (11.25)	8 (21.05)	1 (2.38)	
Xhosa	3 (3.75)	0 (0)	3 (7.14)	
Other	15 (18.75)	1 (2.63)	14 (33.33)	
Relationship status				0.0085
Married/cohabiting	47 (58.75)	28 (73.68)	19 (45.24)	
Single/divorced/widowed	33 (41.25)	10 (26.32)	23 (54.76)	
Employed†	15 (18.75)	10 (26.32)	5 (11.90)	0.15
Highest level of education				**<0.0001**
Primary school	10 (12.5)	0 (0)	10 (23.81)	
High school (without matric)	28 (35)	2 (5.26)	26 (61.90)	
Matric	11 (13.75)	7 (18.42)	4 (9.52)	
Undergraduate qualification	14 (17.5)	12 (31.58)	2 (4.76)	
Postgraduate qualification	17 (21.25)	17 (44.74)	0 (0)	
Household income per month				**<0.0001**
<ZAR3 500	34 (42.5)	0 (0)	34 (80.95)	
ZAR3 500 - ZAR10 000	7 (8.75)	2 (5.26)	5 (11.90)	
ZAR10 000 - ZAR20 000	4 (5)	1 (2.63)	3 (7.14)	
ZAR20 000 - ZAR50 000	19 (23.75)	19 (50)	0 (0)	
> ZAR50 000	16 (20)	16 (42.11)	0 (0)	
Internet access	46 (57.5)	34 (89.47)	12 (28.57)	**<0.0001**
Medical aid	36 (45)	35 (92.11)	1 (2.38)	**<0.0001**
Disease duration variables				
Time since diagnosis				0.073
>15 years	9 (11.25)	3 (7.89)	6 (14.29)	
10 - 15 years	8 (10)	4 (10.53)	4 (9.52)	
In the last 10 years	53 (66.25)	29 (76.32)	24 (57.14)	
Very recently	10 (12.5)	2 (5.26)	8 (19.05)	
Duration of symptoms before diagnosis				0.03
A few months	46 (57.5)	17 (44.74)	29 (69.05)	
1 year	13 (16.25)	10 (26.32)	3 (7.14)	
≥2 years	21 (26.25)	11 (28.95)	10 (23.81)	

IQR = interquartile range.
*Unless otherwise indicated.
†Employment includes self-employment, part-time and full-time employment.
Significant differences highlighted in bold.

of treatment types. Additionally, the median QoL scores varied significantly across income levels for all QoL measures. For both the total QoL and the social and environment domains, individuals earning ≥ZAR20 000 had higher median scores than those with lower incomes. In the physical and psychological domains, those earning ≥ZAR20 000 also had higher median scores than those earning ≤ZAR3 500. Furthermore, individuals with internet access had significantly higher median QoL scores across all measures, with the most pronounced difference observed in the environment subdomain.

This study aimed to examine the significant disparities between PWPD who use public v. private healthcare services. In brief, the results indicate that PWPD using public healthcare services in our sample have less access to treatment and experience lower QoL, which seem to be driven by lack of treatment availability, and mostly by the detrimental effects of poverty.

Specifically, PWPD using the public healthcare system have significantly less access to diverse treatment options compared with participants in the private system, with most patients in the public sector relying primarily on medication to manage PD symptoms. Available evidence indicates that treatments beyond pharmacotherapy play a crucial role in significantly improving the functional capacity of individuals with PD.[28] Interventions such as DBS,[6] physiotherapy, OT[7] and speech therapy[9] have been shown to alleviate symptoms and enhance motor and cognitive

Table 2. Descriptive statistics and comparisons between the private and public healthcare sectors for Parkinson's disease treatment-related variables (*N*=80)

Treatment	Overall, *n* (%)	Private, *n*=38, *n* (%)	Public, *n*=42, *n* (%)	*p*-value
Medication	79 (98.75)	38 (100)	41 (97.62)	>0.99
Physiotherapy	22 (27.5)	19 (50)	3 (7.14)	**<0.0001**
DBS	12 (15)	12 (31.58)	0 (0)	**<0.0001**
Psychiatry/psychotherapy	7 (8.75)	7 (18.42)	0 (0)	**0.004**
Speech therapy	5 (6.25)	3 (7.89)	2 (4.76)	0.66
Occupational therapy	4 (5)	4 (10.53)	0 (0)	**0.047**
Dietician	2 (2.5)	2 (5.26)	0 (0)	0.22
CBD therapy	2 (2.5)	2 (5.26)	0 (0)	0.22
Other*	7 (8.75)	7 (18.42)	0 (0)	**0.004**
Treatments, *n*				
1	49 (61.25)	10 (26.32)	39 (92.86)	**<0.0001**
2	14 (17.5)	13 (34.21)	1 (2.38)	
3	9 (11.25)	7 (18.42)	2 (4.76)	
≥4	8 (10)	8 (21.05)	0 (0)	
Current treatment				
Medication only	49 (61.25)	10 (26.32)	39 (92.86)	**<0.0001**
Medication plus other treatment(s)	31 (38.75)	28 (73.68)	3 (7.14)	
Treatment satisfaction				
Treatment works very well	38 (47.5)	15 (39.47)	23 (54.76)	0.12
Treatment works well	23 (28.75)	15 (39.47)	8 (19.05)	
Treatment does not work as well as it used to	17 (21.25)	8 (21.05)	9 (21.43)	
Other	2 (2.5)	0 (0)	2 (4.76)	

DBS = deep brain stimulation; CBD = cannabidiol.
*Largely botulinum toxin therapy.
Significant differences highlighted in bold.

Table 3. Descriptive statistics and comparisons between the private and public healthcare sectors for quality of life (WHOQOL-BREF) total and domain scores (*N*=80)

Quality of life domains	Overall, median (IQR), range	Private, *n*=38, median (IQR)	Public, *n*=42, median (IQR)	*p*-value
Total	85 (75 - 101), 46 - 122	101 (90 - 111)	76 (66 - 84)	**0.0016**
Physical domain	63 (56 - 69), 25 - 88	69 (63 - 75)	56 (44 - 69)	**0.0001**
Psychological domain	50 (44 - 63), 19 - 81	63 (44 - 69)	44 (31 - 56)	**<0.0001**
Social relationships domain	69 (56 - 81), 19 - 100	81 (75 - 94)	69 (50 - 69)	**<0.0001**
Environment domain	69 (50 - 94), 19 - 100	94 (88 - 100)	50 (44 - 63)	**<0.0001**

IQR = interquartile range.
Significant differences highlighted in bold.

functioning. Additionally, mental healthcare (i.e. psychiatric and psychological services)[11,29] have proven beneficial in addressing burdensome non-motor symptoms, further improving the QoL for PWPD. Lastly, botulinum toxin injections[14] have been used to manage a myriad of localised symptoms. Together, these treatments underscore the importance of a multidisciplinary approach to managing PD and enhancing patient wellbeing. Nutritional interventions and CBD therapy[6] are also available to those in the private sector, though their efficacy remains debated.[30,31] No participants in our sample used traditional healing therapy to manage their symptoms, which is in contrast with other findings in the country and continent.[32,33] This could be attributed to a sample bias, as we only included patients under neurological care.

Overall, our results reinforce the idea that discrepancies in treatment access are associated with income inequality,[34] which is a marked and rising trend in sub-Saharan Africa,[35] where multidisciplinary treatments are rare or completely unavailable in most government-run healthcare settings.[33]

Unexpectedly, we found no significant differences in treatment satisfaction between the two groups. The majority of participants reported that their treatment works well (28.75%) or very well (47.5%). This contrasts with other evidence that reveals, first, lower treatment satisfaction in PWPD,[36] and second, significant associations between treatment satisfaction in PD and QoL.[37,38] A study conducted in SA suggests significant cultural variability in attitudes toward PD, which may influence perceptions of treatment efficacy,[32] and could explain the misalignment with international literature.

Considering the established benefits of treatments such as DBS, physiotherapy and OT in alleviating PD symptoms,[7,39,40] it is evident that PWPD in the public healthcare group are not receiving optimal care, as it is not aligned with the scientific literature that supports the use of different treatment modalities at different stages of the disease.[41] This likely contributes to the significantly lower QoL across all domains observed in the public healthcare group when compared with the private sector.

Notably, significantly higher scores ($p \leq 0.0001$) in the environment domain of QoL were observed in the private healthcare group,

Table 4. Descriptive statistics and group comparisons for Quality of Life (WHOQOL-BREF) domains for public healthcare, private healthcare and total sample (N=80)

		Quality of life domain, median (IQR)				
Variable		**Total**	**Physical**	**Psychological**	**Social relationships**	**Environment**
Treatments, *n*						
1	49	80 (68 - 89)	63 (56 - 69)	50 (38 - 63)	69 (56 - 75)	56 (44 - 69)
2	14	97 (81 - 109)	69 (56 - 75)	60 (44 - 69)	75 (69 - 81)	94 (81 - 100)
≥3	17	97 (87 - 04)	63 (56 - 69)	56 (44 - 69)	75 (69 - 81)	94 (88 - 100)
p-value		**0.001**	0.57	0.27	**0.017**	**<0.0001**
Income						
<ZAR3 500	34	75 (66 - 81)	56 (44 - 69)	44 (31 - 56)	69 (56 - 69)	50 (44 - 60)
ZAR3 500 - ZAR20 000	11	84 (68 - 90)	63 (56 - 69)	50 (31 - 63)	69 (44 - 81)	63 (50 - 81)
ZAR20 000 - 50 000	19	102 (94 - 109)	63 (56 - 75)	63 (50 - 69)	81 (75 - 94)	94 (88 - 100)
>ZAR50 000	16	103 (87 - 114)	75 (63 - 81)	60 (44 - 75)	78 (69 - 94)	94 (88 - 100)
p-value		**<0.0001**	**0.0030**	**0.0004**	**<0.0001**	**<0.0001**
Access to internet						
Yes	49	97 (81 - 104)	66 (56 - 75)	56 (44 - 69)	75 (69 - 81)	88 (75 - 100)
No	14	77 (67 - 85)	56 (44 - 69)	44 (31 - 56)	69 (56 - 75)	53 (44 - 63)
p-value		**<0.0001**	**0.0097**	**0.0032**	**0.0038**	**<0.0001**

IQR = interquartile range.
Significant differences highlighted in bold.

reflecting greater financial resources, better living conditions, greater access to healthcare services, transportation, and educational opportunities, and increased participation in leisure activities. This shows how poverty and inequality are intrinsically linked to QoL and healthcare access,[42] a reality with an underlying racialised nature in SA[43] and globally.[44] Both groups, however, faced significant challenges in the psychological domain of QoL, which includes aspects such as emotional wellbeing, self-esteem, body image and spirituality. PWPD commonly experience depression, anxiety, stress and apathy, which severely affect QoL.[45-47] Despite the profound impact of these non-motor symptoms, they are often left untreated, as evidenced by our sample, where only 7.5% of participants accessed psychiatric or psychological services. Addressing mood disorders is essential for improving QoL in PD.[9] However, mental health services remain scarce and underfunded in SA, making them inaccessible to most PWPD,[48] which likely contributes to the low QoL scores in this domain.

Our analysis revealed significant correlations ($p \leq 0.0001$) between income, internet access and all QoL scores, further supporting the notion that household income is a predictor of access to treatment for PD.[34] In contrast, the number of treatments utilised by participants showed a significant correlation with the total QoL score, and with the social relationship and environment domains. Although our data were insufficient to disentangle the relationship between number of treatments and QoL, it may illustrate not only the impact of poverty on treatment access and overall QoL,[34] but also the financial burden of PD on patients and their families not living in poverty, which exacerbates disparities in healthcare engagement.[33]

Participants in our study had diverse socioeconomic backgrounds, with stark differences in household income between those in the public and private healthcare sectors. Most participants in the public sector reported a monthly household income of <ZAR3 500, a sum largely allocated to food expenses, making out-of-pocket medical expenses impossible because the coverage of basic needs is already at a bare minimum.[49] Moreover, the absence of free multidisciplinary services in both urban and rural areas is a critical shortcoming in the SA healthcare system, as well as in other parts of sub-Saharan Africa,[33,50] which directly contributes to the low QoL observed in PWPD,[44] but could mitigate the effects that poverty has on healthcare access and general wellbeing for the majority of the SA population.[50] In short, our study highlights the urgent need to address the intricate impact that socioeconomic factors such as poverty have on QoL and treatment availability for PWPD in SA.

Conducting research on PD in the African context presents considerable challenges, with several limitations arising from constrained resources.[51] In our study, the sample size was inadequate to disentangle the relationships between specific demographic and treatment variables and QoL. The use of two different administration modalities may have introduced unintended variability, but we believe the primary limitation was that all data collection was conducted in English, a language that was not the first language of all participants. This may have influenced how participants understood and responded to the assessment protocol.[52] Future research should strive for a more representative sample of the SA PD population, incorporating a wider range of linguistic and sociocultural diversity. Furthermore, it should offer a more nuanced examination of treatment protocols and the subjective experiences of PWPD, particularly focusing on QoL and treatment satisfaction.

Conclusion

PWPD using the public healthcare sector had reduced access to PD treatment and poorer QoL than those using the private healthcare sector. The number of treatments, household income and internet access were strongly correlated with QoL outcomes. Our results emphasise the need for better healthcare in the public sector for people with PD to improve their QoL, and we join the call for improving equitable access to multidisciplinary treatment for PD motor and non-motor symptoms.

Data availability. The anonymised data set that supports the findings of this study is available upon reasonable request from the corresponding author (AFC).

Declaration. This study was conducted as part of the first author (SH)'s Master's in Research Psychology degree from the University of the Witwatersrand.

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