The achievement of community integration and productive activity outcomes by CVA survivors in the Western Cape Metro Health District

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ABSTRACT

Introduction: *According to the South African National Rehabilitation policy, achieving advanced outcomes such as community integration and productive activity, should be the focus of the rehabilitation services. However, according to the literature, rehabilitation does not often progress beyond basic outcomes such as mobility and self-care.*
The aim of this study was to describe the achievement of community integration and productive activity outcomes by a group of CVA survivors in the Western Cape Metro Health District.

Methods: *A descriptive study was carried out. Quantitative data were collected from 57 CVA survivors and caregivers. All these CVA survivors had received in-patient rehabilitation at the Western Cape Rehabilitation Centre (WCRC). Data were collected by means of a medical and demographic questionnaire, the Barthel Index and the Outcome Levels according to Landrum et al.*

Results: *On discharge from in-patient rehabilitation seven (12%) stroke survivors were at level II ie they had achieved only the basic rehabilitation outcomes necessary to preserve long term physiological health, whereas 37 (65%) stroke survivors were discharged at an outcome level III ie ready for residential integration, and 12 (21%) were at level IV ie community integration, and one (2%) at level V (productive activity). Assessment at the time of the study showed a general improvement post discharge, with 21 participants (37%) improving by one or two outcome to achieve community integration and five (9%) achieving the outcome level of productive activity through informal income generating activities.*

Conclusion: *Thirty three (58%) stroke survivors achieved community integration, while six (10%) progressed to employment. One would like to see further progress to employment especially for those participants who were employed before the stroke. Clinicians might be able to assist more stroke survivors to achieve this through using the outcome levels and incorporating the interventions to reach productive activity such as performing work and skills assessments, employer education and assistance with reasonable accommodations in rehabilitation goals.*

Key words: Cerebro vascular accident, outcome levels, productive activity

Introduction

Rehabilitation should enable a person to achieve independence, social integration, economic self sufficiency, improved quality of life and self-actualisation, besides addressing issues like the equalisation of opportunities, adaptations to the environment and the promotion and protection of human rights[1]. The South African National and Western Cape Provincial policy documents such as the National Rehabilitation Policy (NRP)[2] and the Comprehensive Service Plan for the Implementation of Health Care 2010[3] reflect the above definition of rehabilitation and further states that comprehensive rehabilitation should be offered along a continuum of care, from primary through to tertiary level health care services. However, South Africa (SA) is failing to implement comprehensive rehabilitation practices[4]. This failure is caused by an array of challenges such as a lack of personnel and other resources[5], lack of transport[6], poor co-ordination of services[4], a lack of intersectoral co-operation[7], a protracted health transition process[5] and a complex, quadruple burden of disease [5].

According to Landrum, Schmidt and McClean[8] rehabilitation should not only be provided along a continuum of care between services, it should also follow a continuum of progression in individual lives from basic outcomes like physiological stability and prevention of secondary complications, to advanced outcomes, such as community integration and employment. In order to map this progression they proposed six chronological outcome levels through which a person should progress during the rehabilitation process[8]. It is important that rehabilitation professionals understand the levels and the objectives to be achieved in each since failure to fully achieve the objectives of a lower level will impact negatively on the progression to higher levels. For instance failure to prevent secondary complications (level II) will hamper a person's ability to be successfully employed (level V)[8].

Since rehabilitation should strive to achieve community integration and economic self-sufficiency[1,2,3], it is important that therapists have a way to assess whether patients achieve this. Furthermore, it is necessary to structure individual patient rehabilitation pathways and set goals in a way that these outcomes can be achieved as efficiently as possible. The outcome levels can assist therapists to do this[8].

There is little information available on the extent to which stroke survivors in South Africa achieve advanced outcomes like community integration and productive activity (level IV and V). The current article aims to contribute some information towards addressing this void. The aim of the research was therefore to describe the extent to which CVA survivors in the Western Cape Metro Health District achieved community integration and productive activity (level IV & V).

Literature review

Table 1 provides an overview of the six outcome levels according to Landrum et al[8] and broad descriptions of what aspects should be addressed at each level.

It is important to note that a person does not have to be independent in doing the tasks as described in *Table 1* to achieve any given level, but must be able to direct a caregiver in assisting in the performance of the tasks. Thus a person can achieve level

Table 1: Outcome levels according to Landrum, Schmidt and McClean[8]

Level	Description	Tasks that must be achieved to achieve the level
Level 0: Physiologic instability	Acute diagnostic and medical issues are not addressed and managed.	Directly following a health incident such as stroke.
Level I: Physiologic stability	All major acute diagnostic and medical issues are appropriately addressed and managed.	• Diagnosis made • Treatment plans decided on and implemented e.g. Hypertension controlled through medication
Level II: Physiologic maintenance	Achievement of basic rehabilitation outcomes necessary to preserve long-term physiological health.	• Client and family educated and trained • Rehabilitation and long-term management plans in place • Strategies to prevent secondary complications in place: - Bladder and bowel - Diet, swallowing and aspiration - Prevention of chest infections - Pressure sore prevention - Prevention of contractures - Emotional support - Pain management Limited physical and cognitive outcomes such as mobility and communication can be achieved but are not the focus of this level.
Level III: Residential integration	Achievement of status where the person can function reasonably and safely in a residential setting.	• Self-care tasks performed • Mobile in and around dwelling • Effective general communication system • Safe in home Activities such as self-care can be performed by another person, but must be directed by the client
Level IV: Community integration	Achievement of an appropriate level of function within the person's community, i.e. participate in social activities such as shopping, church and sport according to individual needs.	• Manage personal affairs & finances • Socially competent • Community mobility • Complex home-making abilities • Self-directed health management
Level V: Productive activity	Work at a competitive level within physical, functional, and/or cognitive capabilities and appropriate to life stage & interests. This can be vocational, avocational or educational.	• Environment, disabilities & job requirements play a role • Work & skills assessment • Vocational training • Employer education • Reasonable Accommodations
* Note that at all levels, tasks can be performed by another ie a care giver, but all must be client-directed		

V even if dependent on another for activities such as washing, dressing and community mobility[8] if they can direct caregivers, and service providers such as taxi drivers to assist them. To paraphrase Shakespeare[9] all of us pay people to perform certain tasks for us and accept assistance from others. Why should persons with disabilities be seen as different if they pay someone to wash or dress them?

The importance of applying outcome levels in the planning process for individual patients lies in the ability of outcome levels to guide goal setting, since lower levels must be reached before higher ones[8]. Thus rehabilitation professionals can determine a current level on first assessment and then project a maximum level according[10] to assessment findings and set specific goals to be achieved so that progress through levels can be made during rehabilitation until the patient has reached his maximum level[8]. In addition the use of outcome levels can prevent omission of important aspects early in rehabilitation that might hamper outcomes at a later stage, and they can prevent rehabilitation from becoming impairment focused without translating gains to functional outcomes[8]. Finally it can assist in ensuring that rehabilitation is followed through to the patient's maximum outcome level[8].

While any of the levels can be achieved in an array of rehabilitation settings, levels I and II are best achieved in an acute hospital setting while level III is achieved during in or outpatient rehabilitation and levels IV and V in a community rehabilitation setting[3,8]. Furthermore during the first few days post stroke the emphasis of therapy should be on education, prevention of immediate as well as future complications and the establishment of long term rehabilitation and management plans as opposed to hands-on treatment. Once these crucial aspects have been dealt with, issues of self-care, mobility, communication and home making are addressed followed by social competency and participation, community mobility, management of finances and health. From this point rehabilitation progresses to productive activity such as employment or education[8].

Rehabilitation has an important role to play in preparing CVA survivors for employment and in supporting both CVA survivors and employers during the initial phases of employment post-CVA[11,12]. Return to work has advantages for stroke survivors such as improved recovery and satisfaction with life[12]. However, the complex nature of CVA and the wide array of impairments which result from it, can leave CVA survivors severely disabled[12] and have caused CVA to be strongly associated with early retirement[13]. Post-CVA return-to-work figures generally vary between 19% and 65%, but figures as low as 2% have been found[9,10,11,12,13]. These studies were all from industrialised nations and all CVA sufferers received rehabilitation[11,14,15,16,17,18]. No studies assessing the actual impact that rehabilitation has on return to work post CVA could be found. Factors such as less severe physical and cognitive impairments [16,17,18], younger age[11,18], higher levels of education[11,18], full time employment before the CVA[16], social support[14,17], vocational rehabilitation[18] and a flexible work environment[14] were found to positively impact on return to work. In addition literature stressed the importance of treatment that focused on mood and working memory[19]. Fear of deterioration of the health condition[11,14], architectural barriers[18], poor local economy[18], transport challenges[18] and stereotyping of persons with disabilities[18] were found to be barriers to employment after stroke.

Methods

Aim: To describe the extent to which community integration and productive activity outcomes have been achieved by CVA survivors in the Western Cape Metro Health District.

Study design

A quantitative, descriptive design was used as the researchers wished to explore the achievement of advanced rehabilitation outcomes of stroke survivors[20].

Population and sample

The population for the study consisted of all stroke survivors who were admitted to the Western Cape Rehabilitation Centre (WCRC) for in-patient rehabilitation in 2006, and their caregivers. While participants might have suffered the CVA earlier than 2006 they all received in-patient rehabilitation in 2006. The actual date of the insult was not determined. All participants had to reside in the Western Cape Metro Health District in a family home, and had to require the assistance of a caregiver to ensure that the maximum outcome level was reached. All participants who met the inclusion criteria were included in the study. Reasons for exclusion are presented in *Figure 1*. Data were therefore collected during 2009 from 57 stroke survivors and their caregivers.

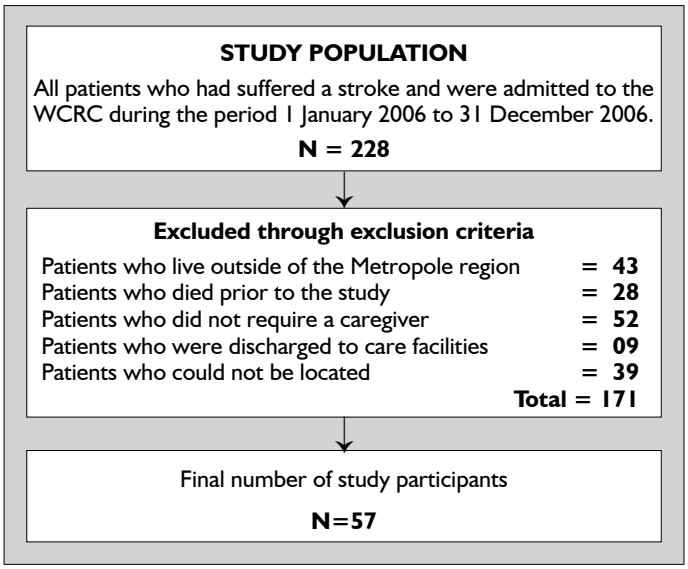

Figure 1: The study participants

Data Collection Tools

Data relevant to this article were collected from the stroke survivor, patient folder and the caregiver. Three tools were used i.e. a demographic and medical questionnaire, the Barthel Index (BI)[21] and the outcome levels[8] (*Table I*).

The patient's outcome level at discharge and during the time of the interview was recorded. The outcome levels were used as a measurement instrument since it combined information on impairments and activity limitations to provide a broad overview of the level at which the patient functioned[8]. In order to determine the patient's outcome level an assessment of impairments, activity limitations, participation restrictions and contextual factors were necessary[8]. Thus two additional instruments were used in the study to provide the information to determine patient outcome levels i.e. the questionnaire and the Barthell index at the time of interview.

The first of these was a demographic and medical history questionnaire. Demographic details included age, gender, level of education, employment status and finances. The medical history and the level of recovery of the patient at the time of discharge were also recorded. In addition problems with cognition, perception, personality changes, speech and language were recorded on the questionnaire. Findings on these aspects were based on information from caregivers. Objective testing of these aspects would have provided more reliable information since under-reporting of cognitive and perception problems can occur through a lack of understandingof these issues[22]. The omission of these tests was a shortcoming in the study.

The questionnaire was developed in English and translated into Afrikaans and Xhosa. Thus, it was available in the three languages most commonly spoken in the Western Cape. The questionnaire was not tested for validity and reliability however; it was developed in consultation with a statistician and experts in the field of CVA rehabilitation and piloted twice before use in the main study. During the initial pilot study two questionnaires were used to collect patient data: one to gather data from the WCRC folders and one to gather data during the interviews. This was found to be cumbersome and duplication occurred. Therefore the two questionnaires were combined into one and piloted again. During the second pilot study the combined questionnaire was found to be easier to administer and no further changes were indicated.

The second instrument was the BI[21], a ten category, weighted index, used to measure physical dependency. This index provides a cumulative score, with a maximum of 100 indicating complete physical independence, and a minimum of zero indicating total physical dependence[22]. It was chosen since it can be administered through interview[21] and provides a single numerical value. Reliability and validity of the BI is high[21,23]. The researchers were of the opinion that the limitations of the BI according to Horgan and Finn[24] i.e. a lack of sensitivity to small changes, changes in high functioning stroke survivors, lack of a measure of improvement in quality of movement and not distinguishing between gains in function as a result of motor recovery and those that result from compensation, would not impact negatively on the results of this study.

Data collection

Data collection commenced with the preliminary collection of demographic and medical data as well as the discharge outcome levels of stroke survivors from WCRC patient folders. This information was entered onto the questionnaire. The questionnaire was thereafter completed during a structured interview with each stroke survivor and/or his or her caregiver at their places of residence. First demographic and medical data collected from medical records were verified with the stroke survivors and caregivers. After completion of the questionnaire the BI was completed through questions and no physical testing was done.

Outcome levels of stroke survivors on discharge were obtained from the completed multi disciplinary case notes in their folders. The case co-ordinator was responsible for completing these case notes. The stroke survivor's outcome level at the time of the interview was determined by the researcher (1st author) through the interpretation of the collected information. This did introduce a level of bias into the results since the researcher's interpretation of the requirements for scoring at a specific level might differ from that of the various case co-ordinators.

Collection of data were done in English, Afrikaans or Xhosa depending on the preference of the participants. If participants preferred English or Afrikaans, the first author did all the data collection. A trained research assistant assisted with data collection from Xhosa-speaking participants.

Data analysis

Data were entered onto an Excel© spread sheet and a statistician calculated the means, medians and distribution of the data. Data were presented through graphs and tables as applicable. Comparative statistical analysis on the impact of follow up rehabilitation on the achievement of advance rehabilitation outcomes and changes in outcome levels could not be done since no participant received follow up rehabilitation.

Ethical considerations

The study proposal was approved by the Committee for Human Research at the University of Stellenbosch and permission to perform the study at WCRC was obtained from the director of WCRC. Participation was voluntary and all participants signed a written informed consent form. All data were treated as confidential.

Results

Demographic information

There were 33 (58%) male and 24 (42%) female participants. The majority of the participants were between 40 and 59 years of age and had had some secondary education. The educational levels of these stoke survivors are presented in *Table 2*.

Table 2: Levels of education of stroke survivors

Education level	No of stroke survivors
Primary school	13 (23%)
Grade 8 - 11	36 (63%)
Grade 12	7 (12%)
Tertiary education	1 (2%)

The most prevalent unresolved effects of the CVA were personality changes 42 (74%) (the presence of personality changes were indicated by care givers and not assessed in depth), and communication problems 36 (63%), some participants demonstrating both problems. According to BI scores 20 (35%) of the CVA sufferers were physically dependent at the time of the study (as indicated by a score of 60 or less). A study limitation is that this information was based on caregiver observation and none of the impairments were objectively evaluated.

Outcome levels

Table 3 shows that seven (12%) stroke survivors were at level II ie they had achived only the basic rehabilitation outcomes necessary to preserve long term physiological health whereas 37 (65%) stroke survivors were at an outcome level III (residential integration) on discharge from WCRC, while 12 (21%) were at level IV (community integration), and one at level V (productive activity). Assessment at the time of the study showed a general improvement post discharge, with 33 (58%) stroke survivors moving to level IV and 17 (30%) to level III. In total, 30 (53%) stroke survivors improved one level and three (5%) improved two levels. Most improvement was seen with stroke survivors moving from level III to IV (26, 46%). Four (7%) stroke survivors regressed one level (see *Table 3*).

Table 3: Rehabilitation outcome levels achieved by stroke survivors on discharge and at time of interview

Outcome level	No of stroke survivors at each level on discharge	No of stroke survivors at each level at the time of interview
Level I	0	0
Level II	7 (12%%	1 (2%)
Level III	37 (65%)	17 (30%)
Level IV	12 (21%)	33 (58%)
Level V	1 (2%)	6 (10%)

Table 4 shows that 28 (47%) of the 44 stroke survivors who fell within the economically active age range (that is, females younger than 60 and males younger than 65) were employed before the CVA, and of these one (3.7%) went back to formal employment after the CVA and rehabilitation.

Table 4: Employment status of stroke survivors in economically active age group

	Before CVA (n = 44)	After rehabilitation (n = 44)
Unemployed	16 (36%)	38 (87%)
Formally employed	28 (64%)	1 (2%)
Income generating projects	0	5 (11%)

Discussion

It is important to acknowledge that through selecting a sample of stroke survivors who needed caregiver support a group of survivors for whom poorer achievement of advanced outcomes might be expected were included. However, the outcome levels allow for assistance as long as the person who is being assisted directs this assistance.

The policy of the Western Cape Department of Health states that rehabilitation should be provided along a continuum of care.[3] It further states that a person should be discharged at level III (residential integration) from in-patient rehabilitation, while levels IV (community integration) and V (productive activity) should ideally be achieved while the person is already integrated back into the home environment, through community-based rehabilitation (CBR) in conjunction with the primary health care system[3]. In accordance with these guidelines the majority of participants (37 / 65%) in the current study were discharged at level III. However, as reported in a previous article, none of the participant's received CBR or any other follow-up programme or therapy that could be construed as aimed at reaching levels IV or V after discharge[25]. A need for rehabilitation intervention at primary level after discharge from in-patient rehabilitation is demonstrated by the finding that 24 of the caregivers (42%) requested community rehabilitation services[25].

Even so the results indicated that 33 (58%) of CVA sufferers showed an improvement in outcome level in the period between discharge from WCRC and data collection for the study in spite of not having received any rehabilitation. A committed caregiver can support and facilitate outings as well as involvement in social and religious activities – the focus of community integration (level IV). However, the caregiver might not have the expertise to deal with the complex requirements of the formal labour market, such as work assessment, vocational rehabilitation and ensuring that reasonable accommodations are made, tasks necessary to ensure successful integration into the labour market and achievement of level V, as indicated in the outcome levels (*Table1*). Re-entering employment, as opposed to community integration, often requires the special skills of a therapist to support patient and employer alike[12]. The above argument is supported by the example of one participant in the current study who was re-employed in the open labour market after spending eight days as an in-patient in WCRC during which period therapists assisted with his reintegration to the workplace.

This particular participant was the only one to enter the open labour market again. The other five participants to reach productive activity (outcome level V) did so through informal income generating projects. This low employment figure, 2% of the participants in the economically active age group or 3.6% of previously employed participants, is supported by another Western Cape study which found a re-employment figure of 3.5% of the economically active age group[26]. Education and training levels do play an important role in re-employment after disability[11,18]. Therefore the fact that few (8; 14%) of participants had grade 12 or tertiary education might have impacted negatively on re-employment of the stroke survivors in this study.

International studies[11,15] from two very similar populations (drawn from one, multi-condition, inpatient rehabilitation unit) showed varied findings. A study from Singapore found that 45.6% of stroke survivors who were employed before the CVA were back in paid employment six months after discharge[11]. However, from Israel, Hartman-Maeir et al. reported that only 2.5 % of CVA survivors who were employed before the CVA, were employed one year post-CVA[15].

Participants from the Singaporean study formed a select group who had moderate to mild physical disability (score of 50 – 90) on the Bartel Index (BI)[11] whereas the current study looked at all participants no matter what their BI score was. Scrutiny of the data indicates that only four (6.75%) of the previously employed stroke survivors in the current study had a BI score of less than 60, and that seven (29.9%) had a

BI score of more than 90. In the light of this, better employment figures for the current study participants could have been expected since literature indicates that higher levels of physical independence act as a facilitator to re-employment [16,17,18].

While causality cannot be proved since no participant received any follow up rehabilitation[25] which meant that variables could not be compared, the authors feel that a lack of follow-up rehabilitation might have contributed to this low re-employment figure. Failure of rehabilitation programmes to address advanced outcomes like community integration and productive activity has been reported on in the literature[7,27]. Participants in the study by Gzaca & Visagie[7] made a connection between inadequate rehabilitation, receiving a disability grant, and perpetuating a situation when the person with a disability lacks the self-belief necessary to enter the labour market. According to Medin, Barajas & Ekberg[27] CVA rehabilitation focuses on the biomedical health perspective and clinical outcomes such as the recovery from impairments. This is adequate to get CVA survivors functioning again, but not sufficient to enable them to enter employment[27].

According to the literature the possible causes of the problem in SA is multi-faceted and includes factors such as a lack of therapy staff at primary level[4], a lack of vocational rehabilitation services[28], transport challenges[6], lack of follow-up[4], poor communication between service providers from the different levels of health care[4], and high overall unemployment figures[29]. Still, the National Rehabilitation Policy[1] promotes full inclusion of persons with disabilities, thus government and society are responsible for addressing the various challenges in order to create an environment in which the necessary support towards full integration is available.

Conclusion

Study findings indicated progress from lower outcome levels such as II and III to IV, but little progress to level V. It is heartening to see that most of the stroke survivors reached level IV, however, one would like to see further progress from level IV to level V especially for those stroke survivors who were employed before the stroke. Through using the guidelines provided for intervention to reach outcome level V, as indicated in *Table 1*, such as performing work and skills assessments, employer education and assistance with reasonable accommodations, clinicians might be able to increase the number of stroke survivors that go back to employment.

Limitations

The authors acknowledge that findings could be negatively influenced by the following issues:

- Results presented in this article came from a study that focused on the experiences and needs of caregivers of CVA survivors following in-patient rehabilitation. It was therefore not the primary aim of the study to establish the extent to which rehabilitation facilitated advanced outcomes or to determine if rehabilitation services are indeed offered along a continuum of care. However, findings were compelling enough to warrant the results being made known.
- Since the primary aim of the study was on caregiver strain only stroke survivors with caregivers were included in the study sample; thus a group that might show poorer advanced outcomes such as productive activity were included.
- The questionnaire and the outcome levels were not tested for validity and reliability.
- All data were collected through interview and no objective evaluation was done to determine residual effects of the CVA such as cognitive and memory problems.
- The date of the stroke was not established which made it impossible to determine the time lapse between stroke and data collection.

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Curriculum transformation: A proposed route to reflect a political consciousness in occupational therapy education

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ABSTRACT

Introduction: Curriculum review is an ongoing, dynamic, long-term process that forms part of occupational therapy education. The Department of Occupational Therapy, University of the Western Cape (UWC) recently responded to the challenge of becoming socially responsive and politically relevant by engaging in curriculum review. The review revealed that political reasoning was not clearly delineated previously in the curriculum. In response to this problem, over a period of several years we engaged in a process of curriculum transformation so that students become politically conscious.

Methods: The process entailed environmental scanning, feedback from teaching staff and clinicians, students' evaluations, regular curriculum revision meetings, academic development meetings, workshops and seminars. A qualitative study using a cooperative enquiry approach was conducted to analyse the data.

Findings: From the analysis the following themes emerged: (1) identifying the essence of occupational therapy education at UWC, (2) understanding political practice on a theoretical and then a personal level, (3) integrating and operationalising political consciousness into the curriculum. We discuss the debates and critical questions raised in our efforts to develop a curriculum that prepares graduates to be politically conscious and socially responsive. Finally, we present key strategies for the way forward.

Conclusion: Curriculum transformation around a political practice of occupational therapy does not merely mean just a change in curriculum content, but requires the internalisation of a political consciousness by educators individually and collectively.

Key words: curriculum transformation, occupational therapy education, political consciousness

Introduction

In recent years, occupational therapy education programmes have been challenged to prepare their graduates to deal with occupational injustices in rapidly changing and different political, social, and economical contexts. This is evident in World Federation of Occupational Therapy (WFOT) Position Papers on Human Rights[1] and Community-based Rehabilitation[2]. The implications for occupational therapy are also addressed in recent literature on transformation through occupation[3], occupational justice[4], service learning and practice in occupational therapy[5], enabling occupation[6], occupation-based occupational therapy, and a political practice of occupational therapy[7,8]. There is a move in occupational therapy education and practice to become politically conscious. According to Kronenberg and Pollard[9], political consciousness allows occupational therapists to critically understand the influence of politics on human occupation and on the practice decisions that they make.

In order for occupational therapy curricula to facilitate political consciousness in students, there is a need for the curricula to be socially responsive[9,10,11]. Socially responsive education underpins values such as commitment to whole person care, reflective practice, human rights and community development[9]. For this reason, Kronenberg and Pollard[11] refer to socially responsive occupational therapy education as politically relevant education that enables students to critically understand the influence of politics on human occupation and the practice decisions that they make. They maintain that it is necessary for occupational therapy education to consider how it prepares graduates to contribute to addressing their country's health and social needs through being agents of social change. Pollard, Kronenberg and Sakellariou[8] assert that occupational therapy curricula should provide students with opportunities to explore how people who experience occupational injustices understand their realities and how occupational therapists can address those realities in practice. They assert that it is imperative that occupational therapy education facilitates students' understanding of the influence of politics on human occupation in order for occupational therapy curricula to become more socially responsive. Kronenberg and Pollard[11] propose the 3PArchaeology (3PA) as an approach to raise political consciousness. The 3PA refers to an in-depth critical exploration at inter-related personal-, professional-, political- levels of who we are, where we come from, what we value and stand