

Occupational Therapy and its potentially positive influence upon the CD4 count of individuals with HIV: A single case study.

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ABSTRACT

This article is a case study of a young woman in her early twenties in advanced stages of AIDS, who is on antiretroviral (ARV) medication and has a CD4 count of 51 that has remained static for the past six months. An intensive palliative occupational therapy programme has commenced twice weekly with emphasis on uplifting her mood and giving her a sense of control over and purpose in her life. Secondary aims included improving her endurance and independence.

Using a qualitative approach, her progress was chronologically evaluated from diagnosis, hospitalization to discharge, tracking changes in her mood and state of health. After commencing the mostly palliative OT programme her CD4 count increased significantly and her mood and general health improved such that this was repeatedly noted in her file and she was discharged 6 weeks later i.e. nearly 6 months after admission. Although this single case study cannot be considered conclusive evidence of the positive effects of OT on the CD4 count and health status of individuals in advanced stages of AIDS, it suggests further investigation of this potential.

Key words: CD4 Count, palliative programmes, case study

Introduction.

Occupational therapy departments in public hospitals in South Africa are currently being overwhelmed by referrals of individuals suffering the consequences of HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune-Deficiency Syndrome)1. Many of these present an array of complex neuropathies and other conditions or may simply be individuals in terminal stages of the disease who are in need of the palliative care and support that occupational therapy may bring them.

Apart from the stress caused by the pain and suffering from the various opportunistic infections and other conditions that accompany the virus, there is also the existential distress caused by the stigma attached to HIV and AIDS, as well as knowing that one is living with an incurable illness that may, without ART (Antiretroviral Treatment), cause one's death within months or years. An increasing

body of research evidence indicates that psychological stress can negatively alter basic immune processes2.

Occupational enablement focuses upon improving the physical, functional and psychological well-being of individuals who suffer from conditions which disable them physically or mentally or put them at risk for such disablement. Individuals living with HIV and AIDS are likely to undergo both physical and mental disability and its concomitant stress. Occupational therapists are thus in a position to implement programmes which contribute to maintaining and improving the physical endurance and strength of individuals with advanced HIV infection. In addition, they promote an improved sense of wellbeing of these individuals which, it is proposed, should have the added effect of boosting their immune system.

The authors maintain that programmes which elicit positive



emotional responses through the enjoyment and mastery of various occupations and activities, can have a positive effect, not only upon the immune system but also upon the quality of life of individuals with AIDS. Lewis³ quotes Marciel who suggests that this intervention can "add life to their days rather than days to their life". When an individual is participating in pleasurable and meaningful activities the body releases endorphins which are its own pain killers. Occupational therapy has the potential to make an important contribution within the medical team by providing the individual with a holistic quality of life experience, which is more than pain and symptom control³. Tigges⁴ in his article about the practice of Occupational Therapists within palliative medicine says: "the generic model of occupational behaviour is the most appropriate, economic, and efficient model to stabilize and/or maximize the terminally ill persons' occupational roles and thus promote and improve their perception of competence and achievement, generating a feeling of well-being and quality of life."

As early as 1919, Ishigami, a pioneer in psychoneuroimmunology, discovered the connection between stress, the immune system and infectious processes. In research with persons with chronic tuberculosis he found that during periods of increased psychological stress there was a decrease in the phagocytic activity of leucocytes which he suggested, induced immunodepression and increased their susceptibility to pulmonary tuberculosis⁵.

The immune system consists of specialized cells originating in the bone marrow which, after maturing in particular organs such as the lymph nodes, thymus and spleen, are released into the blood. The identification of these numerous specific types of cells is made possible by the development of monoclonal antibodies that adhere to specific receptors found in the blood. These receptors are identified by the term cluster designation (CD) followed by the identifying number of the particular cell². The normal CD 4 count in an HIV negative adult is usually between 500 and 1500 cells per cubic millimeter of blood. In young children the count is even higher than this. An absolute CD 4 count of 200 cells/mm³ is considered to reflect a risk of opportunistic infections.⁶

Antoni⁷ evaluated changes in the immunological status of 25 HIV infected gay and bisexual men; groups were randomly assigned to a stress management programme and those in the control group were put on a waiting list. After 6 to 12 months the researchers monitored changes in the number of transitional naïve T cells (CD4+ CD45RA+ CD29+) and found that those receiving stress management had higher CD45RA+ CD29+ cell counts than did those in the control group. This difference was independent of the initial HIV viral load and number of naïve T cells.

In a study of men who were matched on age and CD 4 levels at baseline, Kemeny and colleagues in Kiecolt-Glaser and Glaser⁸, found that those who were characterized by chronic and severe depression over a two year period demonstrated a sharper decline in CD4 cells than those who were not depressed.

Jean-Baptiste⁹ conducted a study to examine whether there was an association between "the therapeutic use of music as a form of support group, reduction in symptom distress, coping skills of people with HIV and AIDS and improvement in CD 4 cell count." The support group consisted of eighty (80) men and women (in equal numbers). This group met twice a month for 10 months. CD 4 and viral load counts were taken from all participants prior to commencement of the study as well as their individually reported stress perceptions. Sixty four (64) of the men and women whose CD 4 counts had been less than 300 before commencement of the study and who were not on ARV therapy showed significantly increased CD 4 counts and decreased stress levels when tested on reported stress perceptions. Only four (4) subjects showed no improvement and twelve (12) subjects relocated so did not complete the study.

This article suggests that the beneficial effects of a palliative OT programme may contribute to the sense of well-being of an immuno-compromised individual and in so doing can contribute to the process of increasing their CD 4 count.

METHODOLOGY

The aim of this research was to demonstrate the impact of occupational therapy on a person with AIDS through the single case study of a young woman in advanced stages of AIDS who was also on ARV and TB treatment.

Evaluation methods: The study was conducted through clinical observation and document analysis as follows:

- * Her daily programme was evaluated as being one of lying in bed or sitting up in a chair. Her self-care activities were done for her or she was assisted by the nurses in doing some minor ones, such as feeding herself. Interaction with others was minimal due to quick patient turnover in the ward and the fact that many of the patients in close proximity to her were either too sick or too old to communicate satisfactorily with her.
- * Her psychological state was evaluated subjectively by the student, her supervisor and the clinical therapist according to: her mood, whether it was observably up or down, how she had reacted at the commencement of occupational therapy sessions i.e. her level of enthusiasm, endurance and ability to participate for extended periods and observed changes during the approximately 4 weeks that she was in a palliative occupational therapy programme.
- * Recordings in the hospital file were evaluated qualitatively from the date of diagnosis to the date of discharge. The following aspects were regarded as being important and noted:
 - * Medical history related to the diagnosis and treatment of her HIV.
 - * Any changes in her medication and treatment regimen in the two weeks prior to commencement of occupational therapy and during the four weeks that she received occupational therapy.
 - * Her daily nursing notes were also scrutinized to determine any changes in her levels of independent functioning
 - * Comments from other members of the team treating her regarding her mood and general state of health.
 - * The accounts of her progress and records were jointly checked by the student, her supervisor and the clinical therapist for consistency and accuracy.

Ethical considerations:

Permission was obtained from the young woman concerned and her mother to write this article provided it was published in a professional health related journal and that the authors did not reveal any information that could lead to her identification.

Permission was also obtained to conduct the study from the ethical officer and CEO of the hospital concerned. In addition, ethical clearance was obtained through the ethics committee of the University of KwaZulu-Natal where the student and her supervisor are based.

Case study

Mbali* is a young woman in her early twenties, who resides with her mother and younger sister in a suburb of Durban. Their home is a 2-bedroom brick house, with running water and electricity. In 2005 she failed Grade 12, but in an attempt to acquire her senior certificate she attended night classes in 2006. In January 2006 she was diagnosed as being HIV positive and, as a result of constant intermittent illness, she was unable to complete her Grade 12 in that year.

According to Mbali, she entered her first intimate relationship with her boyfriend in 2005. Believing she was in a trusting relationship, she lost her virginity to him only to discover that he was having an affair with another girl. She maintains that he was HIV positive at the onset of their relationship but chose not to disclose his status to her. She emphasised the strong support and love that she has had from her mother during this time and how it has helped her. As it is widely accepted that in worse case scenarios i.e. poverty and malnutrition, it would take approximately three to four years from infection to onset of full blown AIDS, it is likely that Mbali's account above is not completely accurate and that she was probably infected before 2005.

* Not her real name



In September 2006 her hospital record indicated that her CD 4 count was measured at 51 and she was diagnosed with tuberculosis. In November 2006 her medical record revealed that she was put onto ARV drugs (ARVs) when her CD 4 count was still 51. In December 2006 she was admitted to hospital with meningitis and several other HIV-related symptoms including splenomegaly, thrush and TB. She commenced physiotherapy in mid February 2007 which included mobilizing Mbali into a chair and walking with assistance as well as some chest physiotherapy. On assessment by the OT student at the end of March 2007 she presented with a neuropathy i.e. paresis of her lower limbs, inability to ambulate without assistance and moments of slight confusion. She was extremely emaciated and weak due to the side effects of her condition and four months of hospitalization with minimal exercise.

The student's first meeting with Mbali on 20 March 2007 was one in which a positive rapport between Mbali and the student was established. This relationship was consolidated during the sessions held twice a week for a period of six weeks. The student suggested that Mbali's slumped posture, melancholic facial features and frequent crying portrayed someone who was distressed, anxious and moderately depressed, the student's supervisor verified this.

The student, her academic supervisor and the clinical therapist at the hospital decided that the primary focus of intervention at the initial stage should be on palliative care as Mbali's CD 4 count was so low and she was in considerable pain and discomfort at the time. In addition her medical file questioned whether an ARV failure had occurred. Sessions were therefore directed at improving her quality of life through activities that would elicit positive emotional responses and hence distract Mbali from the effects of her condition and provide enjoyment and an improved sense of self-esteem through mastery and self-efficacy. This programme was to be implemented on a twice-weekly basis as the student only attended practical sessions at this hospital on a Tuesday and Friday.

On the 23 March 2006 in an hour-long session, Mbali was given a choice of 'fun' activities and she decided on jewellery making using beads. Choice was therefore a principle of treatment as it allowed her to exhibit some autonomy and control. She was seated on a chair in the ward and a visitor's stool was used as a work surface. She decided to make a gift for her younger sister. After 30 minutes, she began to display physical signs of fatigue and asked to be transferred to her bed. In spite of this obvious fatigue, she was apparently so enjoying the activity that she insisted on completing it sitting up in bed. This demonstrated the inherent power of involvement in appropriate activities that allow the individual to focus on them to the exclusion of pain and fatigue.

The student also used this session for further discussion and to allow her to continue to express her feelings regarding her condition. For example at one stage she expressed how helpless she felt observing some of the older females in the ward perform their toileting and bathing activities independently and knowing that she could not. At the end of her hospitalization the OT did some assisted bathing and dressing with Mbali, but at this stage occupational therapy focused on a palliative and physical maintenance programme.

At this time she also shared some of her regular dreams with the student, the most common recurring dream she experienced was being able to walk and run as she did before only to awaken to her current reality. Mbali also expressed the sense of loneliness and isolation she was experiencing as she only saw her mother for an hour daily and the turnover of patients in the ward was such that establishing long-term friendships was not easy. She revealed having dreams of her mother taking care of her at her bedside only to awaken with no one there. Mbali openly spoke of her fear of dying which occupied her thoughts at night. These accounts suggested that Mbali was utilizing a great deal of emotional energy, both literally and figuratively, in her experience of loneliness and isolation, which was alleviated by her mother's visits.

At the third session on the 27th March 2007, Mbali came to the OT department in a wheelchair. This was the first time since her admission in December that she had been out of the ward.

On the way, she expressed how good it felt to be outside in the sunshine. The treatment session was in a relaxed environment with popular music playing and a peer, with whom she could identify, was participating in her own session close by so that the two could communicate with each other. By comparison with the first two sessions, Mbali appeared more determined and motivated to participate; the student suggested that it was as though her fighting spirit was slowly beginning to emerge from its inertia. In spite of physical signs of exhaustion (sweating, trembling and pallor), she insisted on continuing with the activity for two hours. Reasons for this change could be:

- a) believing that she was improving having been removed from the ward environment; she responded to the relaxed, less clinical and institutional environment of the OT department;
- b) her recognition of other young people in a similar situation, resulted in adjustment of her own perceptions about her illness
- c) the choice of activity in itself could have motivated her to complete it, or
- d) a combination of these factors.

The activity selected for this session was that of making a colourful cardboard picture frame in which to insert a letter. She chose to write this to her mother and present it as a gift to her. Using the card as a medium, she was able to express her deep love and appreciation for her mother. That afternoon at visiting time, she handed the card to her mother who was visibly moved.

In the entire ward notes from her admission prior to commencement of OT, there had been only two positive comments about her condition from the physiotherapist i.e. "Pt. feeling better today" (15/02/07) and "Pt. slightly better this morning" (17/02/07) which suggested that she had been asked how she felt. It is significant that the doctor treating Mbali made a note in her file on 27th March saying "patient looks brighter" and this was the first time such comment was noted by her doctors since she was admitted and suggested that there were visible signs of her improved state of mind. CD 4 counts were done on a regular basis since her admission in December 2007 and her medical records indicated that these remained static on a count of 51. However, on the 28th March her CD 4 count was confirmed as 157. Thus for the first time in 5 months, there had been a positive change in her CD 4 count. i.e. 8 days after commencing the OT programme.

According to Gengiah¹⁰ (2008) a researcher from the Centre for AIDS Programme of Research in South Africa (CAPRISA) straight forward cases show an improvement in biological markers 6 months after initiating ART and clinical improvement may occur even earlier i.e. three months after commencement. A 50 cell increase is what is aimed for at 6 months after commencement of ARV. Mbali's improvement was more than double this in less than 6 months i.e. increased from 51 to 157 and she was a complicated case with multiples opportunistic infections including meningitis and TB on admission.

On the 30th March, in OT Mbali made another picture frame for a chosen biblical verse (Romans 5:1-4) which she had selected from a Zulu Bible. She expressed a desire to place it beside her bed. The student considered this to be a form of positive spiritual affirmation for her to have and be able to use during her lonely, and possibly fearful thoughts of death, especially at night. This positive affirmation is of significance as it allowed Mbali to cognitively deconstruct aspects of her existential distress and replace it with spiritually uplifting and comforting thoughts. By comparison with Mbali's initial body language and mood, she appeared more animated and happy as sessions progressed, and the student described her as being 'more talkative and radiant'. At the end of this session, Mbali held the frame close to her chest and said that she loved it so much she couldn't wait to show her mother.

On the 3rd April the student did a self care activity with Mbali with the aim of improving her general strength and independence as well as providing feel good components such as pleasant smelling soaps and body lotions, and culminating in a nail care and polishing session. She started off the activity hesitantly and ended much more enthusiastically.



Notes entered into her file by her doctor from the 30th March noted positive changes in Mbali (see Medical Notes below) prior to this there were no such comments:

Medical Notes

- * 30th March read "patient appears to be improving".
- * On 2nd April the doctor's notes further stated that the "patient (is) looking brighter".
- * On the 4th April doctor noted that "patient looking well." At this stage Mbali's medical practitioners suggested that she was now in a stable enough condition for a pass out to visit her home.
- * 10th April: Doctors notes state "general condition improved".
- * 17th April: Doctors notes state "much improved".

At the time when it was recommended that Mbali be given a week-end pass to go home and the student went on a weeks vacation, Mbali was referred to the clinical therapist working at the hospital. The clinical therapist continued with facilitating more independent self-care, improving her general strength and endurance and providing supportive therapy during the student's absence (see summary below).

Summary of the OT programme

- * 10th April the clinical therapist visited Mbali for short reflective discussion on ward.
- * 16th April the clinical therapist reviewed her functional self-care during visiting hours when her mother was present and focused on the importance of her mother allowing independent eating and drinking as the therapist had found her mother helping her with this.
- * 17 April Therapy included writing a letter to her sister to be picked up and delivered by her mother in the afternoon.
- * 20th April: Therapy included making a sandwich both for enjoyment and improving independence in simple meal preparation for when she returns home, as her mother works during the day.
- * 24 April: Mbali was discharged 6 weeks after commencement of the OT programme. At this stage her CD 4 had increased by 106 to 157 and her peripheral neuropathy although still present was improving, she was walking with minimal assistance and was doing basic self care activities such as feeding, bathing, toileting and simple meal preparation independently.

Discussion:

As this is a single case study and considering that she had been on ART for 5 months it cannot be considered as conclusive evidence regarding the possible impact of occupational therapy upon Mbali's improved CD 4 count. However, the relatively premature onset of recovery considering the seriously compromised condition she was in at onset of ART, and the fact that the CD 4 count more than doubled the 50 cell expectancy without any significant change or addition to the other treatments she was receiving at the time, is suggestive of a positive link between the occupational therapy programme and the rise in her CD4 count. The notable improvement in her physical and psychological condition and her regained independence in self-care activities is also suggestive of this link. It is significant that for the first time since her admission the doctor treating her began to make repeated comments about her noted improvement. In addition, she became more co-operative with physiotherapy in mobilizing with a walking frame after OT had commenced.

Ramugondo¹¹ suggests that the overwhelming proximity of death for those living with HIV and AIDS disenfranchises them. This is particularly relevant for those who are also institutionalized in hospitals where a form of imposed disempowerment occurs by virtue of rigid ward programmes and hospital routines that exist and are often accompanied by patronizing attitudes of health workers. When they are able to reconnect with their ability to be and do through meaningful participation in occupations that enhance their sense of self worth and confidence, this lowers the stress caused by the reality of this close proximity to death.

The growing demand for antiretroviral treatment amongst people living with HIV and AIDS in South Africa has necessitated the development of guidelines and procedural arrangements at national and provincial level to roll out ARV treatment in the public sector¹². These arrangements have necessitated substantial mobilization of human resources as well as commitment of considerable financial backing both for human resources and supply of enough ARVs to meet the demand. The total government spending on HIV and AIDs in South Africa in 2005 was estimated to be in the region of R15 billion.¹³ However the potential for prolonging lives can be jeopardised when individuals who are on ARV medication, require prolonged hospitalization and fail to show improvement in their CD 4 counts. Thus any intervention that can positively influence an individual's low CD 4 count to move from an initial inertia and to climb to more stable heights should be vigorously pursued and implemented.

Conclusion

The authors suggest that carefully planned and sensitively implemented occupational therapy programmes for individuals with HIV and AIDS who have very low CD4 counts, can contribute towards boosting the CD 4 count in the following ways:

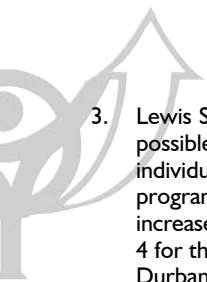
- * They can relieve stress by involvement in activities that refocus the psyche of the individual on enriching and pleasurable experience through purposeful, enjoyable and successful occupations which are aimed at making the individual feel more positive about themselves.
- * They can raise self-esteem by enabling previously disempowered individuals to realize that they still have the ability to be productive and continue with life's essential tasks and have some control over what and how they do things.
- * By providing opportunities for attainment of greater quality of life in situations where there is relatively little quality of life, as a result of the physical and mental pain, suffering and anguish caused by HIV and AIDS.
- * By contributing to the maintenance and improvement of the general endurance and strength of these individuals which through its positive effect upon circulation and respiration should also work positively upon the immune system.
- * By providing opportunities for individuals to express and share their inner emotions and concerns through verbal or written means, which is a way of relieving stress but also facilitates personal growth and resolution of inner distress.
- * Through positive psychological support and engagement in activities which enable task satisfaction and a feeling of accomplishment.
- * OT programmes can improve the general motivation and participation levels.

The authors would thus like to strongly recommend that other occupational therapists working in settings where there are large numbers of people such as Mbali, monitor their programmes for these individuals to establish whether the CD 4 counts improve during the progress of therapy. Apart from contributing to the quality of life of individuals and their general health and well-being this would result in considerable fiscal savings as it can reduce hospitalisation and the need for additional medication and treatment for opportunistic infections.

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