# An Assessment of Occupational Therapists' and Physiotherapists' knowledge and perceptions concerning the treatment of patients with HIV and AIDS

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## ABSTRACT

*With the prevalence of the Human Immuno-deficiency Virus (HIV) being approx 18% in South Africa, it is highly likely that occupational therapists (OTs) and physiotherapists (PTs) working in hospitals will be in daily contact with patients who are HIV positive. It is therefore important that these therapists be knowledgeable about the condition, its causes, progress and the rehabilitative intervention if they are to make a difference in the lives of these patients. This study therefore aimed at evaluating the knowledge and perceptions that a sample of OTs and PTs had of HIV and AIDS as previous studies had found the knowledge and attitudes of health professionals towards these patients to be poor. It was therefore thought to be important to ascertain whether this had changed in more recent years.*

*A purposive sample of 49 OTS and PTs, drawn from the list of therapists who were employed in the public hospitals of Limpopo Province where both OTs and PTs worked, were selected for the study. These therapists were required to answer a questionnaire which contained both open and closed questions covering knowledge and perceptions of HIV and the Acquired Immune-Deficiency Syndrome (AIDS). The questionnaire was given to the therapists at specially organised meetings at each of the hospitals selected. Thirty five therapists who attended these sessions, answered the questionnaire.*

*The findings of this study confirmed that of other researchers, namely that there is a relatively poor knowledge base of HIV and AIDS, and therapists generally are uncomfortable being in contact with this type of patient. Thus indicating that, in spite of the increased number of patients who are HIV+ and who have AIDS and the consequent increase in contact between therapist and client, the knowledge base of OTs and PTs in this sample was no different from that found in previous studies. Thus pointing out that there is an urgent need to address these deficiencies through training and mentoring.*

**Key words:** HIV, AIDS, transmission modes, stages of HIV progression, therapy.

## Introduction

The prevalence of the Human Immuno-deficiency Virus (HIV) in South Africa is among the highest in the world. The prevalence rate was estimated at 16.2% among individuals aged between 15 and 49 years in 2005[1]. Based on a wide range of studies, at the end of 2007 UNAIDS/WHO[2] estimated a prevalence rate in SA of 18.1% in those aged 15 - 49. This means that in effect 5.7 million South Africans were estimated to be living with HIV in 2007[2]. Bearing in mind the opportunistic infections and conditions that arise from being HIV+ and therefore the need to access health services, it is reasonable to assume that occupational therapists and physiotherapists will be in daily contact with patients who are HIV+ and who may be living with the Acquired Immune-Deficiency Syndrome (AIDS). It is thought that at least 30% of a general hospital population suffers from AIDS related conditions[3].

Being HIV+ and having AIDS results in a complex set of conditions both medical and social. Worthington et al[4] identified in their research, four elements of the HIV and AIDS condition that have to be taken into consideration in the rehabilitation process ie

1. The "**fluctuating, dynamic nature"** [4:261] **of HIV and AIDS** requires that intervention should be considered as providing a continuum of care and rehabilitation. In addition the physical conditions that need treatment are complex and debilitating for the patient. This is further exacerbated by the psychological effects of being HIV+ making the giving of relevant rehabilitation complicated.
2. The **advent of antiretroviral therapy (ART)**, has turned HIV and AIDS into a chronic long term condition with the antiretroviral drugs (ARVs) introducing a different set of complexities that need to be considered in rehabilitation such as side effects and adherence.
3. The **attitude of the therapists** to those who become HIV+ and their life style choices may also influence treatment.
4. The **social context of the disease**, discrimination suffered by those who make their status known, as well as the difficulty of working with people whose diagnoses may not be known add another dimension to treatment.

Oyeyemi *et al* [5] emphasised the components of "adequate knowledge, positive attitude and willingness" [5:177] as being important factors in rendering competent and compassionate care to patients.

It is clear from the above that occupational therapists (OTs) and physiotherapists (PTs) providing rehabilitation to People Living with AIDS (PLWAs) need an extensive knowledge of the condition as well as a positive attitude if treatment is to be successful. It is therefore of concern to note that studies conducted to ascertain the knowledge that nurses and doctors[6,7,8] speech therapists[9], physiotherapists (PTs)[3,5,10] and occupational therapists (OTs)[11] have of HIV/AIDS reveal that in spite of the attention given to HIV/AIDS and its treatment, health professionals still have negative perceptions regarding the disease, insufficient knowledge of its transmission modes, treatment and the level of risk associated with treating PLWAs.

It has been reported however that knowledge alone did not always guarantee safe work practices or correct attitudes towards HIV infected patients[12]. Balogun et al[13] found that, although knowledge about AIDS and attitudes towards people with AIDS improved after a five hour AIDS lecture to PT and OT students – the willingness to provide services to people with AIDS did not increase. The feelings of vulnerability experienced by the PT and OT students were shared by staff and students of a Medical School Faculty in the USA who were found to be fearful of infection and harboured strong negative feelings towards AIDS patients[14]. In another study, Currey et al[15] demonstrated that over one third of the students in the medical, dental, nursing and allied health care professions that they surveyed had reservations about treating patients with AIDS. The individuals in this study also believed that health care workers had the right to refuse care to AIDs patients.

A survey of PTs employed in public and private hospitals in South Africa carried out by Puckree *et al*[10] in 2002, revealed a number of significant findings: although 90% of the 114 participating PTs believed that they knew about HIV/AIDS only 78% could identify all viral transmission modes. Of the 38 who believed that they knew the stages of an HIV infection Puckree *et al* found that only 11% actually knew them, 28% could not explain them and 61% were vaguely aware of the stages thus indicating that there was an inadequate knowledge base among this group of professionals. In addition only 38% of the 114 PTs were completely at ease when treating HIV/AIDS patients despite the fact that 98% believed physiotherapy was an integral component of the management of an AIDS patient. Oyeyemi *et al*[5] several years later in 2008, also found in their survey of 131 physiotherapists in teaching and general hospitals across Nigeria, that they showed inadequate knowledge about AIDS, harboured negative attitudes toward People Living with AIDS (PLWA) and some were unwilling to provide care for PLWAs.

Studies of the knowledge and attitude of health care workers towards HIV/AIDS generally demonstrate a lack of complete understanding of this condition and the two studies conducted in South Africa, one in 1991[9] and the second in 2002[10] showed similar trends as those prevailing internationally. Due to the high prevalence rate of HIV and AIDS in SA, it was felt to be important to establish whether the knowledge base among physiotherapists and occupational therapists still mirrored the international trends. In a study carried out by O'Brien *et al*[16] in 2009 which was aimed at identifying key research priorities in HIV and rehabilitation, the importance of this type of evaluation was reinforced by the key informants who identified the need to evaluate the impact that education had on the knowledge, attitudes and practices of rehabilitation professionals on a regular basis**.** This study therefore aimed at assessing the knowledge and perceptions (attitudes), that a sample of occupational therapists and physiotherapists had of treating people living with HIV/AIDS. In this study, knowledge was defined as 'insight into the pathophysiology, transmission, prevention, risk factors, and management of HIV/AIDS' and attitude was defined as 'the biases and beliefs associated with HIV / AIDS'. It was hoped that the results would provide guidelines for the educators of the above mentioned therapists.

## Study Methods

### Study Design

A qualitative study using a survey research design was used.

### Population

All OTs and PTs registered with the Health Professions Council of SA, including those doing their community service year (first year after graduation) and who were working in the 44 hospitals of the Limpopo Province, during the time of the study, composed the study population. Sixteen of the hospitals had no PTs, and eight had no OTs. There were a total of 56 PTs and 55 OTs employed by the Limpopo Province at the time.

### Study sample

The aim was to obtain at least twenty therapists from each group i.e. (35,7% of the PTs and 36,3 % of the OTs in the province) to participate. The list of all the hospitals and of their staff was obtained for the purpose of this study. Hospitals that employed both PTs and OTs were chosen with the exception of a psychiatric hospital where only occupational therapists were employed. All the staff of these hospitals was selected thus providing a sample of 25 OTs and 24 PTs. Thus sampling was purposive.

### Measurement tool - Questionnaire

A questionnaire was constructed in English to cover the aspects identified by Oyeyemi *et al*[5] as being important factors in rendering competent and compassionate care to patients" i.e. "adequate knowledge, positive attitude and willingness" [5:177] to treat patients. The questionnaire contained both open and closed ended questions (12 and 15 respectively) to cover firstly theoretical knowledge such modes of transmission, disease progression and pathology as well as rehabilitation procedures. Secondly questions covered attitudes towards PLWAs and fears related to working with PLWAs. The closed ended questions were included in order to acquire measurable data, and the open ended questions to provide more insight and raise issues of concern. Although the questionnaire was tried out on a therapist in order to sort out ambiguities in the questions no reliability or validity studies were conducted. This is a limitation of this study.

### Research procedure

The Research procedure was as follows:

The therapists at the selected hospitals were contacted and their permission obtained to visit them to introduce the research and to hand out the questionnaires. A date for the visit and the completion of the questionnaires was agreed upon.

The researchers visited the selected hospitals and after verbally introducing the research project and the design of the questionnaire, handed out detailed written information on the project. Since understanding the questionnaire was of importance, the researchers were present at the time to assist the participants with interpreting questions that might have been unclear. The participants were also informed that their participation was totally voluntary and anonymous. Those participants willing to participate in the research then signed the consent form. Four therapists did not complete the questionnaires during the time available and they were asked to continue the completion thereof in their own time. These questionnaires were collected a week later. Telephonic assistance was offered to these four participants.

Once completed, the participant placed the questionnaire in an envelope and sealed it to maintain confidentiality. No envelopes were opened until all completed questionnaires were obtained from all hospitals. All the completed questionnaires were randomly numbered to assist in handling the data.

### Data analysis

Gender, age, profession, university of training, length of work experience (years) and number of years spent treating HIV/AIDS patients were noted. Descriptive information was complied from both the close ended and open ended questions on the questionnaire. The answers to the questionnaires were identified according to the two themes of "knowledge" and "attitudes".

### Ethical approval

Ethical approval was obtained from the University of Witwatersrand, Göteborg University, Sweden and the Provincial Rehabilitation and Clinical Support Representatives Limpopo Province.

## Results and Discussion

Thirty five therapists in total answered the questionnaire - 17 OTs and 18 PTs. This gave a response rate of 68% for the OTs and 75% for the PTs. The reasons for not answering the questionnaire were: being on maternity leave, busy with a patient, in a meeting, sick or other commitments at the time the questionnaires were handed out.

The demographic details of the sample of participants can be seen in *Table I*. The mean age of the participants was 25.9 years with the majority being female (28 versus 7 males).

The participants' answers to each question are discussed below:

## Theme One - Knowledge of HIV and AIDS

### a) The extent to which therapists felt that they had enough knowledge

When asked whether they felt that they had enough knowledge to treat HIV+ patients, 26 (74%) of the participants felt that they had enough knowledge while 9 (26%) stated that they did not think that they knew enough. Those that answered that they did not have enough knowledge mentioned the following aspects which they felt needed greater attention i.e. eight (89%) would like to *"get an update on medical and therapeutic knowledge on HIV"*. Two (22%) participants *"wanted to know more about treatment programmes"'*, two (22%) *"wish to learn more about health talk to relatives"*. Other issues that the participants wanted covered in a continuing professional development programme were: *"statistics on treatment efficiency"*, *"HIV relation to neurology"' "how to help a dying patient"* and *"how to clear up misconceptions of contraction"'* These later four suggestions were mentioned once each.

*Table I: Demographic characteristics of the sample*

| Age (years) | n = 35 |
|---|---|
| Mean | 25,9 |
| Median | 25 |
| Range | 21 - 39 |
| **Sex** | |
| Female | 28 |
| Male | 7 |
| **Number of therapists** | |
| Physiotherapists | 18 |
| Occupational therapists | 17 |
| **University of training** | |
| Medunsa | 18 |
| Pretoria | 8 |
| Witwatersrand | 4 |
| Free State | 2 |
| Stellenbosch | 2 |
| Unknown (section not completed) | 1 |
| **Number of years working as a therapist** | |
| 0-1 | 16 |
| 2-5 | 13 |
| 6-10 | 3 |
| 11+ | 2 |
| Unknown | 1 |
| **Number of years treating HIV/AIDS** | |
| 0-1 | 7 |
| 2-5 | 22 |
| 6-10 | 2 |
| 11- | 1 |
| Unknown | 3 |

### b) Knowledge of transmission modes

The participants were asked to name all the possible ways of contracting HIV. The answers were grouped by the researchers into the following categories: *"Sexual transmission", "vertical transmission", "blood borne transmission", transmission through bodily fluids", "transmission through open wounds"* and other ways of transmission. The results indicated that 29 (83%) of the participants stated that *"sexual intercourse"* was one way of contracting HIV, sixteen (46%) gave *"blood transfusion"* and *"dirty needles"* as another way and 13 (37%) named *"needle prick accidents"* as yet another way (see *Table II*).

The answers on the transmission modes were categorised into the three most commonly recognised groups[17] by the researchers ie:

1. Unprotected sexual intercourse with an infected person (primarily anal and vaginal)
2. By exposure to contaminated blood (either through blood transfusion; contaminated needles, syringes, razor blades and

*Table II: Therapists knowledge of transmission modes*

| Ways of transmission | Subgroups | Number (n=35) | Percent (%) |
|---|---|---|---|
| **Sexual:** | Sexual intercourse | 29 | 83 |
| | Sexual fluids | 3 | 9 |
| | Oral sex | 1 | 3 |
| **Vertical:** | Mother to child | 10 | 29 |
| | Breast feeding | 4 | 11 |
| **Blood borne:** | Blood transfusion | 16 | 46 |
| | Blood | 11 | 31 |
| | Dirty needles | 16 | 46 |
| | Needle pricks | 13 | 37 |
| | Needles (other) | 2 | 6 |
| **Bodily fluids:** | Bodily fluids | 12 | 34 |
| | Saliva | 1 | 3 |
| **Wounds:** | Open wounds | 8 | 23 |
| | No gloves when treating open wounds | 3 | 9 |
| **Other:** | Accident (other) | 2 | 6 |

other sharp instruments or sharing injection equipment associated with intravenous drug use or

3. From mother to child during pregnancy childbirth and breast feeding.

The regrouping of the results is seen *Table III*.

*Table III: Summary of stated ways of contracting HIV/AIDS*

| Transmission modes | Number (n=35) | Percent (%) |
|---|---|---|
| Sexual intercourse | 31 | 89 |
| Exposure to blood | 32 | 91 |
| Mother to child | 12 | 34 |

Although 74% of the therapists felt they had enough knowledge concerning HIV and AIDS, only eight (23%) were able to name all three transmission modes. By comparison, 78% of the PTs in the Puckree *et al*.[10] study were able to identify all viral transmission modes.

## c) **Stages of progression of HIV/AIDS**

The participants were asked to name the different stages of progression of the illness. Eleven of the 35 participants (31%) named the four different stages (the other correct answer being five stages). Fourteen (40%) participants gave three stages and four (11%) suggested two stages. Only one (3%) participant named the five stages, two (6%) did not answer the question and another two (6%) gave answers that were not applicable. One (3%) participant answered that she "*did not know*". Although staging is not essential for rehabilitation purposes it does give the therapist an indication of what to expect of the client and the activity level expectations are particularly useful. Knowledge of the CD4 count is also important for assisting patients to access grants. Therapists based in hospitals, as was this group, are more likely to see patients when they have reached stage three or four. This may account for their inability to name the stages of the illness accurately as they rarely see patients falling within stages one and two. The type of treatment suggested by those who named three stages suggested that they were referring to stages three and four of the illness.

For reference purposes the four stages mentioned by WHO[18] and five stages[19] are given in table *Table IV* has been compiled for reference purposes.

## d) Knowledge of the physical and psychological consequences of the disease

As the result of the effect of HIV on the immune system a number of opportunistic conditions may appear at different stages of the disease process. It is therefore important that therapists are aware of these conditions so that adequate therapy can be provided. The participants were therefore asked what they thought were the common physical and psychosocial problems experienced by their HIV and AIDS patients.

The physical problems enumerated were grouped by the researchers into four problem areas i.e. 'general physical problems', 'neurological problems', 'infectious problems' and 'constitutional problems'. 'General weakness' (n=22) was the most frequently stated answer (see *Table V on page 14*) and weight loss the next most frequently mentioned problem. It is noted that not all of the problems were noted by all of the therapists.

All 35 participants named one or more psychological/psychiatric problems which may be seen as a consequence of HIV/AIDS. The answers could be divided into two major categories: 'Mental conditions' and 'expression of feelings'. 'Mental conditions' were further divided into two subgroups. The first represents diagnoses and the second symptoms of the condition as some participants stated the symptoms rather than the diagnosis. Depression was the most frequently mentioned condition (n=23). (See *Table VI* on page 14). The psychological / psychiatric sequela of HIV other than depression and anxiety are seldom discussed in the literature but are never-the-less extremely important in dealing with the overall function of the PLWA and are essential for therapists to consider in treatment.

The authors felt that providing a list of problems and conditions that was compiled according to the literature[17,18,19,20] would assist therapists to offer relevant therapy (see *Table VII* on page 14). Although this categorisation appears to

*Table IV: Stages of progression of HIV/AIDS*

| ***WHO Four Stages***[18] | ***Five Phases***[19] |
|---|---|
| **Stage I - Asymptomatic – Infection stage (silent stage)** | Phase I– The Primary infection phase or acute sero conversion illness |
| *The client may have:*<br>❖ A sore throat and flue- like symptoms sometimes<br>❖ Enlargement of the lymph nodes<br>❖ Muscle and joint pains<br>**Performance scale**: 1 - Asymptomatic – Normal activity<br>**CD4 Count: 500 – 800 cells/mm3** (Normal 800 - 1200 cells/mm3) | ❖ Glandular fever type of illness<br>❖ Sore throat, headache, mild fever, fatigue,<br>❖ Swelling of Lymph nodes<br>❖ Muscle and joint pains<br>❖ Rash<br>❖ oral ulcers |
| | **Phase II – Asymptomatic or latent phase** |
| | ❖ No symptoms |
| **Stage II - Minor Symptoms** (3-7 yrs after infection) | **Phase III Minor Symptomatic phase** |
| *The client may have:*<br>❖ Weight loss < 10% of body weight<br>❖ Skin rashes with a chronic itchy skin<br>❖ Mouth ulcers and infections<br>❖ Infection of the nails<br>❖ Shingles<br>❖ **Respiratory tract infections**<br>❖ Venereal Disease NB<br>**Performance scale 2: normal activity / symptomatic**<br>**CD4 count: 350 – 500 cells/mm3** | *The client may have:*<br>❖ Weight loss up to 10% of body weight<br>❖ Swelling of lymph nodes<br>❖ Occasional fevers<br>❖ Herpes zoster or Shingles<br>❖ Skin rashes dermatitis, chronic itchy skin<br>❖ Infection of nails<br>❖ Recurrent oral ulcerations<br>❖ **Recurrent upper respiratory track infections**<br>❖ **Malaise fatigue and lethargy** |
| **Stage III - Symptomatic Phase** (5-8yrs after infection) | **Phase IV – Major Symptomatic Phase** |
| *The client may have:*<br>❖ Weight loss >10% of body weight.<br>❖ Same conditions as previous stage<br>❖ Chronic diarrhoea > 1month.<br>❖ **Prolonged fever and pneumonia**<br>❖ **TB**<br>❖ **Depression, anxiety and worry**<br>❖ **Opportunistic disease and conditions of various types (see table VI)**<br>**Performance scale 3: bedridden <50% of day**<br>**CD4 count: 200 - 350 cells/mm3** | *The client may have:*<br>❖ Weight loss >10% of body weight<br>❖ Oral and vaginal Candida<br>❖ Recurrent herpes<br>❖ Bacterial skin infections<br>❖ Unexplained fever<br>❖ Chronic diarrhoea<br>❖ Generalised lymphadenopathy<br>❖ Abdominal discomfort and headaches<br>❖ TB<br>❖ **Opportunistic disease and conditions of various types (see table VI)** |
| **Stage IV - Severe HIV related disease** (18months later) | **Phase V AIDS defining conditions**: |
| ❖ Same conditions as previous stage<br>❖ Chronic diarrhoea > 1month.<br>❖ Prolonged fever and **pneumonia**<br>❖ **TB**<br>❖ **Depression, anxiety and worry**.<br>❖ **Opportunistic disease and conditions of various types (see table VI)**<br>**Performance scale 3: bedridden <50% of day**<br>**CD4 count: 200 - 350 cells/mm3** | ❖ Continuous diarrhoea causing patient to become thin and emaciated<br>❖ All above symptoms<br>❖ Pneumonia<br>❖ Wasting of body tissues |

Table V: Main physical problems of HIV/AIDS patients

| **General physical problems:** | **Number (n=35)** | **Percent (%)** |
|---|---|---|
| General weakness | 22 | 63 |
| Poor endurance | 9 | 26 |
| Muscle wastage | 7 | 20 |
| Reduced ambulation | 6 | 17 |
| Immobility | 6 | 17 |
| General body pain | 4 | 11 |
| Fatigue | 3 | 9 |
| ADL problems | 2 | 6 |
| Contractures | 2 | 6 |
| Developmental delay | 2 | 6 |
| Reduced muscular strength | 2 | 6 |
| Poor muscle development | 1 | 3 |
| **Neurological problems:** | **Number (n=35)** | **Percent (%)** |
| Para-/tetra-/hemiplegia | 4 | 11 |
| Peripheral neuropathy | 3 | 9 |
| Tone problems | 2 | 6 |
| CVA | 2 | 6 |
| Other (Guillain Barré, migraine, neurological damage, tremor) | 4 | 11 |
| **Infectious problems:** | **Number (n=35)** | **Percent (%)** |
| TB or other chest infections | 16 | 46 |
| Low immune system | 4 | 11 |
| Skin infections | 2 | 6 |
| Sores that won't heal | 2 | 6 |
| Meningitis | 1 | 3 |
| **Constitutional problems:** | **Number (n=35)** | **Percent (%)** |
| Weight loss | 8 | 23 |
| Loss of appetite | 4 | 11 |
| Diarrhea | 4 | 11 |
| Malnutrition | 1 | 3 |
| Other | | |
| Dental problems | 2 | 6 |

Table VI: Main psychological/psychiatric problems of HIV/AIDS patients

| **Diagnosis** | **Number (n=35)** | **Percent (%)** |
|---|---|---|
| Depression | 23 | 66 |
| Anxiety | 7 | 20 |
| Psychotic disorders | 7 | 20 |
| Dementia | 7 | 20 |
| Others (suicidal tendencies, personality disorder) | 2 | 6 |
| **Symptoms** | **Number (n=35)** | **Percent (%)** |
| Hallucinations | 5 | 14 |
| Loss of judgment | 5 | 14 |
| Loss of concentration | 4 | 11 |
| Confusion | 3 | 9 |
| Other (disorientation, thought process disorganisation, violent) | 3 | 9 |
| Memory loss | 2 | 9 |
| **State of mind:** | **Number (n=35)** | **Percent (%)** |
| Denial | 7 | 20 |
| Anger | 4 | 11 |
| Apathy | 4 | 11 |
| Fear of rejection by others | 4 | 11 |
| Isolation / Withdrawal | 3 | 9 |
| Low self esteem | 2 | 6 |
| Reluctance to share status with others | 2 | 6 |
| Other (death fear, lose will to live, indifference, fear of dependency, regret, fear of stigmatisation) | 6 | 17 |

Table VII: Diagnostic groups

| | |
|---|---|
| **IMPAIREMENTS** | |
| Neuropathogenic | |
| Meningitis | Fever<br>Headache |
| HIV encephalopathy | Hemiparesis<br>Language deficits<br>Sensory loss<br>Ataxia or tremor<br>Visual field defects<br>Confusion<br>Memory loss<br>Loss of vision<br>Poor concentration<br>Seizures |
| Polyneuropathy | |
| Peripheral neuropathy<br>HIV related Guilane Barre Syndrome | Pains<br>Numbness<br>Weakness of distal muscles |
| Sensory neuropathies | Severe pain<br>Diminished temperature sensation |
| Spinal cord and nerve roots | Paraplegia<br>Peripheral nerve dysfunction |
| Other | |
| Myopathies | Weakness of the proximal muscles |
| Eye conditions | Blindness<br>Double vision<br>Blurred vision |
| Respiratory conditions | TB, pneumonia |
| Secondary cancer | Karposi's sarcoma |
| Secondary infections | |
| Bone and joint disorders | |
| Constitutional disease | Fever, weight loss, diarrhea |
| Disturbance in Mental function | |
| Aids dementia complex | |
| Mood disorders | |
| Anxiety disorders | |
| Psychotic disorders | |
| Post traumatic stress disorder | |
| Internalised shame | Shame, guilt, anger, |
| Grief | |
| | |
| **ACTIVITY LIMITATIONS** | |
| Impact of daily function | |
| Delayed developmental milestones | Cognitive, physical, behavioural |
| | |
| **PARTICIPATION RESTRICTIONS** | |
| Social Sequela | |
| Job loss and poverty | |
| Social rejection and isolation | Preventing the individual from obtaining social support |
| Burden of care in family | |
| Adherance problems | |
| Lifestyle changes | |

emphasise a medical approach it is important as mentioned by Worthington *et al*[4] that HIV/AIDS is seen as a multilayered condition with psychosocial consequences. The psychosocial consequences, some of which have been mentioned in *Table VI*, are numerous and far reaching and some of them are often difficult to assess and deal with within the hospital environment where all the participants were employed. It is notable that neurological complications; cognitive defects with associated depression, loss of motivation and apathy; respiratory problems including TB are among the most common problems experienced by PWAs[3,17,18,19].

## e) Knowledge of the relevant therapy

The participants were asked to state what treatment they would give at each stage of the disease progress. Only the answers that stated there were three or four stages are presented here as the suggested treatments in the answers could be compared. The participants stating **four** stages gave the answers shown in *Table VIII* on page 15 and those stating **three** stages gave the answers shown in *Table IX* on page 15.

Apart from giving the patients information about the disease and the way that it changes their lives and giving support, most of the answers suggested symptomatic treatments and were focused on maintaining health and preventing disabilities. It is surprising that giving advice on functional

*Table VIII: Care given at the four different stages of HIV/AIDS*

| Stage 1: Preventative work | Number (n=11) | Percent (%) |
|---|---|---|
| Maintenance of healthy lifestyle | 3 | 27 |
| Counselling | 2 | 18 |
| Prevent complications | 2 | 18 |
| No treatment (too healthy) | 2 | 18 |
| Other (eat good diet, preventive skills, stress management) | 3 | 27 |
| **Stage 2: Maintenance of health** | **Number (n=11)** | **Percent (%)** |
| Prevent opportunistic diseases through healthy eating | 3 | 27 |
| Exercise | 2 | 18 |
| Give functional advice if required | 2 | 18 |
| Prevent complications | 2 | 18 |
| Education | 2 | 18 |
| No treatment (too healthy) | 2 | 18 |
| Other (provide support groups, encourage taking medication) | 2 | 18 |
| **Stage 3: Symptomatic treatment** | **Number (n=11)** | **Percent (%)** |
| Chest physio | 2 | 18 |
| Strengthening exercises | 2 | 18 |
| Symptomatic treatment | 2 | 18 |
| Advice to carers/family | 2 | 18 |
| No treatment (too sick) | 1 | 9 |
| Other (balanced diet, mobilisation, day planning, advice on functional problems, Home Based Care, treat and support, education) | 9 | 82 |
| **Stage 4: Making patient feel comfortable** | **Number (n=11)** | **Percent (%)** |
| Bed mobility | 2 | 18 |
| Guiding through death process | 2 | 18 |
| Support | 2 | 18 |
| No treatment (too sick) | 2 | 18 |
| Other (balanced diet, exercise, teach family to care for patient, adaptation, make patient comfortable, hospital based care) | 6 | 55 |

*Table IX: Care given at the three different stages of HIV/AIDS*

| Stage 1: Preventative work, focused on psychological aspects | Number (n=14) | Percent (%) |
|---|---|---|
| Counselling | 6 | 43 |
| Support | 4 | 29 |
| Exercise and muscle strengthening | 4 | 29 |
| Advice | 2 | 14 |
| Medication | 2 | 14 |
| Advice on diet and healthy lifestyle | 2 | 14 |
| Other (active participation in activity, chest physio, enhance quality of life, insight, education, socio-emotional groups) | 6 | 43 |
| **Stage 2: Symptomatic treatment** | **Number (n=14)** | **Percent (%)** |
| Manage physical and psychological symptoms | 4 | 29 |
| Chest physio | 3 | 21 |
| Medication | 3 | 21 |
| Group therapy | 2 | 14 |
| Muscle strengthening | 2 | 14 |
| Others (assistive devices, counselling, advice on lifestyle and nutrition, encouragement to walk, auto-assisted exercises, mobilisation, prevent pressure sores) | 7 | 50 |
| **Stage 3: Help patient maintain capabilities for as long as possible** | **Number (n=14)** | **Percent (%)** |
| Medication | 5 | 36 |
| ROM management | 3 | 21 |
| Maintenance of activity | 3 | 21 |
| Chest physio | 2 | 14 |
| Prevent complications | 2 | 14 |
| Other (supportive care, energy conservation, maintain strength, support, increase independence, coping with death, memory books, info about legal matters) | 8 | 57 |

problems was mentioned so few times. It is also disappointing that no mention was made of community integration programmes as well as self help and other income generating groups. Again this may be due to the participants being hospital based.

It is interesting that although all participants recognised that one or more psychological problems occurred as part of HIV/AIDS, of the 11 participants who named the four stages only three mentioned psychological intervention when asked about what treatment they preferred to give at each stage i.e. stress management. On the other hand, of the 14 participants who gave three stages, eleven mentioned the psychological aspects of treatment i.e. socio-emotional groups and managing psychological symptoms. The treatment mentioned by the participants, although not given in relation to the problems that could be experienced by the PLWA, covered very generally the treatment that could be given. It is also interesting that "giving medication" has been mentioned 10 times. One would assume that they mean supporting patients taking medicine as therapists are clearly not involved in providing medication. None mentioned that they would need to deal with the side effects of medication and or the fluctuating nature of the condition.

The literature has provided some guidelines for physiotherapy and occupational therapy, McClure[21] giving a comprehensive description of physiotherapy intervention for symptoms that may be experienced by PLWAs according to the area affected i.e. central nervous system, peripheral nervous system, inflammatory conditions, respiratory disorders, and Karposi's sarcoma. She mentioned specific techniques such as TENS for different problems and that exercise, relaxation, and general advice should be given at an early stage and that aerobic exercise is particularly beneficial. She suggested that AIDS related complications could be delayed by exercise thus inferring that treatment should start during stages one and two. A modified exercise regime should therefore be given early in collaboration with occupational therapy energy conservation strategies. Cusak and Singh[22] have also provided specific therapeutic guidelines for both PTs and OTs.

Pizzi[23] applied the Model of Human Occupation (MOH) to adults with HIV. Pizzi suggested that as occupational and functional levels can vary dramatically throughout the course of HIV infection, occupational therapists can support people to lead productive lives through adaptation of favoured roles, discussion on role changes as well as providing adaptive equipment, self ranging occupations, physical activity to maintain physical well being and daily activity that balances activity and rest. Pizzi placed an emphasis on a structured functional approach to care, focusing on occupational role performance, control and mastery of life, productivity and the value and meaning of life activity. The authors are of the opinion that structuring treatment through the use of the MOH would be particularly useful in dealing with the multi-facets of HIV/AIDS.

Models such as the MOH and the Canadian Model of Occupational Performance as well as frameworks are useful for structuring treatment. Fish and Rudman[24] presented the potential role of occupational therapy in acute care with clients with HIV/AIDs using the Canadian Model of Occupational Performance and O'Brian *et al*[24] developed a conceptual framework of existing HIV curricula to inform future curriculum planning for the education of rehabilitation professionals both of which can help OTs provide relevant treatment.

Joubert *et al*[26] mentioned that programmes which "elicit positive emotional responses through the enjoyment and mastery of various occupations and activities, could have a positive effect not only on the immune system but on the quality of life of individual with AIDS"[26:15]. This could have a positive influence on the patients CD4 count. Concha[27] found that PLWAs participating in an activities of daily living programme showed substantial improvement in their ability to carry out these activities independently and expressed ‘happiness’ as a result.

Worthington *et al*[4] also developed a conceptual framework for the rehabilitation of PLWAs through extensive consultation with the various stake holders including PLWAs. They stated that although the same rehabilitation principles i.e. being client centered and goal focused, apply to PLWAs, as to those living with other conditions, “the context of HIV made rehabilitation different”[4:261]. The different layers of context have already been mentioned but Worthington *et al*’s definition of rehabilitation is worth quoting here as it summarises the previous treatment reviews:

> “It (rehabilitation) should include maintenance, restoration, and enhancement of well-being among those Living with HIV/AIDS…. It should be seen as client-centered and goal orientated; that it could be involved at any stage of the disease process along a wellness and illness continuum from prevention to palliation; and that it could address impairment, activity limitation, or participation restriction experienced by someone living with HIV/AIDS”[4:265].

They also felt that it was important that multi-dimensional rehabilitation domains such as health promotion, prevention, education, community development, and policy development should be part of the services offered.

Judging by the answers to the question concerning types of treatment that are preferred by the participants , much could be gained by the respective professions offering formal courses covering all aspects of HIV/AIDS and rehabilitation including the ignored aspect of poverty reduction and the ways in which self help groups can contribute to the health and well being of PLWAs.

## Theme Two - Attitudes toward PLWAs

### a) Fear of contracting the disease

The participants were asked whether they knew if their patients had been diagnosed with HIV/AIDS before they commenced treatment. Twelve (34%) participants answered ‘Yes’, 14 (40%) answered ‘No’ and nine (26%) answered ‘Sometimes’. The participants were also asked whether they were afraid of contracting HIV/AIDS when treating their patients and 17 (49%) answered ‘Yes’, another 17 (49%) answered ‘No’ and one (3%) answered ‘Don’t know’ to this question. In comparison only thirty eight percent of the physiotherapists in the Pucktree et al[10] study were completely at ease when treating HIV/AIDS patients.

They were then asked whether knowing more about the disease would decrease their fears. Of the 17 participants that answered ‘Yes’ they were afraid of contracting the disease eight (47%) said that knowing more about HIV/AIDS would decrease their fears, and the remaining nine participants (53%) answered ‘No’ ie increased knowledge would not do so.

When the ‘*age of the PT/OT*’ and ‘*fear of contracting HIV/AIDS when treating a patient*’, was examined it was seen that the age group 21-25 years had a higher percentage (59%) of therapists afraid of contracting the disease than the age group 26+ (41%). Sheen and Green[28] found that PTs who had previous experience of working with HIV and AIDS patients were significantly more positive towards this patient group than those who did not thus indicating that practice exposure had a role to play in improving attitudes.

Other studies have found a high degree of fearfulness among health professionals about the possibility of becoming HIV+ through their work[11,14,28]. Atchison et al[11] explored the attitudes, knowledge and fears of occupational therapists and certified occupational therapy assistants with regards to AIDS and HIV and found that many had significant fears which in turn may affect their willingness to care for persons with AIDS. Gatsi et al[29] also found that 54.6% of a sample of physiotherapists surveyed by them expressed fear of becoming infected while treating patients.

It appears that our sample of rehabilitation professionals is no different from others when it comes to experiencing fear in relation to treating PLWAS. What is of concern however is the effect that this fear may have on effective service delivery. It is clear that educationalists need to find ways of overcoming these fears.

### b) Able to tell by looking at somebody if they have AIDS

The participants were asked whether they were able to tell by looking at somebody whether they had HIV/AIDS, 10 (28.5%) answered ‘Yes’ to this question, while 17 (48.5%) stated ‘No’ or ‘Don’t know’ and an additional 8 (23%) answered ‘Sometimes’.

When comparing the ‘*years working as an PT/OT*’ with the above information it was found that 12% of the PTs/OTs who have been working for less than a year answered ‘*Yes*’, compared to 39% among those who had been working for more than a year. Furthermore, the first group answered ‘Sometimes’ in 35% of the cases, while only 17% of the second group gave the same answer.

It is of concern that several therapists felt that they were able to make a diagnosis just by looking at a patient as it indicated that therapists are making value judgments about the patients. This may influence the treatment that they give and provides a strong indication that knowledge about HIV/AIDS should be improved.

### c) Precautionary guidelines

When the participants were asked whether they knew if precautionary guidelines existed for the treatment of HIV/AIDS and other infectious conditions at their place of work 24 (69%) out of 35 stated that precautionary guidelines did exist at their workplace but 10 (29%) stated that there were no such guidelines, and one (3%) did not know. When asked if they felt safe when following these guidelines, of the 24 participants that stated that the guidelines existed 18 (75%) answered that they did feel safe, four (17%) answered that they still did not feel safe, one (4%) did not know and one (4%) stated that she sometimes felt safe when using the precautionary guidelines. The fact that 29% of the participants stated that there were no precautionary guidelines for HIV at their work place was of concern especially as 30% of a hospital patient community are said to have HIV related conditions[3]. Although using the precautionary guidelines, there were four participants that still did not feel safe.

The participants were also asked if they always took all the necessary precautions when dealing with HIV/AIDS patients and twenty five 25 (71%) answered ‘Yes’. Two of the participants who answered yes added a comment “*You try most of the time to protect yourself, but accidents do happen*.” “*But only if necessary i.e. where no body fluid exchange possible such as interviews and home training*.” Nine participants answered *“No”* (26%) and one (3%) said that he/she “*Did not know*”.

The participants who did not take precautions were asked what their reasons for this were. Two of the nine participants who said that they did not take precautions said that the reason was that wearing protection makes “*the patients feel small, unliked and offended*”. One answered that children were often afraid when gloves were used and two of the nine said that they, on occasion, forgot to take the necessary precautions. Another two said that they did not always take precautions: “*If you treat a patient who does not have open wounds and does not bleed so there is no need for me.*” “*If there is no danger of contraction I do not use, for example treating chest patients and doing percussions without removing clothes you can’t get it by touching clothes.*” One found it to be “*too much of a hastle”* and one stated time constraints as a reason for not taking precautions.

The fact that as many as 26% of the therapists stated that they did not always take the necessary precautions when dealing with HIV patients is worrying considering that they had scanty knowledge of the transmission modes (only eight subjects gave the three correct transmission modes). Two participants stated that if there was no risk of exposure, they would not take precautions. To “*forget to take precautions*” can happen, but to find it to be “*too much of a hastle*” is of concern.

Eighty two percent (17) of the participants who answered that they were ‘*afraid of contracting HIV when treating a patient*’ always took precautions, 18% were afraid, but did not always follow the precautionary guidelines. Thirty percent (17) of the participants who revealed that they "*are not afraid*'" do not always take precautions.

In the Pucktree et al[10] study, eighty percent of the PTs working in the public sector wore gloves compared to only 34 percent in the private sector. Almost 20% of respondents indicated that they would not treat the patient if the patient had open lesions.

The participants were also asked to name the clinical situations where they felt that they may be at risk. Forty six percent did not feel that there were any clinical situations where they were at risk of contracting HIV. This is interesting, considering that they are working in situations where contaminated body fluids, mucous membranes or open wounds could occur, for instance: helping a patient with activities of daily living involving sharp objects, doing chest physiotherapy, treating a patient with open wounds and having a needle prick injury. A surprising finding was that 50% of those who said that there were no specific clinical risk situations still felt afraid when treating patients with HIV and AIDS, which further points out the need for education concerning transmission modes and increased knowledge about universal precautions and clinical situations where there is a risk of being infected.

The clinical situations where the 18 participants who felt that there were clinical situations where they could be at risk are given in *Table X*.

*Table X: Clinical situations presenting a risk of contracting HIV*

| Situations | Number (n=18) | Percent (%) |
|---|---|---|
| Treating open wounds | 9 | 50 |
| Sputum in eye/open wound | 6 | 33 |
| Sharp objects involved | 3 | 17 |
| Needle prick injury | 2 | 11 |
| If not using protective gear | 2 | 11 |
| Unknown HIV status of patient | 1 | 6 |
| Children may bite/vomit | 1 | 6 |

Generally[30] there is a low risk associated with the treatment of HIV/AIDS by therapists[31] however this does not mean that precautions should not be taken in treatment particularly in situations where percutaneous injury is possible. Adler[32] reported that by December 1999 approximately 96 caregivers world-wide had contracted the disease in work related incidents, mostly through percutaneus exposure to contaminated blood. The rate of transmission after a single percutaneus exposure to HIV positive material is 0,32% and by 1993 no PTs had been infected[33].

The participants were then asked if they would refuse to handle an HIV/AIDS patient if they had a laceration on an exposed part of their body even if they took precautions. Two participants (6%) said "*Yes*" they would refuse to handle a HIV/AIDS patient if they had lacerations. Thirty one (89%) participants answered "*No*", and two (6%) did not know if they would treat a patient under these conditions.

Gershon *et al*.[30] found that compliance with universal precautions was correlated with key factors such as 1) perceived organisational commitment to safety, 2) perceived conflict of interest between workers' needs to protect themselves and their duty to provide medical care, 3) risk taking personality, 4) perception of risk, 5) knowledge regarding routes of HIV transmission and 6) training in universal precautions. As 29% of participants stated that there were no precautionary guidelines at their place of work and several did not take any precautions as well as the high number being afraid of contracting HIV from their patients, health institutions need to disseminate guidelines and policy as a matter of urgency. This need was confirmed by Dijkstra *et al*[34] who found that more than a quarter of the medical staff at a major South African state hospital (including OTs and PTs) had insufficient knowledge of HIV/AIDS.

### d) Does rehabilitation make a difference?

The participants were also asked whether they thought that rehabilitation made a difference in the lives of their HIV/AIDs patients. Twenty six (74%) of the participants felt that it did, two (6%) answered "*No*" to the question, six (17%) said that they "*Don't know*", and one participant (3%) answered "*Sometimes*". The participants were then asked in what way they felt that rehabilitation had made the difference (see *Table XI*). The two subjects who answered "*No*" to the question about making a difference gave these reasons: *"Pure HIV/AIDS patients aren't really seen regularly, so it doesn't make much difference. Individuals with other complications i.e. stroke from HIV/AIDS we can make difference – and it's much easier than pure HIV/AIDS." "They get exhausted when giving them exercises as they need strength instead they're weak."*

*Table XI: Ways therapists feel they make a difference to the HIV/AIDS patient*

| Physical help | Number (n=26) | Percent (%) |
|---|---|---|
| Enhance physical fitness | 8 | 31 |
| Give independence in ADL | 6 | 23 |
| Enhance mobility | 5 | 19 |
| Treat secondary complications | 3 | 12 |
| Compensate for loss of function | 3 | 12 |
| Prevent bedsores | 2 | 8 |
| Positioning | 2 | 8 |
| Ergonomic adaptation | 1 | 4 |
| Decrease pain | 1 | 4 |
| **Psychological help** | **Number (n=26)** | **Percent (%)** |
| Improve quality of life | 7 | 27 |
| Help patient come to terms with condition | 5 | 19 |
| Give support | 4 | 15 |
| Improve mood | 4 | 15 |
| Give information (*"on HIV"* and *"teach patient precautionary measures"*) | 3 | 12 |
| Help patient adapt to new life style | 3 | 12 |
| Give hope | 2 | 8 |
| Provide group support | 2 | 8 |
| Destigmatise | 1 | 4 |

Of the six participants that had said that they did not know if they had made a difference only one commented: "*Because I'm not sure if they benefit from my treatment.*" The one who answered "*Sometimes*" stated that: "*You can give patient advice to lead a healthier lifestyle. Keep them active and explain that they can lead a normal life. To keep them as independent as possible.*" In spite of some participants saying that they did not make a difference in the lives of their patients, the answers still reflect a positive attitude towards the effects of rehabilitation. Unfortunately the participants were not asked about their knowledge of ARVs and the effect of taking these medications. The positive effects of rehabilitation found by Concha[27], in her work with PLWAs indicates that knowledge of HIV and AIDS and the relevant rehabilitation is paramount if we as therapists are going to make a difference.

As many patients die at home there is a burden of care placed on the family. The participants were therefore asked if OTs and PTs should be giving "Home Based Care"(HBC). Home based care refers to more than just rehabilitation but also to home nursing care. In response 17 (49%) participants thought that PTs/OTs should give HBC, 14 (40%) did not think so and four (11%) answered *"Don't know*". The participants who answered that they thought that OTs and PTs should give HBC were asked to list what it was that they needed to learn to be able to give this care. The answers can be seen in *Table XII on* page 18.

Those participants who answered that they did not feel that OTs and PTs should give HBC were asked to name whom they felt should provide this service. Of the 14 participants who replied "*No*" eight of them stated that 'Community Rehabilitation Workers' (CRWs) should be giving this service, and six mentioned 'nurses' (see *Table XIII* on page 18). One subject suggested that the PT/OT should teach the family about Home Based Care, and that a branch of PTs/OTs should be specialised in giving Home Based Care to HIV/AIDS patients.

## Conclusions

Among the sample of Occupational Therapists and Physiotherapists surveyed for this study there are many who do not appear to

*Table XII: What therapists feel need to learn to give Home Based Care*

| Skills needed | Number (n=17) | Percent (%) |
|---|---|---|
| Principles of treatment in home environment | 5 | 29 |
| Medical information on HIV/AIDS | 4 | 24 |
| Counselling for patient and care givers | 4 | 24 |
| How to cope with death and dying | 4 | 24 |
| How to prepare a nutritious diet | 3 | 18 |
| Advocacy | 2 | 12 |
| Social relationships with HIV positive | 2 | 12 |
| Cultural/ language education | 2 | 12 |
| Others (Self defence, Information on resources available, Principles of assessment, How to cope with patients asking for money) | 4 | 24 |

*Table XIII: Other individuals suggested to give Home Based Care*

| Individuals suggested: | Number (n=14) | Percent % |
|---|---|---|
| Community Rehabilitation Workers | 8 | 57 |
| Nurses | 6 | 43 |
| Home Based Carers* | 5 | 36 |
| Volunteers | 3 | 21 |
| Other (doctors, pastors, people chosen by the community) | 3 | 21 |

*Home Based Carers are: family, friends and people from the community usually volunteers. They are NOT professionals.

have a good understanding of HIV and AIDS, of the transmission modes, of the progress of the disease and of the different types of therapy suitable for each stage. It is not surprising therefore that a high percentage (49%) felt afraid when treating patients who were HIV+. Although this fear seems to decrease with experience there is still enough evidence to suggest that it is still present. In spite of this therapists do not always observe universal precautions.

Although the sample used in this study is relatively small the results indicate that there is insufficient knowledge and understanding of HIV and AIDS and verifies the findings of other studies. As one participant suggested, there may be scope for a specialised study of HIV and rehabilitation. However, it would be difficult for therapists working within the public health system in South Africa to escape working with PLWAs and for them to rely on specialists in the field. This means that there must be better student training, clinical guidance and support after qualification for therapists to enable them to feel comfortable treating PLWAs and to provide relevant therapy. It is also clear that the psychosocial needs of PLWAs would be best catered for at the community level where they can benefit maximally from all the different aspects of rehabilitation. Studies on the effectiveness of rehabilitation (other than exercise the value of which has already been proved)[16] with PLWAs could also provide incentives to provide therapy.

As there are large numbers of PWLAs and with the current willingness of the Department of National Health to improve the uptake of ARVs, it is also important that OT and PT education provides information on the side effects of taking ARVs and the way in which theses can be dealt with in rehabilitation.

As Concha[27] has demonstrated, this field of practice can produce very positive results for the clients and is therefore well worth the energy needed to improve the knowledge of therapists with regard to treating PLWAs.

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