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MAINSTREAMING HIV/AIDS IN PHYSIOTHERAPY EDUCATION AND PRACTICE

Hellen Myezwa

A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy

Johannesburg, 2008

DECLARATION

I, Hellen Myezwa, declare that this thesis is my own work. It is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

……

…….day of ……., 2008

PUBLICATIONS AND PRESENTATIONS IN SUPPORT OF THIS THESIS

H Myezwa

PUBLICATIONS

Myezwa H, Stewart A, Mbambo N, Nesara P,2005, Status of referral to physiotherapy among HIV positive patients at Chris Hani Baragwanath Hospital Johannesburg South Africa
The South African Journal of Physiotherapy: 63 (2) 27-31

Van As M, Myezwa H, Stewart A, Maleka D, Musenge E, The international classification of function (ICF) in adults visiting the HIV outpatient clinic at a regional hospital in Johannesburg, South Africa. AIDS CARE online version

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Myezwa H, Stewart A, Nesara P, 2007, Impairments, activity limitations and participation restriction: prevalence determined by ICF for patients living with HIV/AIDS admitted to CHBH- part 1
Platform presentation -School of Therapeutic Sciences Research Day University of the Witwatersrand 20th August 2007

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ABSTRACT

This thesis centres around the issues concerning HIV/AIDS and physiotherapy education, curriculum and practice. In particular, this thesis examines which HIV specific content should be included in a physiotherapy curriculum and ultimately presents a conceptual framework for HIV input into the curriculum.

There is a vast body of literature available on HIV. For physiotherapists, however, apart from a brief review given by Nixon and Cott (2000) using the ICIDH, no comprehensive literature is available that places information on HIV into a framework that speaks to physiotherapists as part of the rehabilitation fraternity. The literature on impairments is descriptive and buried in the medical model as symptoms. Section one of the literature review placed the literature in such a framework and provided a comprehensive description using the ICF and related aspects that concern physiotherapists. The ICF captures all the elements of current rehabilitation theory and practice and the literature is presented in an ICF framework. In addition, important background information on prevalence, its determinants, treatment approaches and subsequent impacts were reviewed. As most of the literature available still remains in the medical model, the conditions that manifest and from which patients develop impairments, were reviewed.

The effects of HIV on body systems are extensive and pervasive. In each body system HIV has direct effects on mature and maturing cells e.g. progenitor cells and mature muscle cells. In the musculoskeletal system HIV impacts on functional systems and organs resulting in pathophysiological changes that manifest as impairments such as muscle wasting. Conditions manifesting in all body systems were reviewed and outlined. Impairments such as pain, breathlessness and proximal muscle weakness were reported in the literature. In addition to impairments, analysis of the literature revealed studies that had found high levels of functional and activity limitations as well as impacts on Health-related Quality of Life in HIV. The literature also presents the current status of physiotherapy interventions. Many studies have reported that exercises are a safe and effective mode of intervention not-withstanding the limitations encountered.

The second part of the literature review focussed on aspects concerned with curriculum. Previous studies have focused on establishing baseline knowledge, attitudes and practices (KAP) to HIV and the impact of training programmes on KAP. What the actual content was for health workers, in particular physiotherapists and the approach to incorporating HIV into curricula is a gap in the literature.

To inform the overall aim, with context-appropriate HIV content, this study undertook a number of studies in order to obtain the necessary information on HIV, specific to physiotherapy. Therefore the overall approach was a mixed methods one employing both a quantitative and qualitative study mix.

The first and second studies informed the clinical picture and were both cross-sectional and descriptive. In both studies descriptive statistics were used to analyse data, especially in determining the absence or presence of conditions. Study 1 sought to establish the level of referral to physiotherapy by retrospectively examining the patient records of patients admitted with HIV-related conditions over a period of one year. Of the 732 patient records reviewed, 139 (19%) had diagnoses considered suitable for physiotherapy and 3% were referred to physiotherapy.

Study 2 aimed to establish a relevant overview of the functional and participation limitations of people living with HIV. Two groups of patients were studied i.e. an in-patient group and an out-patient group. The out-patient group was from a well resourced mining out-patient setting. The ICF checklist was utilised to collect the data and statistical analysis was performed to indicate the presence or absence of impairments, activity limitations and participation restrictions. A logistic regression was done to determine the odds of activity, limitation or participation restriction given certain levels of domains. Both groups showed high levels of impairment. For the in-patient group loss of muscle power 75%(n=60) energy and drive 75%(n=60), disturbed sleep 71%(n=56), emotional problems 62%(49), mild-severe pain 80%(66), weight maintenance difficulties and diarrhoea were apparent. In the out-patient mining group memory problems, energy and drive functions 36%(n=18), sleep 24% (n=12) and emotional functions 28% (n=14), seeing 32% (n=17), hearing, vestibularproblems 28%(n=14) and pain 55%(n=28), blood pressure and respiratory problems 24%(n=12), weight maintenance 63%(n=32), sexual functions 22%(n=11) and reduced proximal muscular power 24%(n=12) were encountered. The in-patient group had high levels of activity limitations and participation restrictions, while the out-patient mining group did not. There was association between the different domains and in the in-patient group gender (p=0.02) and marital status (p=0.01) were likely to influence the activity and participation levels and the experience of the environment.

The remaining three studies involved aspects related to informing the curriculum component of this thesis. Study 3 audited the universities' curricular documents to establish what the current curriculum included. Seven of the eight universities that offer physiotherapy training were reviewed and their curricula were generally scanty on information regarding HIV/AIDS. When compared to the areas outlined as a result of the literature review, the study of the patients and focus groups

with clinicians and academic staff, revealed some gaps, in particular; the types of conditionsand the influence of HIV on other body systems which are pertinent to the clinical reasoning process for the physiotherapist: The philosophy of care and approach to management and the physiotherapists' role in HIV prevention, treatment and care were evident gaps.

Study 4 sought to develop a framework of HIV content for a physiotherapy curriculum. This was done by integrating the results found so far and verifying and enriching this data by gaining clinicians' and academics' insights and perceptions around HIV, based on their clinical and educational experience. Focus group discussions were conducted and a qualitative approach was undertaken for data analysis. A framework for curricula content emerged from this exercise.

In study 5 the framework of HIV content was used to develop a questionnaire that was sent out in the Delphi survey to academic staff with the aim to test the level of consensus. Eighty three components of the curriculum under four outcome areas (Appendix 7.2) were sent to 68 academic staff who were identified. Of the 68 academic staff, 58 were available and 47 responded and consented to participate. All but two topics obtained consensus set at 80% and the remaining two obtained consensus in the second round.

The final chapter discusses the results of these studies and illustrates how these results on HIV affect and can be applied to the physiotherapy curriculum, when applied to the UNAIDS mainstreaming criteria. Applying the mainstreaming principles to the process of including HIV content into the curriculum, ensures that the process is not done in a piece meal fashion but encompasses all important facets which were identified. The programme, if systematically implemented, could result in a coordinated outcome accounting for all the important facets.
A conceptual framework is drawn from the results of this thesis illustrating the three levels of curriculum taxonomy: At the micro level, through the body systems, the meso level through the role of physiotherapy, dealing with internal and external domains and teaching approaches. The macro level is accounted for by the facilitatory activities such as advocacy among clinicians and academics and forming strategic partnerships at all levels.

DEDICATION

To my husband Archie for all his support, love and never once complaining.

To my children Simbai, Chengetai and Danai for your patience and growth in independence.

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DEFINITION OF TERMS

PLHIV — For the purpose of correct use of terminology, the term ***people living with HIV*** (PLHIV) is recommended as the preferable term as it reflects that an infected person may continue to live well and productively for many years (UNAIDS March 2007).

LIST OF ABBREVIATIONS

ADL	-	Activities of Daily Living
AIDS	-	Acquired Immunodificiency Syndrome
BBB	-	Blood brain barrier
CD4	-	Cluster definition 4
CDC	-	Centers for Disease Control
CHBH	-	Chris Hani Baragwanath Hospital
CNS	-	Central nervous System
CSP	-	Chartered Society for Physiotherapy
CT	-	Computed Tomography Scans
CVA	-	Cardio Vascular Accident
DNA	-	Deoxy ribonucliiec acid
DSPN	-	Distal sensory peripheral neuropathy
EFV	-	Efavirenz
EQ5D	-	European Quality of Life Five Dimension
FIM		Functional Independence Measure
GBS	-	Guillian Barré Syndrome
HAART	-	Highly Active Antiretroviral Therapy
HIV	-	Human Immunodificiency Virus
HIV/AIDS	-	Human Immunodificiency Virus/ Acquired Immunodificiency Syndrome
HRQOL	-	Health-related qualityof life
HSRC	-	Human Sciences Research council
ICF	-	International Classification of Function
ICIDH	-	International Classification of Impairments, Disabilities and Handicaps
ICU	-	Intensive Care Units
MOS	-	Medical Outcomes Survey
NMF	-	Nelson Mandela Foundation
NNRTIs	-	None Nucleoside Reverse Transcriptase Inhibitors
NRTIs	-	Nucleoside Reverse Transcriptase Inhibitors
NVP	-	Nevirapine
PCP	-	Pneumocystis jiroveci (formerly carinii) pneumonia
PLWA	-	People living with AIDS
PLWH	-	People living with HIV
PMTCT		Prevention of mother to child transmission
QOL	-	Quality of Life

List of Abbreviations (continued)

RNA	-	Ribonucliiec Acid
RVD	-	Retro Viral Disease
SANHS	-	South African national health survey
SAQA	-	South African Qualifications Authority
SGB	-	Standards Generating Body
STI	-	Sexually transmitted infections
TB	-	Tuberculosis
TENS	-	Transcutaneous Electrical Stimulation
UNAIDS	-	The Joint United Nations Programme on HIV/AIDS
WHO	-	World Health Organisation

CHAPTER 1

1.1 INTRODUCTION

1.1.1 Background

It is estimated that more than 60 million people worldwide have lived with HIV/AIDS since the outbreak of the epidemic. According to the United Nations joint programme on HIV/AIDS (UNAIDS, 2007), over twenty two million people have died of the disease. In 2001 alone, AIDS claimed three million lives worldwide. UN projections in 2007 estimate that 33.2 million people are living with HIV worldwide of whom over half are women. Sub-Saharan Africa is the current epicentre of the pandemic with 24,5 million people projected to be living with HIV/AIDS at the end of 2007 (UNAIDS, 2007). Countries in Southern Africa with the highest prevalence rates are, Swaziland (33.4%). Botswana (24.1%), Lesotho (23,2%), Zimbabwe (20.1%), South Africa (18.8%), Namibia (19.6%), Zambia (17%), Malawi (14.1%) and Mozambique (16.1%) (UNAIDS, 2007). The sub-Saharan region has an infection rate among adults of 7.5%. In each country the epidemic is unique as illustrated by South Africa's statistics in Table 1.1.

The prevalence rates in South Africa are derived from two studies: namely the Department of Health study (1999 to 2002), which estimated the prevalence rate at an average of 27.3% and the Nelson Mandela /HSRC study which estimated the prevalence at 11.4%. Table 1.1 shows the trend in prevalence rates in South Africa compiled by the Department of Health by province from 1999 to 2006.

Table 1.1: Prevalence Rates in South Africa

Province	Year and prevalence %							
	1999	2000	2001	2002	2003	2004	2005	2006
KwaZulu	32.5	36.2	33.5	36.5	37.5	40.7	39.1	39.1
Gauteng (GP)	23.9	29.4	29.8	31.6	29.6	33.1	32.4	30.8
Free State (FS)	27.9	27.9	30.1	28.8	30.1	29.5	30.3	31.1
Mpumalanga (MP)	27.3	29.7	29.2	28.6	32.6	30.8	34.8	32.1
North West (NW)	23.0	22.9	25.2	26.2	No data	26.7	31.8	29
East Cape (EC)	18.0	20.2	21.7	23.6	27.1	28	29.5	29
Limpopo (LP)	11.4	13.2	14.5	15.6	27.5	19.3	21.5	20.7
Northern Cape (NC)	10.1	11.2	15.9	15.1	16.7	17.6	18.5	15.6
Western Cape (NC)	7.1	8.7	8.6	12.4	13.1	15.4	15.7	15.2
National	22.4	24.5	24.8	26.5	27.9	29.5	30.2	29.1
Source from 2001, 2003,2004,2005,2006 Department of Health Report								

1.1.2 Response of the Health and Rehabilitation Sector

HIV is an infectious virus that may be transmitted by blood and contaminated body fluids and tissues (Levinson & O'Connell, 1991). Asymptomatic infection may precede the development of various neurological sequelae before the development of AIDS. AIDS is the final stage in the progression of the illness (Mukand, 1991; Pantaleo et al., 1993). HIV/AIDS has been evolving globally for 22 years. As the aetiology became better known and understood, complications due to the direct effects of HIV/AIDS infection and the immuno-compromised state often lead to diagnoses commonly seen in the rehabilitation setting (Mukand, 1991; O'Dell et al., 1996a; 1998; O'Dell et al., 1996b). Through direct invasions or through secondary infections and neoplasms, HIV/AIDS has the natural tendency to involve multiple organ systems, producing a wide variety of disabling conditions (Levinson & O'Connell, 1991; Mukand, 1991).

The introduction of antiretroviral therapy management of HIV/AIDS (Department of Health, 2007a) has changed the perception of HIV from being a terminal to being a chronic condition (Jelsma et al., 2006; Levinson & O'Connell, 1991; Nixon & Cott, 2000; O'Dell et al., 1991). This development has important practice implications for rehabilitation professionals including physiotherapists and hereafter all discussion will refer to physiotherapists (Jelsma et al., 2006; Mukand, 1991). Physiotherapists are already learning about and treating patients with HIV/AIDS (McClure, 1993). This may be either intentionally

or unintentionally because the manifestation of HIV is pervasive, and within the major physiotherapy areas of practice has not gone unnoticed. However, the need for physiotherapy in the management of clients with HIV at all levels of intervention has been expressed in a disjointed fashion. Recent studies have started to show the importance of rehabilitation professionals playing an increasing role in the management of People living with HIV (PLWH) and in particular enhancing their quality of life (Zonta et al., 2003 ; Zonta et al., 2005). There has been very little research on how physiotherapists can approach the problem of HIV in a manner that brings together all facets of management in which they can make a difference.

The response to the pandemic in the health sector has involved education of the health care professional on the aetiology and wider impact of HIV (DoH report 2004, WHO 2003). It has been recognised that no other disease has generated so much concern, fear, anxiety and prejudice among health care professionals and the general public (Raghavendra & Prasad, 2001). As a result of these emotions displayed by health care professionals, early studies conducted globally, involving physicians, nurses, dentists and physiotherapists found variable to unsatisfactory levels of knowledge and overall negative attitudes towards patients with AIDS (Held, 1993; Seacat & Inglehart, 2003). Sweesty (1989) and Puckree (2004) found that physiotherapists, similar to other health care professionals, had inconsistent knowledge about HIV/AIDS and poor attitudes towards patients with HIV/AIDS.

A number of studies done internationally show that input into educational programmes of health-care professionals impacts positively on their knowledge, attitudes and practice in HIV/AIDS management (Radecki et al., 1999 ; Weyant et al., 1993). The study of Radeckis' (1999) study provided evidence that, despite potential conflicts between physicians' professional obligations towards patients and their freedom of choice with regard to providing care for the individual, the knowledge and values inculcated over the course of training appeared to diminish the impact of many of the factors associated with their reluctance to treat HIV/AIDS patients (Radecki et al., 1999). In addition Perry (1992) emphasised the need not only to learn about HIV/AIDS but also to examine one's own personal belief and value systems, replace fear with compassion and acceptance and to confront one's emotions on disease and death. Seacat and Inglehart (2003) noted that "Other factors that have to be considered are the attitudes of faculty members". A similar study on physiotherapists' knowledge on HIV/AIDS and its prevention conducted in South Africa revealed shortcomings in the knowledge of physiotherapists and students (Puckree et al., 2004; Puckree et al., 2002). Two studies on the knowledge, attitude and practice of

physiotherapy students in South Africa, point to the need to pay more attention to the development of an HIV education programme for physiotherapy students (Puckree et al., 2004; Schlotfeldt & Potterton, 2002).

To develop such a programme requires an understanding of HIV disease within the context that rehabilitation professionals work. The current literature is dominated by the medical model (Nixon & Cott, 2000). Nixon &Cott (2000) in a scholarly paper, proposed that health care professionals must re-conceptualise HIV infection within the framework that considers health-related experience beyond disease, as proposed by the international classification of function (ICF) (see Appendix 2.1). The role played by physiotherapists in the many different manifestations of HIV can be categorised into a purely physiotherapy role and the role physiotherapy plays in rehabilitation. While the formal role of physiotherapy in HIV care is relatively new, rehabilitation strategies in HIV communities are not (Lang, 1993; McClure, 1993; Nixon & Cott, 2000). AIDS service organizations have identified and addressed some of the rehabilitation needs of people living with AIDS (Nixon et al., 2000). With the expansion of the anti-retroviral programme, (ARV) in South Africa, there is need to focus attention on the management of impairments that will have a profound bearing on the patients' functional status. There is no framework to date that guides physiotherapists on how to provide an educational framework that will meet the diverse needs of the HIV/AIDS community.

1.1.3 **Mainstreaming**

An approach that may be considered in developing a framework is that of mainstreaming. ***"Mainstreaming is the process of bringing an issue to the principle or dominant course"*** (Random House college dictionary 1988). The development of mainstreaming has historically evolved from the need to bring to the fore and beyond a marginalized but important issue, as was the case in gender and disability (USAID, 1998). The mainstreaming concept involves incorporating an issue so that it becomes pervasive within each fundamental aspect of a life style or any programme and its components (Verbrugenn, 2004). In HIV, mainstreaming has grown and developed around efforts of integrating HIV into existing programmes. Mainstreaming HIV is not an intervention; it constitutes a range of coordinated strategies for scaling up the responses and addressing the impacts of HIV/AIDS (UNAIDS, 2002). Recently mainstreaming has evolved as an important approach to ensuring HIV/AIDS becomes part and parcel of any programme or agenda such as health and reproductive , nutrition and agricultural programmes (UNAIDS, 2002; Verbrugenn, 2004).

Five main principles have emerged from current experiences (UNAIDS, 2002) Table 1.2 shows the principles and their anticipated application to physiotherapy practice and education.

Table 1.2: Principles of Mainstreaming and their Application to Physiotherapy and HIV

Principle	Application to Physiotherapy
1. Development of a clearly defined entry point for mainstreaming HIV/AIDS	Outline of HIV impacts in the context of physiotherapy practice using the ICF as a framework*
2. Mainstreaming should take place with existing policies and frameworks and located within existing institutional structures	Education - university curricula and policies on HIV/AIDS* Practice - definition of the manifestation of HIV within the scope of practice for physiotherapy*
3. Advocacy sensitisation and capacity building to place manpower in a better position to undertake mainstreaming	Capacity building efforts Advocacy and sensitisation tools and events
4. Distinction between the external and internal domain Internal - staff risks and vulnerability External - institution undertakes interventions based on its mandate capacity in support of national and local strategic efforts	Internal - physiotherapy students' risks and vulnerabilities. Efforts have been made to address these with university policy and principles* External- efforts to integrate HIV within the mandate of physiotherapy practice and education where physiotherapy is guided by philosophy and principles e.g. rehabilitation (Bauer 1980) ICF (WHO)*
5. Highlights the importance of developing strategic partnerships based on the comparative advantage, cost effectiveness and collaboration	Internal domain - university policy specific programmes for HIV* External domain -national policies treatment and prevention programmes* Technical, clinical and programme developments within the field of HIV in other departments' e.g. nursing, medical, pharmacy as well as other non health departments such as social and business. *

*These areas will be addressed partially or in full in this study

The University of the Witwatersrand and other universities have introduced policies for HIV/AIDS in the workplace. The University of the Witwatersrand policy for example, outlines the need to inform staff and students about their rights in the area of HIV/AIDS. Some of the

guidance, given in the policy, to tackle HIV already applies to some of the concepts of mainstreaming. The integration of HIV/AIDS into teaching, research and service activities of all faculties is a key component of HIV/AIDS policy and is one of the core areas of mainstreaming.

The policy therefore begins to give some guideline on how mainstreaming could be implemented by outlining the following areas of intervention:

- all first year University of the Witwatersrand students are expected to have an understanding of HIV/AIDS that will provide the basis of appropriate personal behaviour.
- further integration is expected to take place through teaching with HIV/AIDS incorporated into curricula, specifically into appropriate subject material.
- research in HIV/AIDS.
- in addition faculties and schools are required to link teaching, research and service delivery in the area of HIV/AIDS (University of Witwatersrand, 2000)

The nature of the framework outlined in the University of the Witwatersrand policy illustrates the integrative nature of mainstreaming HIV by outlining links between students' personal behaviour, choices, the teaching in the core subject area in each discipline, service delivery and research. The pervasiveness of HIV into every area of education on campus is fundamentally mainstreaming.

The complexity of response is illustrated in the University of the Witwatersrand's strategic plan. The response in physiotherapy practice and education has been ad hoc and uncoordinated. No study exists to collate the different educational needs for an appropriate response to HIV by physiotherapists.

1.1.4 **Problem Statement**

By managing functional disabilities that are commonly associated with HIV disease, it may be feasible to keep people in the community and at work for extended periods (O'Dell et al., 1991). Rehabilitation could play an important role in minimizing morbidity and costs of custodial care. However, only 38% of qualified physiotherapists in SA were found to be at ease with treating HIV and 11% knew the stages of the disease (Puckree et al., 2002). Newly qualified physiotherapists should graduate fully equipped to be able to deal with the many and varied manifestations of HIV disease. The physiotherapy curricula should equip the physiotherapist to deal with HIV/AIDS rehabilitation. Education is considered the corner-stone of programmes to ensure quality HIV/AIDS rehabilitation.

A clear education programme should be comprehensive enough to take into account the impact of HIV on clients and students and consider the already existing responses in the community (Nixon & Cott, 2000). There was no literature found for the South African context that gave guidance to specific rehabilitation and physiotherapy perspectives that could be covered in an education programme. Rehabilitation and physiotherapy theories should provide a basis for developing a model for education as has been done in nursing (Sarr, 1991).

1.1.5 Significance of the Study

The findings from this study should be useful for

- Preparing the student and qualified physiotherapist for working in an environment where HIV is pervasive
- Responding more appropriately to the needs of clients and patients with HIV within a rehabilitation multi-disciplinary team
- Contributing rehabilitation input to national regional and local responses to HIV/AIDS within the continuum of prevention treatment care and support.
- Stimulating research in HIV around the areas where there are clear rehabilitation gaps
- Providing the educational framework that will ultimately influence physiotherapy practice.

1.1.6 Research Question

What is the appropriate physiotherapy curriculum model to mitigate against the functional disability and participation manifestations presented by people living with HIV (PLHIV) in South Africa?

1.1.7 Aim

To develop a model for mainstreaming HIV into the curriculum and practice of physiotherapy.

1.1.8 Objectives and Location of Results

1. To describe HIV/AIDS disease in terms of the International Classification of Function (ICF) for physiotherapists in the South African context.

Chapter 2: Literature Review Part 1 and chapter 4 Impairments Activity Limitations and Participation Restrictions Described for Two Groups of Patients

2. To establish the referral patterns to physiotherapy among HIV patients admitted into a tertiary hospital in South Africa.

Chapter 3: Referral Patterns Established

3. To obtain a relevant overview of the functional and participation picture of people living with HIV.

Chapter 4: Impairments Activity Limitations and Participation Restrictions Described for Two Groups of Patients

4. To assess the curricula at South African universities in terms of the HIV content in relation to the disease profile and referral patterns.

Chapter 5: Audit of the Eight University Curricula Presented

5. To determine the clinicians and academics perceptions regarding HIV curriculum and practice

Chapter 6: Focus Group Discussion Results of Clinicians and Academic Staff

6. To determine the level of consensus with regard to the curriculum topics among academic staff members

Chapter 7: Results of a Delphi Technique to Ascertain Consensus

7. To assess the curricula according to the United Nations defined mainstreaming criteria.

Chapter 8: Discussion Conducted Using Mainstreaming Criteria

8. To develop a conceptual framework and practice aims that will inform physiotherapy education in South Africa.

Chapter 9: Conclusions and the Developed Conceptual Framework for Mainstreaming HIV into Physiotherapy Curricula

Study Design

A mixed methods approach was used for this study. As stated by Shepherd (2007), combining qualitative and quantitative methods in a single study may yield a more comprehensive and sophisticated analysis that is valid and contains outcomes that are more clinically relevant. Therefore, in dealing with a complex topic like the appropriate HIV/AIDS educational and curricula needs this study assumed a sequential explanatory design for the first two studies and a concurrent triangulation strategy for the second two studies (Cresswell, 2003). This design considers collection and analysis of both quantitative and qualitative data. The two methods were integrated in the interpretation phase of the study. Each of the objectives outcomes, the corresponding study approaches and the studies are outlined in Figure 1.2. This study was given institutional approval and ethical clearance for the different studies included in this thesis by the University of the Witwatersrand, Human research Ethics Committee and an ethical clearance certificate (

clearance number M5050206 no R14/49) was issued as shown in Appendix 1. It is acknowledged at this point that separate studies would be required to address the needs for adults and children. Due to the scope of work required to address both groups this study focussed on adult needs.

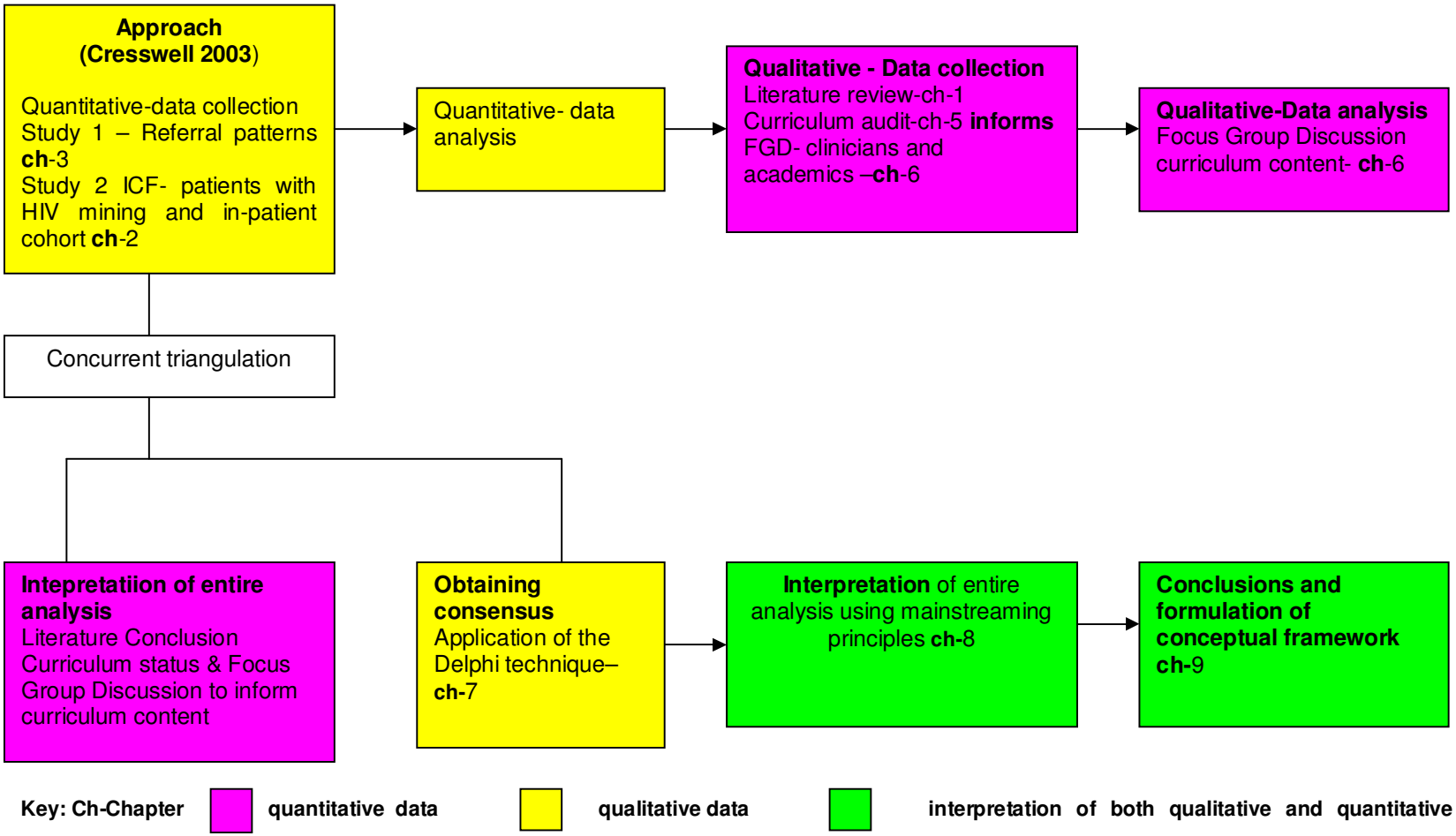


Figure 1.2 The Sequential Explanatory Design and the Concurrent Triangulation Strategy

1.2 CONCLUSION

Despite the rapidly changing position of the HIV epidemiological and management picture, there are still five and a half million people living with AIDS in South Africa (Department of Health, 2005). With improved access to treatment for HIV and its complications, rehabilitation personnel will increasingly become involved in the care of persons living with AIDS. Many disabilities, which can be managed by rehabilitation and physiotherapy, may be associated with HIV infection. In order to provide an appropriate service, physiotherapists need to understand the pandemic and be able to offer services as part of a multi-disciplinary team. This study will contribute to how education can respond and impact on the practice of physiotherapists in HIV rehabilitation using the ICF to guide the process.

CHAPTER 2

LITERATURE REVIEW - SECTION 1

2.1 INTRODUCTION

This literature review consists of two sections. Section 1 describes HIV/AIDS and places the disease into a framework of the underlying pathophysiology, the resulting impairments, functional abilities and participation, as well as quality of life (QOL) limitations. This was done to answer objective 1 which was to describe HIV/AIDS disease in terms of the International Classification of Function (ICF) for the physiotherapists in the South African context.

The impacts of other factors, such as socio-economic, sociodemographic, behavioural and general social factors are briefly reviewed. Section 2 describes elements of curriculum and curriculum planning. Specific elements influencing the physiotherapy curriculum are reviewed briefly. In addition, what influences HIV curricula that has been examined in the literature is also reviewed. Studies related to HIV curriculum and methods of presentation of HIV information are also reviewed. The outline of section 1 of the literature review is given in Figure 2.1 below.

Methodology of Literature Review

The literature review was undertaken by searching for articles using electronic data bases. Pub Med, Science Direct, Thomson Gale, Mary Liebert, Springer, Wiley Interscience, Google and Google Scholar were used to search for articles. The following search terms and combinations of search terms were used HIV, HIV/AIDS, HIV impairments, HIV disease, HIV prevalence, HIV and function HIV and participation, HIV and health-related quality of life, physiotherapy and HIV, treatment approaches and HIV, exercise and HIV, HIV and health education, HIV and curriculum, HIV knowledge attitudes and practice and curriculum development. In addition to electronic searches, a hand search of books and journals was undertaken through the medical library. Literature from 1990 to the present day that focused on describing the prevalence of various aspects of disability was reviewed. In general the studies are descriptive and cross- sectional and were at level 3 evidence.

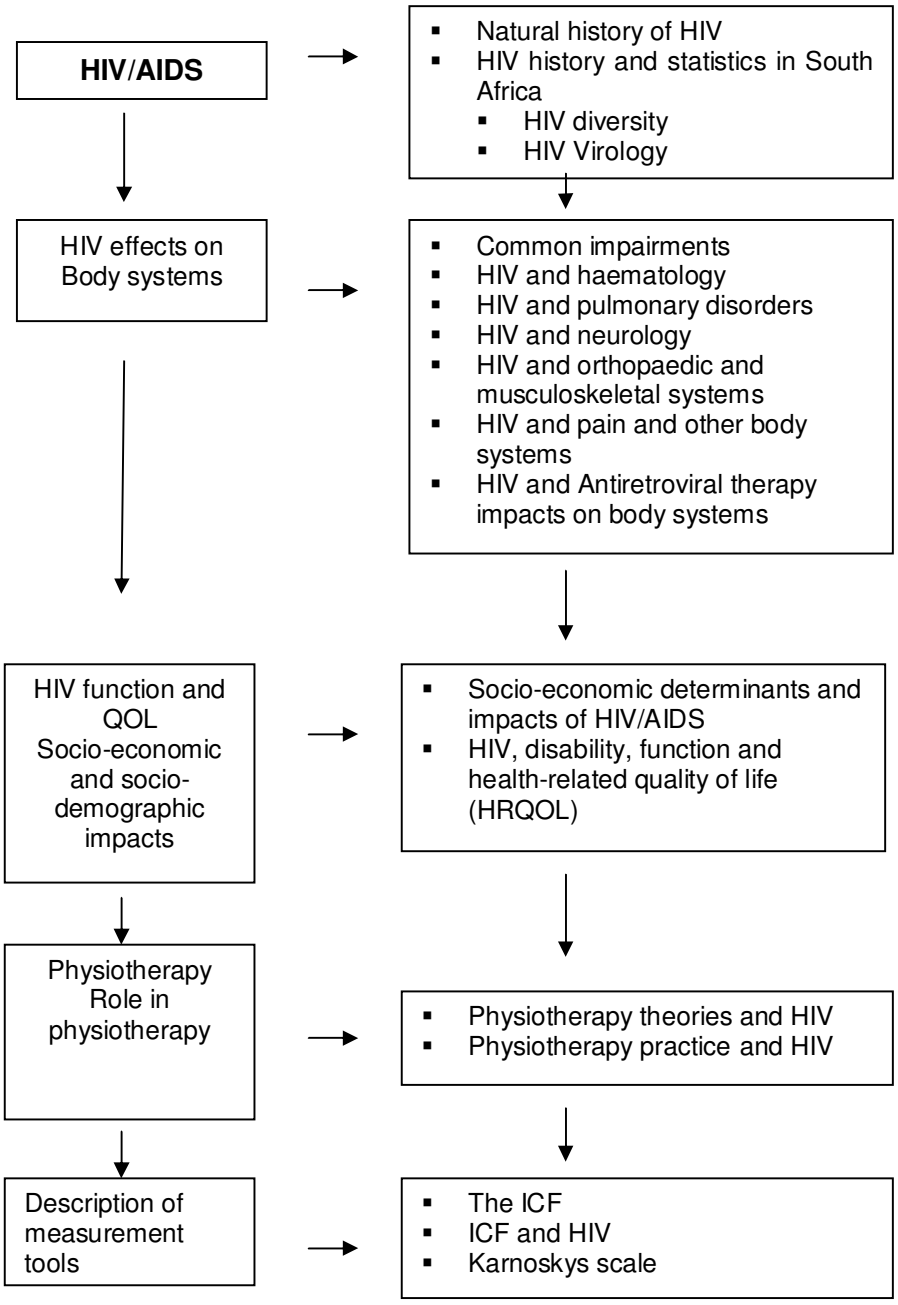


Figure 2.1 Outline of Literature Review 1

Figure 2.1 gives an overview of how the literature review is structured. This structure is informed by the overall objectives of the study and provides the information relevant to the practice of physiotherapy. An additional section that reviews literature related to the tools used to collect patient data within the ICF framework is included.

2.2 HIV/AIDS

2.2.1 Introduction

The Human Immunodeficiency Virus (HIV) is the retrovirus that causes Acquired Immunodeficiency Syndrome (AIDS) (Ungvarski et al., 1999). Immunodeficiency refers to a compromised immune system, one which is unable to counteract those conditions that can be handled by a fully functioning immune system (Brookmeyer & Gail, 1994). The introduction of antiretroviral therapy (ART) and highly active antiretroviral therapy (HAART) has changed the HIV landscape, shifting the disease from a life-threatening condition to one that is more chronic in nature (Nixon & Cott, 2000). In addition to this, events such as the endorsement of the international classification of functioning disability and health (ICF) by the 54th World Health Assembly in May 2001 and the resolution on "disability including prevention, management and rehabilitation" have added to the importance of recognising the chronic nature of HIV. This depicts the World Health Organisation's (World Health Organisation, 2005) shifting focus from infection control, mortality reduction and medical intervention to reducing the burden of disease and morbidity-related issues. It is important, therefore, to understand the natural processes involved in the development of HIV/AIDS and its associated morbidity.

2.2.2 HIV Natural History

The natural history of a disease refers to the processes leading to disease occurrence before intervention and the course and outcome of the disease process. It includes a description of the disease from the first forces creating the disease stimulus within the environment, through its interaction with the host agent and the resulting response in humans including illness, recovery, permanent disability and death (Valanis, 1992). This section of the literature review describes the natural history of HIV within a South African context.

2.2.3 History and Statistics of HIV in South Africa

Thirteen percent of people living with HIV in the world are living in South Africa (Avert.org accessed 22/03/06). The first cases of HIV/AIDS in South Africa were recorded in 1982 among the homosexual white population (AVERT, 2006)., www.avert.org/aids South Africa accessed 23/03/06). The first national antenatal survey to test for HIV reported that 0.8% of pregnant women were HIV-positive and an estimated 74,000 to120, 000 were people living with HIV in South Africa. Antenatal surveys have been carried out annually. The latest data on HIV in South Africa is based on two major studies (AVERT, 2006)., www.avert.org/aids South Africa accessed 23/03/06). The Department of Health's (DoH) antenatal prevalence study puts best-estimate prevalence among antenatal attendees at 26.5% and 22% among

all people aged 15-49 years (Department of Health, 2001; 2002; 2004; 2005). In 2006 the best estimate stands at 29.1%. Based on this data, the study estimates that 6.29 million South Africans are HIV-positive, of whom 3.3 million are women and 104863 are children. This calculation assumes that all pregnant women accurately represent all women aged 15-49 years

A second study, carried out by the Nelson Mandela Foundation (NMF) and the Human Sciences Research Council (HSRC) in 2002, showed lower prevalence rates (Nelson Mandela Foundation & Human Sciences Research Council, (NMF&HSRC) 2002,). This study consisted of a large household survey in which 14450 people were selected to participate. Visits were made to 13518 households with a 30% refusal rate; 8840 people were tested. The differences in the prevalence rates between the NMF/HSRC study and the Department of Health's antenatal data have been attributed to possible selection biases related to convenience sampling in the antenatal study. The household survey had data representative of all age groups from the age of two and older living in households, whereas the antenatal data is derived only from women of child-bearing age (Rehle & Shisana, 2003).

The results from the NMF/HSRC (2002) study showed the highest prevalence in Free State (14.9%), Gauteng (14.7%) and Mpumalanga (14.1%). In contrast, the DoH study found that KwaZulu-Natal (KZN) was the province with the highest prevalence. An overall national prevalence of 11.4% was shown in 2002 NMF and HSRC (2002) and 10.8% in 2005 (DoH).

Table 2.1 shows a comparison of prevalence rates across provinces as reported by the two Department of Health and the Nelson Mandela studies.

Table 2.1: HIV Prevalence Rates Across Provinces in South Africa

Province	DoH Study 2001	DoH Study 2004	Nelson Mandela study 2002
KwaZulu Natal	36.2	40.7	11.7
Gauteng	29.4	33.1	14.7
Mpumalanga	29.7	30.8	14.1
Free State	27.9	29.5	14.9
Eastern Cape	20.2	28	6.6
North West	22.9	26.7	10.3
Limpopo	13.2	19.3	9.8
Northern Cape	11.2	17.6	8.4
Western Cape	8.7	15.4	10.7

(NMF/HSRC, 2002; DoH, 2001, 2004)

The information in Table 2.1 was derived from three major studies - DoH (2004) and DoH (2001) and the NMF and HSRC (2002). These studies were undertaken to determine the magnitude and spread of the HIV pandemic in South Africa. Although there was a difference in prevalence found between the Nelson Mandela Foundation and the Department of Health studies, HIV/AIDS is a problem of such magnitude that it warrants focused attention.

The differences in prevalence from area to area have been attributed to social and behavioural determinants. Some of these social determinants include living in informal settlements, as well as access (or lack of it) to information and education necessary for prevention. Furthermore, knowing people who have been affected or who have died from HIV/AIDS, having another sexually transmitted infection (STI) and having multiple sexual partners have also been documented as behavioural determinants (NMFand HSRC 2002). In the NMF study, unexpectedly high prevalence rates were observed in the age group 2-14 years. The role of possible contributory factors such as sexual abuse, nosocomial infection, and the use of unsterile needles or inadequate medical care were proposed for further study NMFand HSRC (2002). The behavioural determinants of HIV infection include sexual behaviour, substance abuse, perceived susceptibility to HIV/AIDS infection, and knowledge and attitudes towards HIV/AIDS (SANHS,2005).

Studies on the demographic impacts of HIV are ongoing, and therefore the picture is an ever-changing one. One of the key sources of information with regard to the demographic status of the South African population is from the Actuarial Society of South Africa (ASSA). The ASSA model is considered to be a reliable estimate as it uses data from a number of sources to project the potential course of the epidemic and its demographic impact. According to a study based on this model (Dorrington et al., 2006)., the epidemic is mature and the population growth rate is falling, especially in areas worst affected. New infections match the death rates. The highest prevalence of HIV in South Africa is among the 30-34 year group (54.7%).The 15-24 age group has the highest number of new infections, with young women outnumbering young men. Dorrington et al. (2006), estimate that 5.4 million people are living with HIV, of whom 2.8 million are women.

In South Africa and Sub-Saharan Africa, HIV is transmitted predominantly through heterosexual intercourse (UNAIDS, 2006b). Social, political, structural and economic factors determine the spread of the HIV/AIDS epidemic (SANHS,2005). The South African National HIV Survey (SANHS) is a well-designed survey that is representative through stratification by province and locality type. In the survey, key determinants and drivers of the pandemic have been documented from well-designed population-based studies conducted by large agencies such as the Medical Research Council of South Africa (MRC) and the Food and Agricultural Organisation (FAO) (Drimie, 2002; SANHS,2005). Poverty remains a key determinant and risk factor in the spread of HIV. Specific factors related to poverty include the type of housing settlements in which people within South Africa reside. High-density and overcrowded conditions (Moller & Dickow, 2002) result in some of the conditions that drive the spread of HIV. Women, particularly young women, are more vulnerable to HIV infection. This is due to biological factors as well as their position in society (SANHS 2005). Sexual harassment from boys (31% of cases) and male educators (7.3% of cases) was reported among young adolescent girls. This is confirmed by the demographic impact survey that states that the prevalence is higher among women, with the prevalence peaking at 32.5% per 100 000 and at 26.5% pr 100000 for men (Dorrington et al., 2006).

The South African national HIV prevalence, incidence, behaviour and communication survey of 2005 reported that 37% of female children between the ages of 11 and 14 share a bed with siblings or a caregiver. In addition, these young adolescents are involved in activities like running a business from home such as a “spaza” shop (a small informal trading shop set up within or close to the home).This exposes them to different members of society and may put a young child at potentially greater risk. Key behavioural determinants

that are, as previously mentioned, indicators of sexual behavioural risks include sexual debut (i.e., age at first sexual experience), substance abuse, perceived susceptibility to HIV/AIDS, and knowledge and attitudes (SANHS,2005).

2.2.4 **HIV Disease**

HIV and AIDS are not synonymous terms. Natural history studies of HIV infection have documented a wide range of conditions ranging from asymptomatic infection to life-threatening conditions characterised by serious opportunistic infections and cancers. The term AIDS is used to indicate only the most severe diseases or clinical conditions (infections and neoplasms) (Flaskrud & Ungvarski, 1999).

2.2.5 **HIV Diversity**

Currently there are two types of HIV, and both cause AIDS. HIV 1 is distributed all over the world and HIV 2 is prevalent in West Africa. HIV 1 has three sub-types - HIV 1 Major (HIV1M), outlier (HIV O) and HIV N group. Such sub-types have envelope gene sequences that vary by 20% or more among the sub-types. HIV1M has ten distinct genetic sub-types or sub-clades (A to J). The classification is based on the sequence analysis of the env, gag and pol genes (Barré-Sinoussi, 1996; Kostrikis et al., 1996). The sub-types differ in biological characteristics, geographical distribution and modes of transmission. The predominant type of HIV found in South Africa is HIV type 1 sub-clade C (Gordon et al., 2003). Sub-clade C is considered the fastest spreading virus and has been observed in South and Southern Africa (Walker, 2005). This has been attributed to sub-clade C having three functional binding sites whereas the other sub-clades have one or two (Lee & Montaner, 1999).

In South Africa, sub-clade B is associated with the homosexual population, while sub-clade C is associated with the heterosexual population. The latter was confirmed as the dominant sub-clade in KwaZulu-Natal, Gauteng, Mpumalanga and Western Province (Engelbrecht et al., 1999). However, the association between the sub-clade and HIV progression is not conclusive. In a review of the molecular epidemic, (Puren, 2002) reports that the parameters under study are different. Alaeus et al. (1999) studied CD4 cell decline, HI viral load and clinical progression, and found no difference between sub-clades A to D. However, a different study using survival rates as a parameter found that women infected with sub-clade A were eight times more likely to develop AIDS. HIV sub-types O and N are more distant to all other HIV1 sub-types but less so compared to HIV2 (Barré-Sinoussi, 1996).

2.2.6 **HIV Virology**

HIV is a member of the sub-group lentivirus of human lentiviruses, and contains reverse transcriptase that allows RNA to be transcribed to DNA (Pearce-Pratt et al., 1994). Its structure consists of two single RNA strands bound by the p-24 protein (Volberding et al., 2003). Two important structural components of HIV are the envelope proteins encoded by the proteins gag and env. The env gene encodes the protein gp120 that anchors to the outer capsid of the virus by a smaller protein gp41. Through serology, HIV can be diagnosed using the antibody response to these structural elements. The gag gene produces p-24, whose antigen can be detected in the plasma several weeks before the gp120 and gp41 antibodies (Evans & Scadden, 2000).

The helper inducer cells, known as the T4 cells, are a distinct subset of t-lymphocytes (white blood cells) that play a key role in the body's immune system, co-ordinating and activating immunity (Abbas & Lichtman, 2003).,. Their primary role is to detect infection and assist in an active immune response. The T4 cell carries a glycoprotein molecule known as the cluster definition four (CD4) (Zauli et al., 1994). The CD4 surface antigen serves as a binding site for the HIV envelope protein gp-120, allowing the virus to enter the cell. However, binding to the CD4 cell is not sufficient for cell entry and it has been found that the presence of chemokine receptors is also necessary (Freed, 2001).

After the virus has entered the CD4 cell, the virus's genetic information, which is stored on a single strand of RNA, converts into DNA using reverse transcriptase. Reverse transcriptase is also known as RNA-dependent DNA polymerase; it transcribes single-stranded RNA into double-stranded DNA (Freed, 2001).The virus enters the CD4 nucleus and inserts itself into the CD4 DNA. When the multiplication of the T4 cells activates the latent viral genes, the HI virus replicates rapidly. It buds off from the host cell membrane and infects other CD4 cells (Freed, 2001).The infected CD4 cells eventually die, resulting in a reduced CD4 cell count. There is a converse increase of CD8 cells, which are cytotoxic and suppressor cells to the CD4 cells; their main function is to suppress immunity (Dudhane et al., 1996). Another study recently added that the protein on the CD4 cells - that is, gp120 - possesses properties that affect the behaviour of immune cells and skew the immune response to the virus, facilitating viral escape (Stevceva et al., 2007).

The HI virus affects other cells in the immune system, namely the monocytes and natural killer cells. The main function of monocytes is to present antigens to the T cells. They are infected through phagocytosis and not binding as with CD4 cells. Once infected they are

unable to move and kill target cells or produce interleukin I (Azzam et al., 2006; Smith et al., 1984). In addition to this, the monocyte does not die but acts as a reservoir for the HI virus (Azzam et al., 2006).

HIV affects the human body from the cellular component. For example, HIV affects the immune system by attacking the various specialised cells that are part of the immune system. The virus has different direct and indirect effects on the phagocytes, whose main function is to guard the immune system and to sense the initial danger when the body is infected. The cells that it affects include macrophages that identify infection, CD4 cells that fight infection, T cells that destroy foreign bodies, B cells and T cells that regulate the immune system, phagocytes that remove the debris once the infection has been eliminated and memory T cells that store information on the immune system (Bercz & Scentivanyi, 2005). Tumour cells are monitored by natural killer cells, and once the HI virus affects them they become less efficient in this function. This is in spite of their numbers remaining high (Lee & Montaner, 1999).

In addition, HIV infection affects basic cells from other body systems such as the musculoskeletal (Zinna & Yarasheski, 2003), nervous (Kanmogne et al., 2000). respiratory (Huang et al., 2006)., cardiovascular (Mars, 2004a), and haematological systems (Levine et al., 2001). Consequently, organ and body system functions are affected, resulting in the manifestation of disease in the person.

2.2.7 **Stages of HIV Disease**

The World Health Organisation (WHO) and the Centres for Disease Control (CDC) have described two commonly used classifications of HIV disease, and these are outlined below.

The CDC classifies HIV disease according to the CD4+ T lymphocyte count and the clinical conditions associated with HIV infection (CDC, 1993). The classification system is outlined in Table 2.2. Patients in categories A3, B3, and C1-C3 are considered to have AIDS.

Table 2.2: CDC Classification System for HIV-Infected Adults and Adolescents

CD4 Cell Categories	CLINICAL CATEGORIES		
	A Asymptomatic	**B Symptomatic Conditions, not in A or C**	**C AIDS-Indicator Conditions***
(1) ≥500 cells/µL	A1	B1	C1
(2) 200-499 cells/µL	A2	B2	C2
(3) <200 cells/µL	A3	B3	C3
Conditions associated with each category	Acute HIV, or progressive generalised lymphodenoa-pathy	Conditions outlined by CDC include, but are not limited to, the following: ExaBacillary angiomatosis,oropharyngeal candidiasis (thrush),vulvovaginal candidiasis, persistent or resistant pelvic inflammatory disease (PID), cervical dysplasia (moderate or severe), cervical carcinoma in situ, hairy leukoplakia, oral, idiopathic thrombocytopenic purpura, constitutional symptoms, such as fever (>38.5°C) or diarrhoea lasting >1 month, peripheral neuropathy , herpes zoster (shingles), involving ≥2 episodes or ≥1 dermatomes	Conditions outlined by CDC include, but are not limited to, the following: Bacterial pneumonia, recurrent (≥2 episodes in 12 months),candidiasis of the bronchi, trachea, or lungs, candidiasis oesophageal, cervical carcinoma, coccidioidomycosis (disseminated or extrapulmonary), cryptosporidiosis, chronic intestinal (>1-month duration),cytomegalovirus disease (other than liver, spleen, or nodes), encephalopathy (HIV-related), Herpes simplex: chronic ulcers (>1-month duration), or bronchitis, pneumonitis, or oesophagitis, histoplasmosis, disseminated or extrapulmonary, isosporiasis, Kaposi sarcoma, lymphoma, Burkitt, immunoblastic, or primary central nervous system, *Mycobacterium avium* complex (MAC) or *M kansasii*, disseminated or extrapulmonary, *Mycobacterium tuberculosis*, pulmonary or extrapulmonary, *Mycobacterium*,(other species or unidentified species, disseminated or extrapulmonary), *Pneumocystis jiroveci* (formerly *carinii*) pneumonia (PCP), progressive multifocal leukoencephalopathy,*Salmonella* septicaemia, recurrent (nontyphoid), toxoplasmosis of brain,wasting syndrome due to HIV (involuntary weight loss >10% of baseline body weight) associated with either chronic diarrhoea (≥2 loose stools /day)

Source: Adapted from (CDC, 1993)

In addition to and corresponding with the CD4 categories is the presence of HIV copies that are categorised into:

- Category 1 = <10000 HIV copies per millilitre, with a low risk of disease progression.
- Category 2 = 10000 to 100 000 HIV copies per millilitre, with a moderate risk of progression.
- Category 3 = > 100 000 HIV copies per millilitre, with a high risk of disease progression.

This staging system is used in many countries to determine patients' eligibility for antiretroviral therapy (CDC, 1993).

The WHO has a different classification system based on the stages of the clinical condition and CD4+ T Lymphocyte count (see Table 2.3). In this system, staging is based on clinical findings that guide diagnosis, evaluation and management of HIV/AIDS, and does not require a CD4 cell count.

Table 2.3: WHO Clinical Staging of HIV/AIDS for Adults and Adolescents (Interim Definitions)

Primary HIV Infection	**Asymptomatic** **Acute retroviral syndrome**
Clinical Stage 2	Moderate unexplained weight loss (<10% of presumed or measured body weight) Recurrent respiratory infections (respiratory tract infections, upper respiratory infections, sinusitis, bronchitis, otitis media, pharyngitis) Herpes zoster Minor mucocutaneous manifestations (angular cheilitis, recurrent oral ulcerations, seborrhoeaic dermatitis, prurigo, papular pruritic eruptions, fungal fingernail infections)
Clinical Stage 3	**Conditions for which a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:** Severe weight loss (>10% of presumed or measured body weight), unexplained chronic diarrhoea for >1 month, unexplained persistent fever for >1 month (intermittent or constant), oral candidiasis (thrush), oral hairy leukoplakia. Pulmonary tuberculosis within the last 2 years, severe presumed bacterial infections (e.g., pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia), acute necrotising ulcerative stomatitis, gingivitis or periodontitis **Conditions for which confirmatory diagnostic testing is necessary:** Unexplained anaemia (haemoglobin <8 g/dL), neutropenia (neutrophils <500 cells/µL) ,thrombocytopenia (platelets <50,000 cells/µL)

Table 2.3 continued

Primary HIV Infection	Asymptomatic Acute retroviral syndrome
Clinical Stage 4	**Conditions for which a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:** HIV wasting syndrome, as defined by the CDC (see Table 2.2,) ,p*neumocystis jiroveci* (formerly *carinii*) pneumonia, recurrent severe or radiologic bacterial pneumonia chronic herpes simplex infection (oral or genital, or anorectal site) for >1 month , oesophageal candidiasis,extrapulmonary tuberculosis, Kaposi sarcoma, central nervous system toxoplasmosis, HIV encephalopathy **Conditions for which confirmatory diagnostic testing is necessary:** Cryptococcosis, extrapulmonary , disseminated nontuberculosis *Mycobacteria* infection ,progressive multifocal leukoencephalopathy , c*andida* of the trachea, bronchi or lungs ,cryptosporidiosis ,isosporiasis ,visceral herpes simplex infection, cytomegalovirus infection (retinitis or organ other than liver, spleen, or lymph node), any disseminated mycosis (e.g., histoplasmosis, coccidioidomycosis, penicilliosis) ,recurrent nontyphoidal Salmonella septicaemia, lymphoma (cerebral or B-cell non-Hodgkin) ,invasive cervical carcinoma Visceral leishmaniasis

Source: (WHO, 2005; World Health Organisation, 2005)

The clinical stages shown in Table 2.3 are categorised as clinical stages 1 - 4, progressing from primary HIV infection to advanced HIV/AIDS.

Pantaleo et al. (1993) describe the typical course of HIV infection as:

- primary or acute infection;
- a prolonged period of clinical latency (median 10 years) during which the person is usually symptom-free;
- clinically apparent disease with symptoms; and finally
- the development of AIDS indicator diseases.

Functional abnormalities are characteristic of HIV-1 disease progression (Pantaleo et al., 1993).

2.2.7.1 **HIV staging CDC and WHO**

Early Asymptomatic Stage

Once infected with HIV, the disease enters a dormant phase. This is after a strong immune response from the intact immune system thereby reducing the presence of HIV in the extra cellular fluid (Flaskrud & Ungvarski, 1999). It is reported that HIV does continue to be active in the lymph nodes and the follicular dentritic cells and in up to 10% of the CD4 cells (Mars, 2004a). During this phase, the patient shows signs of persistent generalized lymphadenopathy (PGL). In the WHO staging system, this is known as clinical stage one (WHO, 2005).

Late Symptomatic Stage

Some of the first symptoms are fatigue, intermittent fever, lymphadenopathy weight loss(<10% of body weight), minor muco-cutaneous manifestations seboearrhic dermatitis, prurigo, fungal nail infections, recurrent oral ulcerations, herpes zoster occurrence within the last five years, recurrent upper respiratory tract infections and diarrhoea. In the WHO staging system this is known as clinical stage two.

Worsening symptoms are classified as clinical stage three with further weight loss >ten percent, diarrhoea lasting for more than a month, prolonged fever (intermittent or constant), oral candidiasis, oral hairy leukoplakia, (white patches in the mouth associated with Epstein Bar Virus) severe bacterial infections such as pneumonia and pyomyositis (WHO, 2005).

Advanced HIV Disease Stage

Once the person develops opportunistic infections such as pneumonia, tuberculosis, lymphomas and their CD4 falls below 200 the person is classified as being in the advanced stage (stage C in CDC classification and stage three and four in the WHO classification) and is diagnosed with AIDS (WHO, 2005), (CDC, 1993). They may present with any one of the AIDS defining conditions outlined in the WHO staging system and CDC Table 2.2 and 2.3. They may have cognitive or motor dysfunction interfering with usual activity, progressive over weeks and months in the absence of other conditions to explain the findings, (CDC, 1993), (WHO, 2005).

Each of these stages can be arrested by the use of drug regimens for prevention of further advancement of the disease.

2.2.7.2 **Antiretroviral therapy and highly active antiretroviral therapy**

Antiretroviral therapy (ART) refers to the medications for treatment of infection by the retrovirus HIV. A highly active antiretroviral therapy (HAART) refers to a combination of drugs that are potently suppressive of HIV (Torre et al., 2001).

There are three main types of antiretroviral drugs:

- Nucleoside reverse transcriptase inhibitors (NRTI or nukes) such as lamivudine also known as 3TC (epivir)
- Non-nucleoside reverse transcriptase inhibitors (NNRTI or non nukes) such as efavirenz (sustiva) and nevirapine (Viramune). NRTIs and NNRTIs inhibit the reverse transcriptase enzyme (Robbins et al., 2003)
- Protease inhibitors (PIs) such as lopinavir and ritonavir

  Protease inhibitors inhibit the protease enzyme that is responsible for the splitting of proteins important in the replication of the HIV replication process. Protease inhibitors act in the later stage of the HIV - viral cycle through the prevention of the gag and gag pol proteins cleavage, hence inhibiting mature and infectious HIV 1 virons production. Ritinovir is reported to reduce natural cell death (apotosis) of uninfected T lymphocytes and polymorphonuclear leukocytes thereby improving immune function (Phenix et al., 2000).

In South Africa, the recommended ART regimens are divided into first line therapy regimens and second line therapy. There are strict criteria for the process of ART initiation monitoring and subsequent change of medications (DoH 2005).

The recommended regimens given by the Department of Health for South Africa are:

Regimen 1a - Stavudine (d4t)/ Lamuvudine (3TC)/efavirenz (EFV)

Regimen 1b - Stavudine (d4t)/ Lamuvudine/ nevirapine (NVP)

Regimen 2 - Zidovidine AZT/ Didanosine ddI/ Lopinavir/ritonavir (Department of Health, 2007b)

Antiretroviral medications affect HIV aetiology by arresting the replication of the HI virus through two main mechanisms. The first mechanism inhibits the reverse transcriptase enzyme thereby arresting the replication of the HI virus within the infected cell (Robbins et al., 2003). Secondly, the protease enzyme responsible for the splitting of proteins important in the replication of the HIV is also inhibited (Phenix et al., 2000). A combination of drugs that acts on different aspects of the HIV replication cycle is referred to as Highly Active Antiretroviral Therapy (HAART).

The introduction of HAART has resulted in a significant reduction in AIDS related mortality and morbidity (Palella et al., 1998). In South Africa Dorrinngton et al's (2006) model, projects that ART treatment, impacts on HIV mortality and has reduced deaths per year to 388,000 as opposed to an expected 588,000 deaths (Dorrington et al., 2006). Despite this reduction in the death rate, the roll-out of antiretrovirals is viewed as inadequate in South Africa. This inadequacy, leads to a situation where people infected with HIV and eligible for ARVS may not have access to ARV treatment (Dorrington et al., 2006). Another observed possibility is those who have commenced ARVs but discontinue due to non-adherence (Mocroft et al., 2001).Some of the factors leading to the non-adherence are toxic effects, poor compliance and patient choice (Mocroft et al., 2001). In South Africa, it has been estimated that 711000 people needed antiretrovirals by mid 2006 and so far 225000 are receiving them (Dorrington et al., 2006).

Once on highly active antiretroviral therapies (HAART) the patients may manifest with conditions such as peripheral neuropathies (Simpson & Tagliati, 1994) and lipodystrophy (Milinkovic, 2006; Moylett & Shearer, 2002; Mutimura et al., 2008b; Mutimura et al., 2007; Nicholas et al., 2005). Zidovidine use has been reported to be associated with myopathy within a year of its introduction (Biviji et al., 2002).
Most of the studies done in the early 1990s such as the studies by Levinson and O'Connel (1991), O'Dell (1992, 1997) were on patient groups pre-HAART. With the advent of HAART, the disease patterns have changed. However, in South Africa the roll-out of HAART is still inadequate as described above (Dorrington et al., 2006) and may present a picture pre and post HAART.

Physiotherapists treat patients according to body systems therefore the following section on HIV and its effect on body systems outlines how HIV impacts on body systems. The impact of HAART on conditions manifesting in an HIV population on HAART is included in the review.

2.3 HIV AND ITS EFFECT ON BODY SYSTEMS

2.3.1 Common Impairments

As described in section 2.1.6, HIV affects many body systems directly. Damage to the immune system leaves the body susceptible to opportunistic infections. Table 2.2 outlines through the WHO and CDC classification systems the range of conditions that manifest because of HIV. It is therefore important to outline how HIV affects body systems and the resulting impairments. The range of conditions resulting in HIV is outlined in Table 2.2 illustrates the complexity of the HIV infection from an asymptomatic to symptomatic and finally AIDS stage. The capacity of HIV to infect and affect different body tissues and subsequently systems, manifests through different conditions. The resultant symptoms/ impairments impact on a person's quality of life (QOL), where QOL related to physical status is most adversely affected when the patient is in the symptomatic stage (Burgoyne & Saunders, 2001)

2.3.2 HIV and Haematology

Anaemia is common among any HIV population, with prevalence rates of 63% to 95% reported in the USA and 6.6 % in Africa. Anaemia is prevalent among HIV-infected adults with CD4+ T-cells <200 cells/ml^3 and in patients initiating zidovudine containing regimens (Ssali et al., 2006; Sullivan et al., 1998). Fatigue is a major symptom of anaemia and a common symptom of HIV/AIDS and is responsible for impaired physical function and poor QOL (Volberding et al., 2003). The causes of anaemia in HIV are many; opportunistic infections, such as the parvovirus B19 directly affecting the haemopoetic processes causing depletion of the red and in some cases white blood cells in the plasma (Evans & Scadden, 2000). The presence of receptors and chemokine co-receptors required for viral entry has been described in primitive haemopoetic cells. However, this has been reported as insufficient for viral infection of haemopoetic cells but makes the host susceptible to haemopoesis. HIV indirectly disturbs the cell function by disturbing the cellular environment of the bone marrow and the interaction of the viral and viral gene products with the cell surface (Evans & Scadden, 2000).

Antiretroviral pharmacological agents also impact negatively on haematology. Common drugs associated with anaemia are classified below:

Antiretroviral therapies	▪ Zidovidine AZT
Therapy for opportunistic infections	▪ amphotericin, dapsone, flucytosine, ganciclovir used for cytomegalovirus, primaquine, pyrimethamine, trimethoprin sulphamethoxazole (bactrim), trimetrexate
Antitumour chemotherapy	▪ interferon, anti RhD (Cade et al., 2004; Evans & Scadden, 2000)

When specific immune effector cells are targeted by HIV, the immune system is severely compromised but more pertinent to haematology, HIV suppresses not just a select number of T cells but may infect a number of progenitor cell populations, namely megakaryocytes or monocytes specifically. Stem cells are not directly infected by HIV but have been shown to be affected by alterations in their function (Levine et al., 2001).
Other haematological abnormalities include neutropenias that are found in 5-10% of people with asymptomatic HIV and in 50-70% of patients with advanced HIV disease (Evans & Scadden, 2000). Similar to anaemia, HIV is believed to have an effect on myeloid progenitor cells and disturbs the bone marrow environment thus suppressing normal cell production (Levine et al., 2001).

Severe anaemia is reported to reduce exercise capacity through a lowering of oxygen-carrying content and arterial partial pressure of oxygen of the blood resulting in a lower VO_2. Compensation occurs through an increase in the cardiac output (Cade et al., 2004) This may lead to additional cardiac problems. The full implications of HIV on the cardiac system are discussed fully in section 2.2.10.

2.3.3 HIV and Pulmonary Disorders

As with other body systems, HIV affects the lungs directly and through opportunistic infection.

Epidemiology

Pneumocystic carinii pneumonia (PCP) is a common pulmonary infection found in HIV infected individuals. However, in countries where ARVs have been available for a while, its

epidemiology has changed. In Africa where TB is prevalent, the picture is said to be less clear. For example, a study conducted in Zimbabwe demonstrated that 33% of a cohort of 64 patients diagnosed with acute diffuse pneumonia was infected with PCP and a further 6% had PCP and co-infections (Malin et al., 1995).

Tuberculosis and bacterial pneumonias account for a large proportion of the other lung infections i.e. 500 cases per 100,000 population (Edginton et al., 2005). In South Africa TB still remains a major problem and accounts for a large proportion of HIV-related admissions and illnesses (McShane, 2005).

Underlying Mechanisms and Pathophysiology

Diaz et al. (1999) reported that accumulated evidence shows that diffusion impairment in the lungs develops in people with HIV prior to opportunistic infection. In a cross-sectional observational study Diaz et al. (1999) using pulmonary functional tests and high resolution computer tomography and bronchoscopy, showed that most HIV positive subjects maintain their lung volumes but have a reduced diffusion capacity and lowered capillary blood volume. None of the HIV positive patients' scans showed changes consistent with interstitial fibrosis, hence the well-preserved lung volumes. Diaz et al. (1999) argue that if the diffusion capacities are secondary to alveolar thickening a drop in total lung capacity (TLC) would be expected to parallel the drop in diffusion capacity. The lowered blood capillary volume is justified by the authors as being a result of HIV individuals being predisposed to vascular abnormalities and is the probable explanation of the lowered diffusion capacity. Those subjects with low diffusion capacity showed evident emphysema on CT scans. Another interesting finding reported in this study is the association between the decreased diffusing capacity and the patients' body mass index. This finding is indicative of the role of nutritional deficiencies in the development of gas exchange abnormalities (Diaz et al., 1999).

Pulmonary related symptoms/impairments that are reported in the literature are spontaneous pneumothorax, chest pain, dyspnoea, cough and breathlessness among others:

Spontaneous pneumothorax is 450 times more likely in patients with HIV than those without and may be the aetiology for chest pain (Drake & Burnett, 2002). Spontaneous pneumothorax is also cited in conjunction with PCP (Afessa, 2000). Wachtel (1992) reports that in the absence of HIV-related pulmonary infections, respiratory symptoms such as cough, phlegm production and dyspnoea are prevalent. Significant differences in the prevalence of respiratory symptoms among HIV positive people (without opportunistic infections) and an HIV negative population were found to be cough ($p=0.05$), wheezing,

phlegm production (p=0.01) and dyspnoea (p=0.0001) (Diaz et al., 2003). A significant, interesting but not surprising finding in the Diaz (2003) study is that smoking was significantly associated with the development of respiratory symptoms in HIV positive patients. Diaz et al. (2003) hypothesises that HIV or inflammatory changes related to HIV may add to the damaging effects of smoking (Diaz et al., 2003).

Most of the respiratory impairments outlined above are further complicated by opportunistic lung infections. Table 2.4 below outlines the pathophysiology and the signs and symptoms of pulmonary conditions.

Table 2.4: Common Opportunistic Infections of The Lung

Condition	Pathology	Signs and Symptoms	References
-Pneumocystitis carinii pneumonias	Pneumocystis organism is a member of the fungi family and is found only in the lungs. It causes pulmonary inflammation resulting in lung injury. It is associated with alterations in the pulmonary surfactant system and develops where CD4 cells are less than 200. Antigen specific CD8 cells are part of the mechanism of lung injury. HIV directly affects the immune response of the lung tissues; it impairs phagocytocis, respiratory burst (release of these chemicals from immune cells) and inflammatory activation of alveolar macrophages in response to pneumocytis. In addition, proteins are expressed in higher concentrations in the lung during HIV infection and the loss of macrophage action results in these proteins accumulating in the alveolar spaces.	-Higher arterial oxygen tension and lower alveolar - arterial oxygen gradient. -Chest radiograph bilateral diffuse, symmetric reticular interstitial or granular opacities and reticulo-nodular shadowing. -Patients present with fever, cough and dyspnoea on exertion. Best confirmed through bronchoscopy. -A respiratory rate of over 40 is found to be a strong predictor of PCP.	(Huang et al., 2006) (Malin et al., 1995)
-Bacterial pneumonias	(Persons with CD4 count of less than 200 are five times more likely to get bacterial pneumonia). Pathogens such as streptococci pneumoniae and haemophilus influenzae are common causes of bacterial pneumonia. Reported as seen concurrently with PCP.	Abrupt onset of fever, cough, purulent sputum and systemic toxic effects	(Flaskrud & Ungvarski, 1999)
-Tuberculosis	An acute or chronic infection caused by mycobacterium tuberculosis and clinically involves a balance between host and infection in which pulmonary or extrapulmonary foci can reactivate at any time. In HIV suppression of the immune system predisposes the host to acute infection	Asymptomatic at first, the pulmonary lesion becomes so large it is visible on x-ray. Systemic symptoms of fever, malaise and weight loss are gradual. Cough initially early morning and subsequently at night, sputum production that may steadily increase, haemoptysis, pleural or chest pain due to recurrent pleural effusions and bronchopleural fistula formation and dyspnoea. Diagnosis is usually confirmed by radiographic changes but this may not be the case with HIV	(Beers & Berkow, 2006)
-Interstitial lymphoid pneumonitis	More common in children but has been reported in adults.		

2.3.4 HIV and Neurology

2.3.4.1 Epidemiology of HIV neurological infection in HIV

At the time of seroconversion, glandular fever-like symptoms occur in 70% of cases infected by HIV. According to Manji and Miller (2004), 10% of cases may have associated neurological signs and symptoms, for example aseptic meningitis, encephalitis, acute disseminated encephalomyelitis, transverse myelitis, polymyositis, brachial neuritis and cauda equine syndrome (Manji & Miller, 2004). Guillian Barré Syndrome has also been described in the symptomatic phase but also during the immunocompetent phase of HIV infection (Brew, 2001).

Forty to seventy percent of people with HIV will develop neurologic disease (Berger & Simpson, 1997). HIV dementia has a 30% prevalence and is reported to be the most prevalent cause of dementia in infected people under the age of forty (Bhigjee, 2005).

The types of neurological conditions found in South Africa (Patel et al., 2005) are generally not different from those reported by Brew et al. (2001) in the United States of America. Disseminated encephalomyelitis, transverse myelitis, polymyositis, brachial neuritis and cauda equine syndrome have been reported as a result of HIV infection and opportunistic infections (Manji & Miller, 2004). Bhigjee (2005) reported that neurological complications in Kwazulu Natal include bacterial and fungal meningitis, intracranial mass lesions, acute disseminated encephalomyelitis, tuberculous meningitis, a variety of spinal cord disorders and peripheral nerve dysfunction. Toxoplasmosis is the most frequent cause of intracranial mass lesions. In Kwazulu Natal, intermedullary tuberculomata, often multiple and spinal epidural tuberculous abscess without bony disease, are more prevalent than in the pre-AIDS era (Bhigjee, 2005).

Before HAART, the CD4 count was used to determine specific aetiologies of opportunistic infections and tumours, for example toxoplasmosis and cryptoccocal meningitis occurred with CD4 counts below 200 cells/mm^3. It is reported that with HAART there is an emergence of the immune reconstitution syndrome (IRIS) that is defined as the paradoxical deterioration in the clinical status attributed to the recovery of the immune system (Manji & Miller, 2004). Progressive multifocal leucoencephalopathy, cryptoccocal meningitis and cytomegalovirus CMV syndromes such as encephalitis and retinitis (Manji & Miller, 2004) tend to occur within clinical reconstitution syndromes.

HIV induced immunnosuppression accounts for 85% of progressive multifocal leucoencephalopathy cases and before HAART 5% of all patients developed progressive multifocal leucoencephalopathy with CD4 counts of below 100 (Kanmogne et al., 2000). Peripheral nerve complications also occur in immunocompromised patients (Klaus, 1996). The most common being distal sensory peripheral neuropathy (DSPN) which is reported to occur in advanced HIV infection and is inversely proportional to the CD4 count (Tagliati et al., 1999). The signs and symptoms of distal sensory peripheral neuropathy are painful numb feet, burning, paresthesia, allodynia or dysaesthesia, hyperaesthesia and decreased temperature and vibratory sensation (Gale, 2003). There is little or no weakness and the upper limbs are not involved.

Peripheral neuropathy also occurs as a result of nucleoside reverse transcriptase inhibitors (NRTIs). A dose dependent peripheral neuropathy occurs when a person has NRTIs as part of their treatment regimen (Keswani et al., 2002). Peripheral neuropathy is reported as commonly occurring and affecting the QOL and function (Gale, 2003). Bhigjee (2005) reports an increased incidence of peripheral nerve dysfunction including related conditions such as Guillian Barré Syndrome (GBS), chronic inflammatory demyelinating polyneuropathy and mononeuritis multiplex in KwaZulu Natal South Africa. It was reported that GBS accounts for 46% of all intensive care units (ICU) admissions in South Africa (Schleicher et al., 2003) and similar patterns of infection were reported in Burkina Faso (Millogo et al., 2004).

2.3.4.2 **Cerebral vascular accidents (Stroke) and HIV**

Stroke is already a major health problem in South Africa and the second leading cause of death globally (Lopez & Mathers, 2006). In South Africa, it has been reported that the prevalence of stroke among stroke survivors is 300/100000 (Connor et al., 2004).

Patel et al. (2005) have shown that cerebral vascular accidents (CVAs) occur in HIV infected individuals but it is reported that no relationship between the two conditions has been established. However, this is contradicted by another study that did find an association between HIV and stroke (Qureshi et al., 1997). Qureshis' (1997) study was similar to Patels, (2005) which was a large case control retrospective study and attributed increased susceptibility of HIV-infected patients to meningitis and protein S deficiency. The conflicting conclusions have been attributed to having no common denominator, in terms of factors, to attribute the risk of stroke to HIV. Oritz (2007) reviewed records of consecutive HIV-infected patients with acute stroke between 1996 and 2004 and found the mechanism of stroke in this group to be very varied. Eighty-two patients were included, 77 with ischaemic stroke

and five with intracerebral hemorrhage. The mechanism of ischaemic stroke was reported as large artery atherosclerosis (12%), cardiac embolism (18%), small vessel occlusion (18%), other determined aetiology in 23%, and undetermined in 29%, including 19% with incomplete evaluation (Ortiz et al., 2007).

A slightly different picture was found in a descriptive study conducted in Malawi where ischaemic stroke was the most common diagnosis (n=25; 58%) among people living with HIV. Ischaemic stroke was followed by infection (n=11; 23% which included tuberculous [n=4], cryptococcal meningitis [n=2], toxoplasmic encephalitis [n=1], neurocysticercosis [n=1], brain abscess [n=1] and progressive multifocal leucoencephalopathy [n=2]). There was a high incidence of vasculitis and hypercoagibility in HIV infected adults. It was found that protein S was related to HIV infection, not stroke occurrence (Mochan et al., 2003). Protein S is a disorder associated with the risk of venous thrombosis (Godwin, 2006). Many of the neurological conditions that are a result of HIV infection manifest some hemiplegic type symptoms and is also reported as the first manifestation of HIV (Mochan et al., 2003).

Pathophysiology

HIV invades the neurological system with invasion occurring early in the course of the infection. HIV is neurovirulent causing possible neuropathy, myopathy, myelopathy and dementia, but it is not especially neurotrophic (Manji & Miller, 2004).The virus is rarely isolated from neurons either in the peripheral or in the central nervous system. Productive infection is usually found within the associated inflammatory infiltrate, predominantly macrophages (Manji & Miller, 2004).

Gabudza and Wang (1999) stated in their systematic review that several chemokine families are used as receptors together with the CD4 receptor. Chemokine receptor CCR5 is the major co-receptor for HIV1 infection of macrophages and microglia. CXCR4 and CCR3 are found on microglia and can mediate infection through certain HIV-1 isolates but are not as efficient as CCR5. Different chemokine receptors are expressed on neuronal and non-neuronal cells in the central nervous system in areas such as the cerebral cortex and other brain regions including astrocytes (Gabudza & Wang, 1999). Therefore, this may allow for direct infection of the nervous system by the HIV.

2.3.4.3 **Underlying mechanism of infection of the nervous system by HIV**

Two models of how HIV affects the central nervous system are presented:

The first states that HIV precipitates neuronal damage or death indirectly, through activation of microglia or macrophages. This process triggers the release of pro-inflammatory cytokines and chemokines and via HIV proteins that cause over activation of glutamate receptors and leads to exitotoxic injury (due to the excitatory function of glutamate) from the exposure of extracellular glutamate (Cherner et al., 2002).

The second model suggests that HIV entry into astrocytes and the CNS is independent whereas macrophages and microglia in the CNS require the CD4 cell as a primary receptor for HIV1 infection (Kanmogne et al., 2000). However, the receptors that mediate CD4 independent HIV1 infection of astrocytes and capillary endothelium cells have not yet been identified (Kanmogne et al., 2000).The preposition that HIV infects the brain directly via the blood brain barrier (BBB) endothelial cells remains controversial although the BBB is reported to be dysfunctional due to HIV infection. A recent article by Ricardo-Dukelow,(2007) has found that HIV infected macrophages affect the endothelial cells in the blood brain barrier, allowing different proteins to enter the BBB and therefore infecting the central nervous system (Ricardo- Dukelow et al., 2007). Once infected, the neuronal and glial cells result in demyelination and possible nerve damage. It has been concluded that HIV-1 is able to infect its target cells if they express viral receptors or co- receptors. Brain endothelial cells do not have CD4 receptors but if HIV co-receptors are present, then CD4 independent infection can occur (Kanmogne et al., 2000). The numerous neurological conditions are testimony to HIV infection of the nervous system (Mamidi et al., 2002) Antiretroviral therapies have reduced the incidence of neurobehavioural symptoms with AIDS however in spite of this, HIV infection in the CNS remains a significant clinical concern (Vitkovic & Tardieu, 1998).

Table 2.5 Summarises commonly reported neurological conditions excluding stroke.

Table 2.5: Summary of Neurological Conditions Associated with HIV

Condition	Pathology	Signs and Symptoms	References
-Global encephalopathy -Primary CNS lymphoma -Intracranial mass lesions,	Brain mass lesions, opportunistic infection or primary nervous system lymphoma (Berger 1997) Reactivation of the Epstein Barr virus resulting in monoclonal B cell expansion (Mamidi et al., 2002).	-Changes in consciousness -Confusion -Lethargy -Memory loss -Hemiparesis -Speech and language disorders -Seizures and cranial nerve palsies	(Berger & Simpson, 1997) (Mamidi et al., 2002)
-Progressive multifocal leucoencephalopathy	Brew (2001) reports that it is unclear whether the progressive multifocal leucoencephalopathy within the CNS results from virus reactivation following immunosuppression or if invasion of the CNS by infected lymphocytes causes it. This results in multifocal cell lysis and demyelination. James Canyon virus (common polyoma virus) is present in 75% of the general population	-May present with progressive -hemiparesis -Heminopia or ataxia. -Cognitive dysfunction may occur -Hemiparesis, hemianopia or ataxia -Focal neurological signs -Dysphagia and seizures resulting from -focal intercranial lesions (Manji and Miller 2004)	Manji and Miller(2004) (Brew, 2001) (Mamidi et al., 2002)
-Aids dementia complex or sub acute/acute encephalitis Or HIV encephalopathy	Brain atrophy, sulcal widening, meningeal fibrosis. Presence of multinucleate giant cells resulting in direct virus induced cell fusion. White matter pallor attributed to demylination and possibly the alteration of the blood brain barrier resulting in extravasation of the serum proteins.	-Disturbed intellect -Bradyphrenia -Fatigue ;-malaise, headaches -increased social isolation and loss of sexual drive -Brady kinesia -Postural instability slow and clumsy gait and altered muscle tone (also signs and symptoms for dementia)	Berger Simpson (1997) Ungvarski et al.,(1999) Berger Simpson (1997) (Mamidi et al., 2002)
-CMV cytomegalovirus	Cytomegalovirus infection with serologic confirmation-results in focal necrosis with necrotising ventriculo encephalitis imbroglio nodules.	-CMV retinitis -Altered mental status -Sub acute dementia -Rapid delirium -Focal deficits such as nyastagmus -Cranial neuropathies	

Table 2.5 continued

Condition	Pathology	Signs and Symptoms	References
Sensory neuropathy and related or unrelated peripheral nerve dysfunction	Production of neurotoxins from infective agents such as mycobacterium avium complex and cytomegalovirus have been hypothesized as causative agents (Gale 2003). There is loss of distal sensory nerves (axonal degeneration and in dorsal ganglia due to inflammation) and unmyelinated nerves. Macrophage activation in the dorsal ganglia. Through skin biopsy there is evidence of reduced nerve density and nerve fibre swelling. The John Hopkins AIDS service hypothesises that axonal degeneration leads to changes in the pain processing region of the spinal cord i.e. substantia gelatinosa through up regulation of sodium channels resulting in hyperexitability of sensory neurons and ectopic impulses that patients perceive as shooting or lancinating pains. Sprouting of myelinated fibres into laminae of the spinal cord, which normally receives unmyelinated fibres. The clinical consequence being allodynia (normally non-painful stimuli are perceived as very painful). Anti retroviral therapy has also been reported as causing sensory neuropathy (Manji and Miller 2004) However the pathophysiological mechanism is still under study.	-Changing sensory perception and pain -Other common impairments are parasthesia, hypersthesia, loss of proprioception distally	(McAuthur, 2001) Gale (2003)
-Guillian Barré Syndrome (polyradiculopathy) Other spinal cord disorders	Acute inflammatory demyelination occurs. Both cellular and humoral mechanisms occur. It is reported that foreign antigens cross act with ganglioside surface components of peripheral nerves. The pathogenesis is still not fully understood (Quinn 1997)	-Rapidly evolving symmetrical limb weakness.	(Quinn, 1997)
Aseptic meningitis, Cryptococcal meningitis	Caused by cryptococcal neoformans. This ever-present organism is found in the excreta of pigeons. Once activated it causes basilar non exudative chronic meningitis	-Headache -Fever -Nausea and vomiting -Altered mental status.	Mamidi et al., 2002
Bacterial and fungal meningitis, Tuberculous meningitis	-Causes lesions located in the gray and white matter or involves the basal ganglia. -Occurs as a result of reactivation of latent organism		Manji and Miller(2004)

2.3.5 HIV and Musculoskeletal Systems

Jellis (1995), followed up different sets of HIV positive patients that were admitted with fractures and reported that closed fractures, managed conservatively, healed. However, with open fractures the non-union and sepsis rate was 72% (Jellis, 1995). In Africa, there is a high prevalence of road traffic accidents in conjunction with a high prevalence of HIV. As a result, it is not uncommon for people with fractures to be HIV positive as well (Harrison et al., 2004).

The muscular and skeletal structures are affected directly and indirectly by HIV and associated treatment regimens such as zidovudine (Montessori et al., 2004). Effects of zidovudine are explained in Table 2.7. Muscle is part of the mechanism for glycogenolysis and protein synthesis and therefore when muscle bulk is reduced, strength is reduced (Sattler et al., 1999; Sattler et al., 2002). Indirectly HIV infection and the progression of the illness results in reduced activity leading to deconditioning and muscle atrophy (Stringer, 2000). Increased energy expenditure at rest and inadequate nutrition contribute to the loss of muscle mass through wasting. Some of the underlying causes of wasting include poor appetite and malabsorption (Weinroth et al., 1995).

2.3.5.1 Epidemiology of musculoskeletal conditions in HIV

Tehranzadeh (2004b) in their review on musculoskeletal abnormalities in association with HIV, grouped musculoskeletal disorders into two: infectious musculoskeletal disorders and myobacterial infections. The list of musculoskeletal disorders in HIV, range from arthralgias and myopathies to rheumatic disorders (Biviji et al., 2002; Plate & Boyle, 2003). Biviji (2002) reported a prevalence of 71% bone, joint and muscle HIV-related infections in a cohort of 101 consecutive patients. Some of the diagnoses reported by Biviji et al. (2002) and Plate and Boyle (2003), include cellulitis, abscesses, pyomyositis, septic bursitis, septic arthritis, osteomyelitis and bacillary angiomatosis**.** Infection of the skin and subcutaneous tissue usually caused by gram-positive cocci such as streptococcus and staphylococcus species normally found in skin flora. A common diagnosis in the musculoskeletal system is cellulites where the tissue involvement may range from simple subcutaneous infection to full-blown osteomyelitis. Pyomyositis is an infection of the skeletal muscle and is readily curable but potentially fatal. Septic bursitis commonly affects the olecronon, prepatellar and subdeltoid regions (Dalakas, 2001). Septic arthritis comprises about 23% of musculoskeletal infections that occur with HIV especially among haemophiliacs (Biviji et al., 2002). The presentation is usually monoarticular with the large joints of the lower limbs (hips and knees) commonly affected. Radiological features of non-HIV infected individuals are not different from those infected with HIV.

After septic arthritis, osteomyelitis is the second most common infection among HIV infected patients. A ten percent prevalence has been reported among the South African HIV population (Frean et al., 2002).The causative pathogen is the same as in the immuno-competent patient staphylococcus aureas. Common sites in the skeletal system are the wrist, tibia, femoral heads and thoracic cage. Bacillary angiomatosis osteomyelitis is a multisystem infectious disease unique to the HIV infected population (Frean et al., 2002).

Rheumatic manifestations in HIV are common and have been reported to occur in 45% of patients (Plate & Boyle, 2003). The pathology is not fully understood but reported to probably involve cytokines and bone ischaemia (Plate & Boyle, 2003). Under rheumatic manifestations, diagnoses include arthralgia and acute polyarthritis, which mimic rheumatoid arthritis. Reiter's syndrome (100% incidence rate) and psoriatic arthritis (10-40% incidence rate) occur with a higher incidence in HIV infected persons. The two are reported to be closely associated and may be difficult to distinguish (Plate & Boyle, 2003).

Table 2.6.1 and Table 2.6.4 summarise conditions of the musculokeletal system seen in HIV/AIDS.

Table 2.6.1: Summary Myopathies Associated with HIV

MYOPATHIES			
CONDITION	**PATHOLOGY**	**Signs and Symptoms**	**REF**
Polymyositis (idiopathic inflammatory myositis)	Invasion of the muscle tissue by the virus causing cell pathology and finally necrosis	-Progressive hip and shoulder girdle weakness confirmed by electromyogram and muscle biopsy showing interstitial inflammatory infiltrates and elevated creatine kinase (CK) levels.	(Biviji et al., 2002)
Pyomyositis	Formation of abscesses in striated muscle	-The condition is divided into three stages: invasive, suppurative and late stage. The first stage lasts three weeks and is characterized by cramp like pain localized to one muscle, induraton and low-grade fever. -Muscle pain and swelling, with or without systemic symptoms, myalgias, muscle wasting, elevated creatine kinase (CK). -Large muscle groups especially of the lower limbs are often affected. -In the second stage the pain and fever increases, oedema, and pus may develop. Left untreated the patient becomes septic and death may ensue. -Medical treatment of pyomyositis includes needle aspiration and or surgical incision and drainage in conjunction with antibiotics.	(Biviji et al., 2002; Dalakas, 2001)
AZT myopathy	Mitochondrial myopathy where there is an increase in size of the mitochondria, lipid drop accumulation and necrosis of the red fibres (Sheikh et al., 1999)	-Myalgia, fatigue, proximal muscle weakness -Myopathic changes on electromyogram.	(Biviji et al., 2002; Sheikh et al., 1999)

Table 2.6.2: Summary Inflammatory Arthropathies Associated with HIV

INFLAMMATORY ARTHROPATHIES			
Inflammatory arthropathies Athralgias	Aetiology unknown	Fever, fatigue, rash, myalgia, arthralgia and parasthesias	Plate and Boyle (2003)
Reiters syndrome -a type of spondyloathritic arthritis also known as reactive arthritis	Not fully understood but HLA-B27 antigen is present in HIV patients. Major theory is that it is an autoimmune response where the immune system not only attacks the infecting bacteria but the HLA-B27 antigen containing tissues.	-Unique manifestation is in the foot "triad of urethritis, conjunctivitis and arthritis". -Enthesopathies (includes achilles tendonitis, lateral / medial epicondylitis, rotator cuff tendonitis and De Quervian tenosynovitis. -AIDS foot" involving plantar fascia, extensor tendons anterior and posterior tendons. Patients walk on lateral border of the foot because of painful heels. The hands and large joints are also affected and associated pathologies are De Quervain's stenosing tenosynovitis of the wrist, flexor tendonitis, rotator cuff tendonitis, lateral and medial epicondylitis	Plate and Boyle (2003)
Adhesive capsulitis	Induced by protease inhibitors.	-Insidious onset of signs and symptoms: pain, restrictive active and passive joint range of motion. Onset is within 12-14 months of commencing treatment.	(Tehranzadeh et al., 2004a), (Major & Tehranzadeh, 1997)
Hypertrophic osteoarthroplasty	A clinical syndrome that presents with athralgias and warmth of the lower mid - extremity joints	-Digital clubbing -Relief of symptoms if limbs are elevated -Closely associated with PCP and lymphocytic interstitial pneumonitis	(Tehranzadeh et al., 2004a), (Major & Tehranzadeh, 1997)
Myositis ossificans	Patho-physiology unknown - suspected as perhaps being a direct result of the infection or antiretroviral therapy		Tehranzadeh et al., (2004)
Avascular necrosis	Ischaemic necrosis of subchondral bone. Avascular necrosis possibly caused by a type of thromboembolic phenomenon with subsequent ischaemia, hyperaemia and increased intraosseous pressures that result in the death of osteocytes.	-Common sites femoral head but can involve scaphoid, lunate, knee and ankle - Deep throbbing pain presenting suddenly or insidiously -Ultimately resulting in loss of mobility. an Magnetic Resonance Imaging is the most sensitive diagnostic tool	(Plate & Boyle, 2003)Tehranzadeh et al., (2004)
Other conditions reported in the literature that manifest with HIV are: 1. HIV associated arthritis whose distinguishing feature is that it is not associated with HLA-B27 or the rheumatic factor. It is reported to be asymmetrical and has a limited duration of 6 months but the patient presents with severe pain and disability (Narsimulu 2006, Tehranzadeh et al., 2004). 2. Painful articular syndrome also characterized by a limited duration between 2-24 hours (Narsimulu 2006). No literature reporting the extent of disability associated with this particular condition could be found.			

Table 2.6.3: Summary of Infectious Musculoskeletal Conditions Associated with HIV

INFECTIONS			
CONDITION	**PATHOLOGY**	**SIGNS AND SYMPTOMS**	**REFERENCE**
Tuberculous infection	Latent tuberculosis osteo myelitis is reported to develop from haematogenous seeding of mycobacterium tuberculosis from a newly acquired pulmonary infection due to susceptibility of a weakened immune system.	-Spine: starts in the anterior section of vertebral body and spreads to adjacent discs. -Lumbar: spreads anteriorly causing psoas abcess, presenting as lower abdominal and groin pain -Thoracic: spreads posteriorly resulting in cord compression -Other bones: metaphysis affected, breaking cortex causing joint sepsis -Xray and Magnetic resonance imaging: calcified soft tissue abscess	Plate et al., 2003 (Biviji et al., 2002)
Bacillary angiomatosis	Cat scratches and bites are a risk factor Skin lesions similar to Karposis sarcoma	-Proliferation of vascularity of the skin viscera and lymph nodes (overlying skin resembles cellulites) -Multiorgan involvement, CNS, lymph nodes and bone -Osseous lesions- cortical damage, medullary permeation, periostitis and soft tissue damage	(Biviji et al., 2002)

Table 2.6.4: Summary of other Neoplastic Conditions Associated with HIV

NEOPLASTIC			
Non Hodgkins lymphoma and Karposis sarcoma	Malignancies: Karposis sarcoma (a neoplasm arising from the cells in the epithelial region) while non Hodgkins lymphoma occurs in the lymphoid cells. In the case of Karposis sarcoma, skeletal involvement is less typical and when it does occur, the involvement is in the hips, ribs, pelvis and spine.	-Non Hodgkins Lymphoma is commonly found in the bone marrow with other common sites being the central nervous system, gastrointestinal sites and mucocutaneous sites. -Pain , fever, weight loss and pathological fractures are common -Osteolytic lesion with cortical destruction and permeative pattern -Xrays: osteolytic lesion with cortical destruction and permeation	Tehranzadeh et al., (2004)

2.3.6 **TB and HIV**

Tuberculosis resurged in the early 1980's and this has been attributed to the AIDS pandemic (WHO, 2007). The incidence of TB in people with AIDS is reported to be 35-500 times the incidence of TB in the general population (Tehranzadeh & Wong, 1994). TB commonly affects the pulmonary system. In 20% of all TB cases, it manifests in extrapulmonary sites such as the musculoskeletal system, gastrointestinal and central nervous systems (Ramanath et al., 2002).

2.3.6.1 **TB and the musculoskeletal system**

Musculoskeletal TB is reported as the fourth most common extrapulmonary manifestation of TB and is found in 1-5% of all patients with TB. Usually skeletal TB lesions in the immunocompetent patient are solitary but in the AIDS patients they may have a multicentric distribution in about 30% of cases (Paradisi & Corti, 1999). Tehranzadeh and Wong (1994) reports that the most common site of musculo skeletal TB is the vertebrae (Potts disease) concentrated mostly in the lower thoracic or upper lumbar segments. Within the category of musculoskeletal TB, the frequency of tuberculous spondylitis is 50-66%, peripheral arthritis 20-30%, osteomyelitis 10-20% and tenosynovitis and bursitis about 1-3% (Paradisi & Corti, 1999).

TB bacillus is believed to spread haematogenously and spinal infections start in the anterior part of the vertebral body, possibly indicating seeding via the paravertebral venous plexus (Griffith et al., 2002). Radiologic presentation of tuberculosis may show vertebral height loss, erosions and paravertebral mass losses.

2.3.7 **HIV and Pain**

Eldridge (1994) reported that pain is a significant and prevalent problem in people infected with AIDS. In a review of the literature, studies by Lebovits (1989) and O' Connell and Levinson (1991) reported the incidence of pain as 54% and 37% respectively and stated it as the second most frequently reported symptom after fever in HIV/AIDS patients. In a retrospective review Eldridge et al. (1994) described the characteristics of pain according to a pain assessment tool. They found that 40% of their sample of 50 was experiencing pain with the mean pain intensity being 7.27 on a scale of 1-10. Multiple sites of pain were reported but pain in the distal extremities was most frequently reported. The authors attributed this to the existence of peripheral neuropathies (Eldridge et al., 1994).

In HIV, localized pain originates from the bone, nerve and viscera. This may be due to tumour invasion, myalgia and arthralgia associated with chronic HIV disease. Other sources of pain are vasculitis, chronic demyelinating neuropathy or inflammatory neuropathy that results from autoimmune responses (Flaskrud & Ungvarski, 1999).

2.3.8 HIV and its Effect on Other Body Systems

2.3.8.1 HIV and Metabolic Disorders

HIV is associated with metabolic function disturbances, notably hyperlipidemia, abnormal body fat redistribution, lipodystropy and lipoatrophy have been reported. Other disturbances include lactic acidosis, insulin resistance and hyperglycaemia. Various impacts occur when HIV is present in the breakdown and conversion of lipids (Montessori et al., 2004; Moylett & Shearer, 2002). Some of the other resultant impacts are hyperglycaemia, hypertriglyceridemia, hypercholesterolemia, glucose intolerance and insulin resistance (Moylett & Shearer, 2002; Mutimura et al., 2007). Lipodystrophy is characteristed by redistribution of fat from the subcutaneous compartment to the visceral compartment. The subcutaneous compomnent subsequently atrophies (Moylett & Shearer, 2002; Mutimura et al., 2007). HAART contributes to altered lipid metabolism in addition to altered mitrochondrial function (Grinspoon & Mulligan, 2003; Mutimura et al., 2007). Body fat changes have an impact on the persons Health-related quality of life (HRQOL) and are a source of stigma.

2.3.9 HIV and Body Mass

Wasting syndrome is associated closely with HIV infection (Castaneda 2006). In the United States it is closely associated with people of colour and women as well as injecting drug users (Castaneda, 2002). The pathogenesis is considered multi-factorial including direct infection by the virus, tissue cytokine activity, recurrent infections and inadequate intake of required calories. There can also be mal-absorption, may be due to injury of the small intestine, or disease of the digestive organs such as cryptosporidiosis or inflammatory bowel disease. Metabolic changes may be because of changes in the hormones that mediate the immune and inflammatory responses resulting in anorexia (Castaneda, 2002).

2.3.10 HIV and the Cardiac System

Bouramoue and Ekoba (1996) reported on clinical manifestations relating to cardiomyopathy in patients in an advanced stage of AIDS (Bouramoue & Ekoba, 1996). Clinical examination showed myocarditis to be the most frequent condition, with a prevalence of 61% (n=81). Specific cardiac diagnoses included isolated liquid pericarditis in 47 cases, 15 of which had blockages in the heart. Twenty five patients had mitral

insufficiency, 16 had tricuspid insufficiency, two had aortic insufficiency due to infectious endocarditis and two had myocardial infarcts (Bouramoue & Ekoba, 1996). This is comparable with the conditions reported by Cade et al. (2004) which included coronary artery disease, pulmonary hypertension, neoplasms and vascular lesions (Cade et al., 2004). HIV-related cardiac abnormalities occur because of the presence of auto-immune antibodies and the direct infection of the cardiac muscle. The impact of antiretroviral therapies on abnormal lipid metabolism is also well-documented (Grinspoon & Mulligan, 2003). As outlined under metabolic disorders, some of the consequences of lipid metabolism disturbance include hyperglycaemia, hypertriglycerideamia, hypercholesteroleamia, glucose intolerance, insulin resistance and abnormal fat distribution (lipodystrophy) (Moylett & Shearer, 2002). These conditions predispose the individual to cardiac abnormalities that may impair left ventricular function and lower oxygen delivery to the musculature thereby diminishing exercise and activity tolerance(Cade et al., 2003; Cade et al., 2004). Sub clinical abnormalities have been reported which may augment other complications of HIV resulting in fatigue and physical exercise intolerance. Cade et al. (2004) proposes that the physical problems experienced as a result of HIV infection are similar to those seen in people with congestive cardiac failure.

2.3.11 HIV and Antiretroviral Therapy Impacts on Body Systems

Although antiretrovirals have reduced morbidity and mortality, significant adverse effects are noted. Commonly reported side effects of antiretroviral regimens include lipodystrophy (Milinkovic 2006) and peripheral neuropathy (Keswani et al., 2002). Gastrointestinal effects such as bloating and nausea, which may be cyclical or temporary, are side effects of HAART. Headache and fatigue may also occur (Montessori et al., 2004). Side effects that are less common but significant and important for the clinician to be aware of, are anaemia, peripheral neuropathy, lactic acidosis, osteoporosis, fat maldistribution, hyperlipidaemia, skin disorders and hepatic steatosis (Montessori et al., 2004).Table 2.7 outlines common adverse side effects of ARVs.

Table 2.7: Adverse Side Effects of ARVs

Drug	Common Adverse effects	Pathogenesis
Nucleoside Reverse Transcriptase Inhibitors (NRTIs)		
Zidovidine AZT Didanosine ddI-EC Zalcaibine	Lactic acidosis, nausea headache and rash GI intolerance, Pancreatitis, gout and reversible neuropathy prevalence-20% (Gale 2003) Reversible peripheral neuropathy prevalence 20-35% (Gale 2003)	-NRTIS reduce mitochondrial function i.e. oxidative phosphorylation and results in formation of lactate. (Montessori et al., 2004) -Mitochondrial necrosis due to direct HIV infection (Montessori et al., 2004)
Protease inhibitors	Diabetes mellitus -Lipodystrophy- peripheral fat loss, central fat accumulation and lipomas (Roge et al., 2002) Increased bleeding episodes	-Direct effects of HIV on pancreatic function may be responsible for this. (Montessori et al., 2004) -Causes are multifactoral with both endocrine and metabolic abnormalities (Montessori et al., 2004) Unknown
Non specific	Osteonecrosis, osteopenia and osteoporosis	-Unclear but reported in a review by Montesorri et al.,2004 as -Direct effect of HIV in inhibiting new bone formation -Indirect activation of vitamin D (Montessori et al., 2004).

2.2.12 Conclusion

HIV affects nearly all body systems directly by infecting specific cells and tissues and indirectly through opportunistic infections. This, results in signs and symptoms and impairments that have an impact on an individual's function.

2.4 SOCIO-ECONOMIC DETERMINANTS AND IMPACTS OF HIV/AIDS

2.4.1 Determinants of HIV

In order to be holistic the direct consequences of the disease should be understood as well as contextual and social determinants and impacts (Aberg et al., 2004).The known determinants of health have been well documented by (Marmot & Wilkinson, 1999). In their publication, which was a culmination of manypublications, they state that ***"peoples' lifestyles and conditions in which they live work strongly to influence their health."*** They, therefore, put forth the position that apart from prolonging survival and improving prognosis after serious disease, the social and economic conditions should be understood in combating the causes and impacts of disease. Known social determinants of health that have been identified from different study types ranging from cross-sectional to intervention studies are:

- Poor social and economic circumstances affect health with those further down the social ladder being at twice the risk of developing serious conditions
- Material and psychological health
- Social and psychological circumstances- causing long term stress (this can culminate in insecurity, continued anxiety, low self esteem, social isolation, and lack of control).
- Stress
- Social support - the amount of emotional and practical support people get differs with social economic status
- Unemployment
- Addiction (both alcohol and drugs)
- Nutrition
- Transport (Marmot & Wilkinson, 1999).

HIV results in a higher burden of illness on households affected by HIV and these households are substantially poorer than those that are unaffected (Bachmann & Booysen, 2003). This study is the only study found that has quantified the economic impact of HIV/AIDS in South Africa by comparing two different cohorts and is a well-designed level 3 evidence study. The study used a wide cross-sectional population and surveyed a varied selection of household therefore obtaining wide representation. The results showed how HIV erodes the economic wealth of the household.

2.4.2 HIV Impacts

HIV impacts on the individual and subsequently their micro and macroeconomic environment (UNAIDS, 2006a). These impacts are complex and are summarised below: The summary below outlines the impact of HIV at a macro level and outlines how it impacts the macro situation such as the macro economy, firms, government and the household. An outline follows of how the individual is affected at household level and as an individual in terms of their quality of life.

AREA OF IMPACT		**WHAT IT AFFECTS**
For Macro economy		
Lower physical and human investment	:	Reduced growth trajectory
Class biased impacts	:	Uneven welfare effects
Firms		
Insurance	:	Costs and savings
Disruption and absenteeism	:	Overall productivity
Worker experience and morbidity	:	Labour productivity
Government		
Expenditure on HIV/AIDS	:	Other spending and resultant deficit
Production shifts	:	Revenue from taxes
Household income	:	Income tax receipts
Households		
Loss of income and increased number of orphans	:	Vulnerable households
Caring for family members with HIV/AIDS	:	Changed Expenditure

(Arndt & Lewis, 2000)

At community level, there is evidence of reduced labour, increased poverty, inability to maintain the infrastructure, loss of skilled labour including health workers, reduced access to health care and elevated morbidity and mortality (Drimie, 2002). The burden of caring for peole living with HIV (PLWH) falls on the elderly because as people fall ill they migrate to households with pensioners or women (Dorkenoo et al., 2003). Businesses feel the impact of HIV through worker absenteeism and reduced productivity (UNAIDS, 2000).

In addition to the above broader impacts, HIV has devastating impacts on the individual, the family and the community. Some of the impacts on the family include: loss of family members and associated grief, change in family composition, forced migration, dissolution, impoverishment, loss of labour, inability of the parent to care for the child, stress and demoralization, long term pathologies such as depressive behaviour of children and adults, malnutrition and further exposure to HIV (Bachmann & Booysen, 2003; Drimie, 2002). HIV also endangers household food security because as the burden of HIV increases family income shifts from household necessities to health care needs (Dorkenoo et al., 2003). This results in poor nutrition and the authors Dorkenoo et al. (2003) warn that provision of care should not be isolated from the need for good nutrition, quoting Sector Network on Rural Development SNRD to illustrate the point ***" Hungry people do not listen to AIDS music" (NRD workshop 2001).***

2.5 HIV, DISABILITY, FUNCTION AND HEALTH-RELATED QUALITY OF LIFE (HRQOL)

The central focus for modern outcome measurement is the tracking and measurement of function and well-being (Wachtel et al., 1992). When physiotherapists manage patients with HIV, they need to ensure that consider at what is measurable so that interventions can be measured. Early in the development of the knowledge base on HIV and disability, the literature focused on outlining the descriptive picture and profile of (PLWH) and people living with AIDS (PLWA) (Nixon & Cott, 2000). Results from population based studies such as Rusch et al. (2004) and Crystal et al. (2000) can be considered representative of the population while the smaller studies are less representative in that they have used convenience or consecutive samples, which may introduce bias. In addition, all studies have included different populations and describe the patient populations using different outcome tools and parameters in the clinical data. For example O'Dell (1992) looks at factors such as length of stay in hospital and duration of AIDs illness while Zonta (2005) uses these same variables as well as muscle strength and CD4 count (O'Dell & Dillon, 1992; Zonta et al., 2005). Levinson and O'Connell (1991) on the other hand, used medical diagnoses. The key results of the studies reviewed are summarised in Table 2.8 below.

Table 2.8: HIV and Functional Limitations

Author Date	Sample Size Population	Tools Used	Results
(Rusch M et al., 2004)	1508 questionnaires mailed, 762 returned (76.6% sexual minority males)	Questionnaire	-High rates of impairment n=(52%) -Impairments were in areas of neuromuscular functions, mental and sensory functions -Significant associations between impairments, activity limitations and social roles and CD4 count
(Crystal et al., 2000)	2836 77.5% - male 22.5% - female	Physical limitation scale and 2-item ACTG SF-21 role functioning scale	-Functional limitations among 51% in role functioning and 64%in vigorous activities (energy demanding activities such as stair climbing or walking, care needs and complex roles) -Associations - higher limitation was associated with age, lower educational attainment, more advanced disease and higher symptom burden. Pain and fatigue were strongly associated with physical and social function.
(Zonta et al., 2003)	74 hospital in-patients 46 men and 28 women	Barthel FIM Rankin score Muscle strength	-Ninety one percent (n-67) exhibited functional deficits and disability (mild to moderate) but 79% were functionally independent
(Benedict et al., 2000)	39 out-patients 32 men 7 women.	Tests and Sickness Impact Profile sickness impact profile	-Significant association was found between: -Neuro psychological impairment and HIV -Employment and instrumental activities of daily living
(O'Dell et al., 1996a)	546 in and out-patients 528 - men and 18 women	Health status from out-patient records medical history and diagnostic studies. Disability - using 20 activities	-High prevalence in instrumental activities for example mobility 38% and lower in activities of daily living (ADL) for example eating 11% and dressing -Strong correlates with medical outcomes study HIV cognitive, social function, employment and fatigue indices
(O'Dell et al., 1991)	37 in patients all male 35.1% black and 24% whilte	FIM	-High prevalence in areas requiring human assistance for example stair climbing 19 (51%) ambulation 14 (37.4%) -Factors such as duration of AIDS diagnosis (p=0.01), LOS- hospital (p=0.05) and number of hosp admissions (p=0.00) were associated with disability.
(O'Dell, 1993)	30 in-patients 25 white males	Medical records	-Functional deficits contributing to disability were de-conditioning, pain, fatigue hemiparesis and quadriparesis. -Referrals 86.7% referral to Occupational Therapy and 26 to Physiotherapy. Aids and appliances ordered in 30% (n=9) modalities used included TENS and US, Slings and splints. -No associations explored
(Levinson & O'Connell, 1991)	51- out-patients 50 men 1 women	Records and questionnaire	-Outlined rehabilitation diagnosis as deconditioning, and weakness 14 (27%) central neurologic deficits 12 (24%) peripheral neuropathy 11 (22%) -Medical diagnosis were predominantly CNS related 17 (33%) systemic infections 17 (33%) and 15 (29%) had peripheral neuropathy -Functional deficits - mobility - 39 (76%), self-care 29 (57%) and pain 19 (37%) -Rehabilitation interventions given to these patients were exercise, gait training and pain management.

Limitations or difficulties with mobility, impaired self-care and pain were commonly found in these studies. The studies outlined show how diverse the functional limitations in a population with HIV are and therefore may point to the need to concentrate on individualized efforts in dealing with functional limitations (Crystal et al., 2000).

It is necessary for the rehabilitation professional to be familiar with the impairments and rehabilitation diagnosis for appropriate treatment plans, identification of patients and outcomes. In addition to physiotherapists identifying potential patients themselves (given physiotherapists have first referral status), the primary care physicians should understand the subsequent disabilities seen in AIDS for proper referral to rehabilitation (O'Dell et al., 1991). Furthermore, knowledge of functional status will facilitate efficient use of available community resources, social services and predict more accurately the course of HIV as a chronic condition (Davis, 2006).

Functional limitations are closely associated with QOL (O'Dell & Dillon, 1992).The measure of quality of life is achieved in several ways and Cleary (1995) outlines four approaches that serve to support the connection of function and QOL.

- Use of one single generic scale suitable for all types of people
- Use of single scale developed for a specific condition
- Use of comprehensive set of subscales
- Focus on a narrow range of measures most important for the group studied (Cleary, 1995).

The second part of this section of the literature review on functional limitations is separated because the studies looked predominantly at HRQOL. The main outcome of reviewing the literature on HRQOL showed a trend of studies that assessed problems in QOL using different tools such as MOS SF 36, MOS -HIV, EQ5D and the sickness impact profile (Wachtel et al., 1992; Wu et al., 1997). The results of these studies revealed difficulties with function and several observations associated with symptoms (Wachtel et al., 1992; Wu et al., 1997). There is a correlation between HRQOL and markers of disease (O' Keefe & Wood, 1996). The impact of HAART on HRQOL has been studied with a generally positive association (Carrieri et al., 2003; Jelsma et al., 2006). All studies involving HRQOL commonly look at function and reinforce the position that HIV negatively influences function (O'Dell & Dillon, 1992) Table 2.9 outlines some specific findings in QOL studies but also illustrates the prevalence in functional deficits.

Table 2.9: HIV and QOL

Author, Date Title	Sample Size Characteristics	Tools Used	Key Results Of Studies
(Wachtel et al., 1992)	520 -in and out-patients 89% male 31% non white	Medical outcomes survey (MOS-36)	-Problems noted in all areas of function -Respondents with four or more symptoms reported significantly lower functional scores (p=0.05) -Age and gender had a significant impact on physical role and mental function while less education had an impact on the mental health score. Symptoms seemed to be the major determinants of well-being.
(O' Keefe & Wood, 1996)	134 -out-patients 42- white 49 - mixed race 43- black	MOS SF -36	-This study compared the status of function at all stages of HIV. -All aspects of QOL measures were affected in asymptomatic HIV positive patients. -Physical function was the only MOS scale to be affected by gender and race where people of mixed race had a lower score p=0.05
(Low-Beer et al., 2000)	179 out-patient population -169 male -10 female	MOS - SF-36	-This study established change in functioning among PLWH after the introduction of protease inhibitors. There were different results with different subsets of patients as illustrated below. -People who were worse off at baseline improved significantly in the MOS-=SF-36 health perception, (p=0.004) physical p=0.03 and social function (p=0.05). Pain and mental health did not change over the study period. -Those with a higher quality of life at baseline experienced a decline in their mental (p=0.001) physical (p=0.007) and social function (p=0.021) social functioning (p=0.003). The researchers attributed this to regression to the mean.
(Burgoyne & Saunders, 2001)	113 out-patients 87% male	SF36	-The study found symptomatic PLWA experience low QOL. -Those with physical function problems required more support. -Significant associations were found with health status variables, symptoms and a positive correlation with social support. p<0.005. The majority of the population were homosexual men.
(Hughes et al., 2004)	123 -out-patients -65% female	EQ5D	-Thirty percent reported mobility problems, ADLs, pain and anxiety and depression resulting in lower QOL
(Carrieri et al., 2003)	654 out-patients 77%-male 23% - female	MOS SF 36	The study followed up patients after the introduction of HAART. They measured HRQOL pre and post HAART -Sixty seven (27%) of 253 patients with normal HRQOL experienced a deterioration in HRQOL. Those with a low baseline experienced an improvement in HRQOL. -Six of the eight HRQOL scales improved i.e. physical role limitation, vitality, general health perception, social functioning, emotional related role and general mental health (p=0.001) -Unemployment was negatively associated with obtaining a improvement in HRQOL. While reporting fewer symptoms had a positive association. Self report symptoms are a good marker for post treatment HRQOL and subsequently poor HRQOL is associated with non adherence
(Hughes et al., 2004)	117 -out-patients -74.5 % female	EQ5D	-HRQOL, through improving the health condition improved upon commencement of HAART. -the study reported a significant difference between measures of self-care (p=0.03), usual activities (p=0.01), pain and discomfort (p=0.01), anxiety and depression (p=0.02) at baseline and 12 months after commencing HAART. The type of HAART is not outlined.

The studies reviewed in Table 2.9 are divided into those studies that assessed the health-related quality of life with the objective of understanding the HRQOL status and the associations between factors and those that established how HAART affects HRQOL.

The studies examining the status of HRQOL reported a lower score in HRQOL and assessed associations between low functional status and reduction in the HRQOL (Hughes, 2004; O' Keefe & Wood, 1996; Wachtel et al., 1992). Results in some of the studies reviewed in Table 2.10 have suggested that HRQOL is not associated with clinical status but with symptoms that result from the HIV disease (Low-Beer et al., 2000) . The more recent studies have assessed how HAART has affected HRQOL (Carrieri et al., 2003; Jelsma et al., 2006). Some of the results are shown in the Table 2.9 above. Carrieri et al. (2003) established the baseline for patients who were commencing on HAART and found that patients who had been HIV positive for a long time and older did not improve in their HRQOL (Carrieri et al., 2003).

Physiotherapy as part of rehabilitation is concerned with restoration of function and function is closely related to HRQOL (Bauer, 1993; Stucki, 2005). All the theories and models that are reviewed below strive to show the pathways from disease or active pathology to various functional consequences. In order to influence function and HRQOL, physiotherapy builds on principles that acknowledge the social contextual and cultural aspects associated with people's health and health-related states (Davis 2006). The ICF (WHO, 2001).and the Nagi disablement process (American Physical Therapy Association (APTA), 1997) are current models used by physiotherapists to guide practice. The understanding of disability and health-related states have developed from a purely medical pathology and impairment focussed approach to one closer to the ICF. Section 2.5 outlines the development of rehabilitation theories and how they have evolved. It is necessary to review the development of physiotherapy theories in order to appreciate the role of physiotherapy in HIV and consequently the inclusion of HIV in the physiotherapy curriculum.

2.6 PHYSIOTHERAPY THEORIES AND HIV

All the conditions mentioned in section 2.2-2.5 affect the patient physically, psychologically, socially and eventually socio-economically. As mentioned above, rehabilitation is concerned with the restoration of function, and improvement of quality of life in all these aspects of a person's life (Stucki, 2005). HIV affects the body starting at the cellular level, to organs, to body systems and finally body functions. Physiotherapists and other rehabilitation professionals concern themselves with the continuum of function (Cott et al., 1995). For the profession to link the aims of physiotherapy with the pathological processes that take place

in disease, one of the early proponents of physiotherapy theory Helen Hislop (1975) suggested the following theory of pathokinesiology which conceptualised movement as occurring at six different levels of the human organism namely: cells, tissues, organs, systems, persons and family (Hislop 1975).

Two basic arguments suggested for her theory are reviewed;

- The first one states that physiotherapy, studies the pathokinesiology as a distinguishing clinical science. This is the study of anatomy and physiology as it relates to abnormal human movement and provides a rational explanation of human motion disorders. Physiotherapy in this context contains a scientific and empiric thought that can be applied to the treatment of a variety of disorders.
- The second one states that says physiotherapy can claim to place the role of exercise in health and disease in a scientific focus and perspective (Hislop, 1975).

The following section will describe the different theories and some of the mid-level models, referred to in the literature as mid-range theories that have been used in physiotherapy. The literature will illustrate how they have developed historically. All literature on curriculum development refers to the need for examining the theoretical underpinnings of a profession so as to guide the inclusion of new information that will affect practice of the given profession (Akker Van Den, 2003; Sarr, 1991). Nixon and Cott (2000) do state that physiotherapy practice in HIV has not had clear philosophical guidance. Apart from guiding the inclusion of new information it is important to ensure that the information itself remains grounded in the physiotherapy philosophy. The development of physiotherapy theory has moved away from the medical perspective and become more bio-psychosocial, therefore the move to fully embracing the international classification of function (ICF).

Hislop's (1975) uses the hierarchy of systems for study and analysis of human structures and function as they relate to physiotherapy. Each of the levels shown in Figure 2.2 is a subsystem of the level above and a system in its own right. Hislop (1975) considers health as the smooth functioning of the interrelated systems (connected by what she refers to as cybernetic loops) and that disease results from the disturbance through any force that upsets the balance of each level/system either individually or at multiple levels.

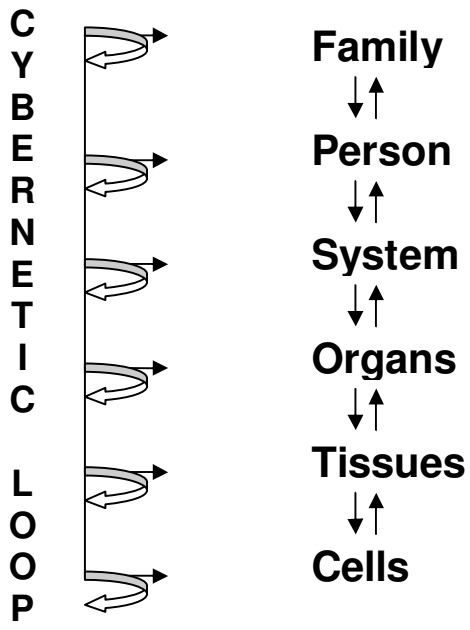


Figure 2.2: The hierarchy of systems for study and analysis of human structure and function as they relate to physical therapy adapted from (Hislop 1975)

Hislops' theory was criticised for being two-dimensional and silent on contextual and environmental issues (Cott et al., 1995). It is described as two-dimensional in that it recognises the levels within the human organism and the physiotherapy interventions. The ICF on the other hand takes levels within the human organism further and provides the link with the context and environment (WHO, 2001). The ICF is discussed fully in section 2.8. Other theories and models have emerged that are based on or support the theory underlying the ICF and emphasise the relationship between impairment and functional limitation as the primary focus of physiotherapy (Cott et al., 1995; Guccione, 1991; Schenkman & Butler, 1989). The connection between movement and function cannot be disputed (Komi 1984) and this may form the fundamental link. Cott et al. (1995) developed the movement continuum theory of physiotherapy that moved further to make linkages between the person and his environment and also linked the different levels within and outside the person's body.

The purpose was to develop a theory that met the following criteria:

"Must be central and unique to physiotherapy, broad enough, apply to all aspects of physiotherapy must be able to inform research and education and must apply to current and future physiotherapy practice." (Cott et al., 1995)

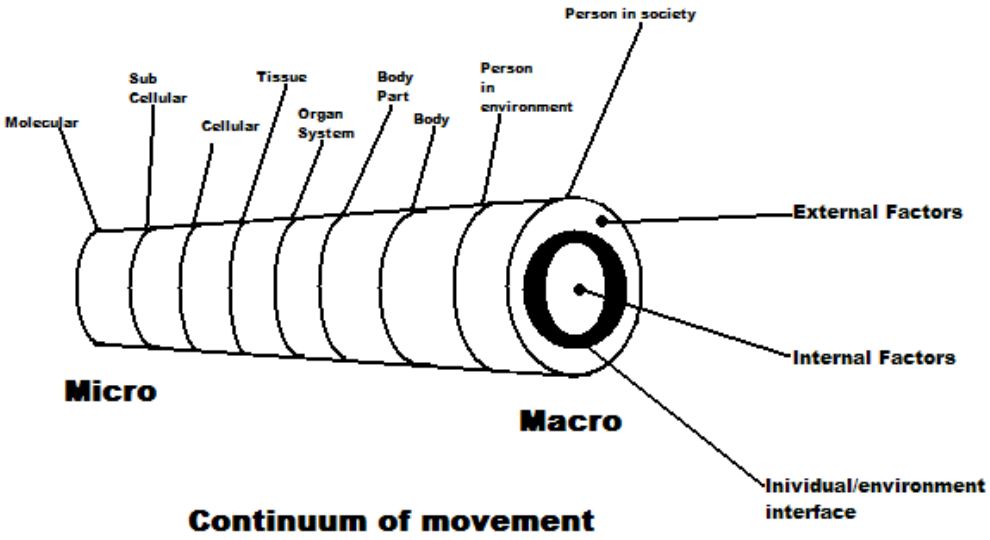


Figure 2.3: Multi dimensional movement continuum (Adapted from (Cott et al., 1995)

Cott et al. (1995) explain that the concurrent circles represent a pathway suggesting that influences at any level are not static and can affect movement in different ways. The model is multidimensional longitudinally, has entry points along the continuum, and cross-sectionally represents influences at any level of the continuum.

The movement continuum theory provides a broad conceptualisation of physiotherapy that subsumes existing mid-range theories(Harris & Dyreck, 1989; Schenkman & Butler, 1989). It builds on Hislop's theory by developing the notion of movement on a continuum to include more macro-level influences. The key concept in this theory is movement on a continuum occurring at different levels. This movement is multidimensional and has internal and external factors that may affect both the quality and quantity of movement. Physiotherapists conceptualise movement on a continuum that incorporates physical and pathological aspects with social and psychological considerations. The movement continuum theory consists of nine principles: There are three general principles and six specific to physiotherapy.

General Principles:

- “Movement is essential to human life
- Movement occurs on a continuum from a microscopic level to the level of the individual in society.
- Movement levels on the continuum are influenced by physical, psychological, social and environmental factors “

These first three principles are shared by other movement sciences (Cott et al., 1995).

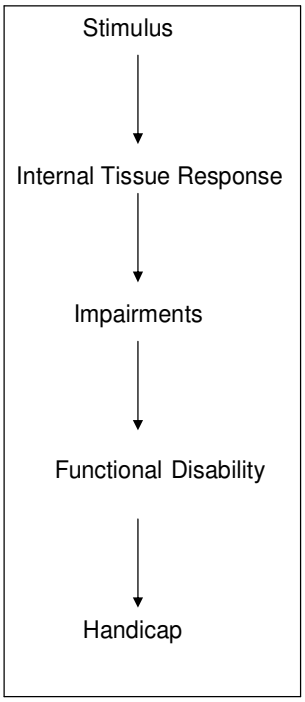
Physiotherapy Principles:

- Movement levels on the continuum are interdependent
- At each level on the continuum, there is a maximum achievable movement potential (MAMP) which is influenced by the MAMP at other levels on the continuum and physical, social, psychological and environmental factors.
- Within the limits set by the MAMP, each human being has a preferred movement capability (PMC) and a current movement capability (CMC) which in usual circumstances are the same.
- Pathological and developmental factors have the potential to change the MAMP and or create a differential between the preferred movement capability (PMC) and the current movement capability (CMC).
- The focus of physiotherapy is to minimize the potential and or existing PMC/CMC differential.
- The practice of physiotherapy involves therapeutic movement modalities, therapeutic ice application, education, technology, and environmental modifications (Cott et al., 1995)”.

Cotts’ theory was preceded by two mid level models that were informed by the ICIDH the predecessor of the ICF. These two models were used to analyse the aetiology of dysfunction specific to orthopaedics (Harris & Dyreck, 1989) and neurology (Schenkman & Butler, 1989).

Models of Orthopaedic and Neurological Dysfunction

(Harris 1989) **(Schenkman1989)**



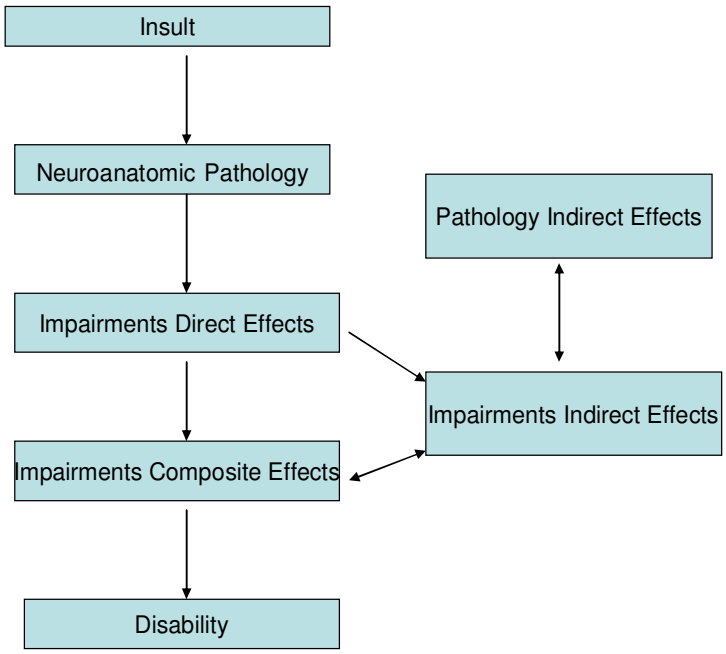


Figure 2.4a Figure 2.4b

Key Figure 2.4a: Overview of model of orthopaedic dysfunction

Figure 2.4b: Outline of model for evaluation interpreting and treating individuals with neurological dysfunction

Schenkman and Butlers' (1989) and Harris' (1989) models were developed as an alternative to the traditional medical model and as a tool to analyse the causes of dysfunction and subsequently make decisions on intervention. Both models are based on the concept of stimulus causes response and the internal tissue responses result in dysfunction (Schenkman & Butler, 1989). The early model of the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH 1980) informed their terminology.

Cott et al. (1995) explains that the physiotherapy profession considers the effects of different pathologies on movement and how internal and external factors such as family and social circumstances impact on movement (Cott et al., 1995). Cotts (1995) model' standpoint is from two perspectives i.e. ***"an understanding of physiological functioning and the effects of pathology on the body and second an understanding that movement must be considered in both the individual social-psychological context***

and the larger physical and social contexts." These contexts shape how individuals perceive movement and their subsequent response. The theories put forward by Hislop (1975), and Cott (1995) are similar to Schenkman and Butler (1989) (Fig2.4b) and Harris and Dyrek (1989) (Fig 2.4a) in that they all refer to the interrelatedness of movement and components of impairments, that are ultimately related to activity and participation. Current guide to practice still relates to these theories but has evolved further to embrace models such as Nagis' model (1997) and the ICF. Both these models look at the person's health status and take the disablement process into account. Nagis' development model has four components i.e. disease, impairments, functional limitations and disability. Functional limitations are a result of impairments and disability results when functional limitations become severe enough to limit the persons age-specific expectations within a social and physical environment (Martin & Kessler, 2007).

As with any other condition, HIV has pathological and physiological effects on a person at multiple levels (Moylett & Shearer, 2002) that will affect the function of the person in his environment and society (Flaskrud & Ungvarski, 1999).

In all the theories and models reviewed above, movement and the impact of various external and internal variables (referred to as insults and stimulus by some authors) on movement remains the central focus for physiotherapists (Harris & Dyreck, 1989; Schenkman & Butler, 1989). The multiple levels at which movement is affected is of importance to physiotherapists in their interventions (Cott et al., 1995). The different theories and models (Shenkman and Butler, 1989; Harris and Dyrek, 1989), developed so far all emphasize the need to understand the normal and abnormal responses of the human body to stimuli (pathologically in a direct or indirect manner) (Cott et al., 1995). Shenkman and Bultler's (1989) model outline how injury or insult result in pathology which result in indirect and direct impairments and which in turn have a direct or indirect impact on functional disability but can be criticised for being unidirectional.

The interrelatedness of these different levels is underscored in the grand theories developed by the WHO (2001) within the ICF and in the movement continuum theory (Cott et al., 1995). As shown by Worthington (2005) in her model for HIV, it is important for the physiotherapist to realise the importance of working at multiple levels of intervention in order to make an impact on the effect of injury or diseases such as HIV. Shenkman and Bultler's (1989) model outline how injury or insult result in pathology which result in indirect and direct impairments and which in turn have a direct or indirect impact on functional disability, but can be criticised for being unidirectional.

2.7 PHYSIOTHERAPY PRACTICE AND HIV

In a Mary McMillan lecture delivered at the 51st annual conference of American Physical Therapy Helen Hislop said in establishing the identity of the profession, "it is a matter of who is to say, what we can do, what will we do and what must we do". In this lecture, Hislop (1975) reflected on the need for the profession to change and keep up, in saying "***for truth changes as new knowledge sheds light on old shadows"*** (1975).This begs the question that if HIV has emerged as a new condition of such wide influence and proportions, (UNAIDS, 2001-2008) over the past 25 years, and physiotherapists have treated people with HIV (Coates, 1990; Lang, 1993; Ungvarski et al., 1999) what role have physiotherapists have played and how should the education system of physiotherapy respond to this new situation? The precise role of physiotherapists in HIV has not always been clear and has not always had a clear philosophical overview to guide its practice and growth (Nixon & Cott, 2000).

Coates (1990) in her original article in which she gives guidance to physiotherapists in dealing with HIV infection and AIDS, said physiotherapists must have an understanding of the natural history of the virus, transmission routes, consequences, and treatment of infection. Physiotherapists must acquire appropriate and adequate knowledge of HIV in order to counsel, treat and make a meaningful contribution to HIV management. This is in line with other conditions that physiotherapists see traditionally and therefore means physiotherapists need an understanding of the aetiology, pathology as well as information on physiotherapeutic principles (Coates, 1990).

Patients who have HIV disease may be referred to physiotherapy (O'Dell & Sasson, 1992), for the management of problems that are directly or indirectly related to HIV. The main modality of intervention utilised by physiotherapists is exercise and activity (Nixon S et al., 2005). In addition, electro physical agents and other alternative modalities are currently under study to determine their impact on the management of symptoms such as pain in HIV (Shlay et al., 1998).

Therefore physiotherapists need to understand HIV pathophysiology in the same manner that they understand other conditions in order to inform themselves and their patients appropriately (Coates, 1990). Some of the roles and areas of need outlined by Nixon and Cott (2000) for physiotherapists are:

- Education of colleagues and PLWH on the benefits of physiotherapeutic intervention.
- Serving the "hard to reach" or "hard to serve populations" of which PLWH are part.

- Physiotherapy curricula must evolve to meet the needs of PLWH
- Another area in whichphysiotherapists have played a role is palliative care. Palliative care is defined as an approach to improve the quality of life in patients and their families who face problems associated with life threatening diseases (WHO, 2004).

As hypothesized by Hislop (1975) and Cott (1995) each sub-system is interrelated, their function is expressed in motion and when this motion is disturbed, homeostasis is disrupted. If motion ceases at the lower levels, destruction of function or even death results and if motion is disrupted at higher levels, signs of disuse and in-coordination ensue. Against this background, Hislop (1975) maintains that the purpose of physiotherapy is to:

"Restore motion homeostasis to the person or his subsystems or to enhance the adaptive capacities of the organism to permanent impairment or loss." (Hislop 1975)

In order to prescribe appropriate interventions the physiotherapist and rehabilitation professional need to understand the spectrum of disease and associated problems. The impact of the main modality, that is, exercise used by physiotherapists must be understood as discussed in section 2.6.1 and also how HIV influences its prescription (Kietrys, 2002). Drake et al. (2002) propose that many rehabilitation populations show better outcomes with early rehabilitation intervention and that this may be true for the growing HIV positive and AIDS rehabilitation population (Drake & Burnett, 2002).

2.7.1 Physiotherapy and Rehabilitation Interventions in HIV/AIDS

Only a few randomised controlled trials were found in this review that documents the effectiveness of physiotherapy interventions in PLWHs. In the area of exercise, there is stronger evidence based literature with a a level one of evidence (Dudgeon et al., 2004; Nixon et al., 2005; O'Brien et al., 2005; Stringer, 1999). This is discussed below under 2.6.1. Other physiotherapeutic modalities such as massage (Henrickson, 2001), electrotherapy, (Posner et al., 2004) manual therapies (Harris-Love & Shrader, 2004). and holistic rehabilitation approaches (Nixon & Cott, 2000) have much weaker levels of evidence (levels 3, 4 and 5). The available literature on physiotherapy interventions is discussed in the following sections.

2.7.1.1 Exercise and HIV

Physiological impacts of HIV infection that have been addressed by exercise or that may influence the prescription of exercise include:

- Muscle changes resulting in wasting syndrome (Dudgeon et al., 2004)
- Changes leading to lipodystrophy (Mutimura et al., 2007)

- Slowing protein degradation caused by direct and indirect HIV infection due to elevated cytokines resulting in decreased lipase activity, energy stores and food intake (Cade et al., 2003; Cade et al., 2004)
- Anaemia due to the inhibited production of erythropoetin (Dudgeon et al., 2004)

Several reviews document the effects of exercise in HIV (Dudgeon et al., 2004; Kietrys, 2002; Nixon et al., 2005; O'Brien et al., 2005; Stringer, 1999) and from these reviews, the preferred benefits of exercise in people with HIV are:

- An improvement in aerobic capacity/ fitness and cardiorespiratory and cardiopulmonary health
- Maintenance of or improvements in lean body mass or weight
- Effects on immune function indices
- Effects on mood/well-being
- Changes in body image
- Reduce disabling consequences such as fatigue, physical disability and health problems caused by HIV (Cade et al., 2003; Cade et al., 2004; Stringer, 1999)
- Improvement in patients HRQOL (O'Brien et al., 2005; Stringer, 1999)

Effects of Exercise on Aerobic Capacity and on the Cardiopulmonary System

Exercise effects on Aerobic Capacity

Stringer identified two factors that contributed to exercise limitation in HIV infected individuals: Maximum oxygen uptake (VO2max) is reduced to approximately 70% of predicted values and lactic acidosis threshold reduced to below predicted values. However, people who are HIV positive and pre AIDS can have these physiological impairments reversed and therefore maintain normal values (Stringer, 1999). Another benefit of exercise intervention found was the improvement of aerobic fitness that may be of clinical significance. The current exercise prescription for aerobic exercise in HIV infected persons includes work at 75% of VO2 Max or 60%-85% maximum heart rate three times a week (Dudgeon et al., 2004). However, the studies testing this intervention had small sample sizes and large drop-out rates (Nixon et al., 2005). The conclusion was that aerobic exercise training three times a week for one hour (moderate or heavy intensity) significantly improves aerobic capacity without detrimental effects to the immune system (Stringer 1999) and ultimately aerobic exercise was considered safe and beneficial for adults living with HIV/AIDS.

A recent study by Galantino et al. (2005) studied the usefulness of Tai Chi exercise and group aerobic exercise to determine strategies and exercise guidelines for long term care of people with HIV. Outcome measures such as function (functional reach and sit up tests, climbing stairs), psychological coping and social interaction were used. The study showed statistically significant improvement in HRQOL and functional outcomes when the two intervention strategies were compared with the control group. No sample size calculation was done for the two interventions (group aerobic exercises and Tai Chi); no differences were found between Tai chi exercise and group aerobic exercise. This study only had 57% power to detect a medium size effect. This is a major limitation for this study but it is compensated for by the use of both qualitative and quantitative data (Galantino et al., 2005).

Effects of Exercise on the Cardiopulmonary System

Physiotherapy in cardiac rehabilitation is well described and provides some insight into evaluation and physical management of people with cardiac abnormalities related to HIV (Cade et al., 2003; Cade et al., 2004). Clinically significant positive changes have been reported in the VO_2 max, total time to voluntary exhaustion, aerobic capacity and decreases in heart rate (Mutimura E et al., 2008a; O'Brien et al., 2005; Rigsby et al., 1992).

Effect on Immune Function Indices

O 'Brien et al. (2004) assessed 10 studies that used CD4 count as an outcome. There was a variation of results between the different exercising groups. Overall no significant difference in the CD4 count between the exercising group and non exercising group was found. The three groups of exercise were the exercising group versus:

- Any type of aerobic exercise- no difference (the weighted difference was 14mm^3. 95% CI -26, 54, n=209).
- Constant aerobic exercise - no difference (the weighted difference was -4mm^3. 95% CI -50, 42, n=164).
- Interval exercising group non significant difference (the weighted difference was 70mm^3. 95% CI -26, 54, n=209).
- Similar results showing small or no increase that was non-significant in CD4 count were reported in a meta-analysis of progressive resistive exercises and combinations of progressive resistive exercises.

Despite this the overall benefits of exercise are still reported as having potential clinical and functional benefits to the person living with HIV.

Effect of Exercise on Weight, Body Composition and Body Image

Progressive resisted exercise or a combination with aerobic exercises compared to a non exercising group demonstrated through a meta-analysis a significant increase in body weight of 3.54kg (95% CI: 2.21 ,4.87 n=68). The same exercise regime, mentioned above conducted at least three times a week for a minimum of four weeks seems to be safe and may lead to statistically and possibly clinically important increases in body weight and composition (O'Brien et al., 2005). Dudgeon et al. (2004) conclude that a programme of progressive resisted exercise results in an improvement of muscle strength, endurance, body composition and mood without compromising the immune system (Dudgeon et al., 2004).

Using the same exercise regimen as described for body weight, a meta-analysis conducted by O'Brien et al. (2005) demonstrated significant changes in body composition where an increase in arm and thigh girth was reported (7.91 (95% CI 2.18,13.65,n=46.). A recent study showed positive results in diminishing the negative HAART related body fat redistribution effects. Positive effects were shown in body composition i.e. weight circumference and waist hip ratio as well as specific skin fold thickness (Mutimura et al., 2008c). The effects of exercise on muscle can be placed into two categories in the studies reviewed by O 'Brien et al. (2005) the focus was on the effect of exercise on muscle bulk while the effects measured by Mutimura et al. (2008c) are concerned with body fat redistribution a condition related to HAART.

Effects of Exercise on the Musculoskeletal System

Related to the body composition exercise has been suggested as an intervention to counteract muscle wasting associated with the progression of disease. Some of the improvements recorded in trials included improved anthroprometric measurements, and muscle performance (Galantino et al., 1998), improved strength and body mass (Rigsby et al., 1992; Roubenoff et al., 2001; Roubenoff et al., 1999). A combination of exercise and hormonal therapy has also been studied and found to be beneficial to lean body mass and strength (Bhasin et al., 2000; Grinspoon et al., 2000; Sattler et al., 1999). These studies were randomized into an intervention and a non-exercising control group. Progressive resisted exercises combined with aerobic exercises were given as an intervention and a resultant increase in strength was observed. None of the studies documented a sample size calculation. They did however report high drop-out rates which compromises the quality of the studies.

Effect on Mood/Well-Being

All the studies that measured the mood, well-being, body image and HRQOL used different outcome measures. MacArthur et al. (1992), reported improved scores for VO_2 max, oxygen pulse and improvement on the mental health inventory for participants who adhered to their exercise programme. A programme of progressive resisted exercise reported an improvement in mood (Dudgeon et al., 2004). Despite some major limitations, in particular a high drop-out rate, the results demonstrate a beneficial effect that may have clinical significance.

Effect on Disabling Consequences such as Fatigue, Physical Disability and Health Problems caused by HIV

Exercise was reported to have an impact on fatigue, physical disability, exercise tolerance (Cade et al., 2003; Cade et al., 2004).

Although Cochrane reviews (Nixon et al., 2005; O'Brien et al., 2005) were conducted to determine the effect of exercise in PLWH the authors warn that the results should be intepretated carefully as the studies included were few and fraught with many problems that are listed below.

- High withdrawal rates greater than 15%,
- Variation in characteristics of the studies reviewed (type, rate and intensity of exercise),
- Only seven studies met the inclusion crtiteria which limited the power of the meta-analysis and the variability in outcomes used, methodological quality and exercise regimens,
- Possibility of the Hawthorne effect owing to the difficulty with blinding due to exercise being the intervention,
- Lack of an explicit description of the assessor blinding process, very close follow-up and the interaction with the intervention group,
- Lack of measurement of the patients HRQOL
- The gender representation of the exercise groups with males over represented (Nixon et al., 2005; O'Brien et al., 2005).

In spite of these limitations the Cochrane reviews concluded that exercise appears to be a useful intervention to people living with HIV. The findings showed significant improvements which suggest that the impact of exercise is important as an intervention for improving patients' quality of life as well as maintaining or improving function. All reviews recommend

that future research would benefit from an increased attention to larger samples, participant follow-up and intention-to-treat analysis. In addition, further research is required to determine the optimal parameters of aerobic exercise and stage of disease in which aerobic exercise could be beneficial for adults living with HIV infection (Dudgeon et al., 2004; Nixon et al., 2005; O'Brien et al., 2005). Mutimura et al. (2008) in a randomised control trial used a larger sample with better follow up, minimal drop-out rates and has demonstrated that exercise is a inexpensive but efficient intervention for counteracting some of the metabolic changes occurring due to HAART and also demonstrated aerobic benefits (Mutimura E et al., 2008a; Mutimura E et al., 2008b).

The characteristics of four major reviews found in the literature will be discussed. The type of intervention utilised is discussed and may give physiotherapists better insight into the specific exercise combinations and their effect on some of the HIV-related impacts. The focus of the reviews were progressive resisted interventions (O'Brien et al., 2005) and aerobic exercise (Nixon et al., 2005; Stringer, 1999).The review by Dudgeon (2004) covered a variety of exercise interventions, including aerobic and progressive resisted exercise, between the period 1990 to 2002 (Dudgeon et al., 2004). Stringer (1999) approached his review from a more scholarly perspective and assessed intervention studies, some of which were randomized and others were not. Nixon et al., (2005) and O'Brien et al. (2005) followed the Cochrane reviews guidelines and covered literature from 1980 to 2003. The four reviews were similar in the parameters they extracted, i.e. authors, subjects, sample populations, intervention and results. However, only the reviews by Nixon et al. (2005) and O'Brien et al. (2005) included a meta-analysis. According to Disler et al. (2002) in grading rehabilitation literature, any systematic reviews of randomized control trials are evidence level one (Disler et al., 2002). Study limitations included low statistical power of the studies, variability in the interventions with regard to type, duration frequency and intensity of exercise needed to elicit a physiological and psychological change in an HIV population. In addition many of the studies reported high drop-out rates due to patient illness and even death. Despite the study limitations as outlined above, significant improvement was reported in terms of the beneficial effects of exercise and therefore could be used to inform service delivery (Dudgeon et al., 2004; Nixon et al., 2005; O'Brien et al., 2005; Stringer, 1999).

The reviews conclude that exercise in general is of benefit to the persons infected with HIV with small but significant improvements in immune function and quality of life. Some of the specific conclusions from the reviews were discussed in section 2.6.1.1 above.

Besides exercise there are other physiotherapy modalities that have been used as interventions in the management of HIV. Some of the modalities are discussed in the paragraph that follows.

2.7.1.2 **Physiotherapy modalities and HIV**

The contribution of other physiotherapy interventions with the exception of exercise are in the developmental stage and are reviewed to ascertain the evidence that is available to determine what interventions are effective. Of note is the mixture of alternative therapies and conventional physiotherapy interventions.

Most studies are at a level 3, 4 and 5 on the evidence rating scale (Disler 2002), are descriptive with no randomisation and used very small sample sizes. Despite these limitations, the clinical implications are useful in guiding further research and pointing to modalities that have been found to be effective and useful clinically. Some of the clinical experiences that have been published are reviewed below.

Gale (2003) describes physiotherapy intervention in two cases with AIDS related neuropathy. The patients in the cases presented were treated with joint mobilization, soft tissue mobilization, micro-current, stretching and instruction of a home programme. Both cases responded positively to physiotherapy, reported decreased pain and decreased use of pharmacological intervention. The information reported from these two cases is useful for developing future research and guiding practice. However, the level of evidence is low (level 5) as it is descriptive and does not have any controls, randomization and did not rigorously collect both quantitative and qualtitative data. Despite this, both cases reported improved function (Gale, 2003).

In another study Galantino et al. (1999) reports that from clinical experience, conventional transcutaneous electrical stimulation (TENS), tends to exacerbate peripheral nerve pain in HIV/AIDS. This level 3 prospective study by Galantino et al. (1999) assessed the use of electro acupuncture for the treatment of neuropathic related pain in HIV. Although it had a relatively high drop-out rate (11 patients and only 7 with complete data), the results of the study may point to TENS potentially counteracting the effects of neuromuscular deficits. A larger sample, with a sample size calculation would be required for conclusive interpretation. Other limitations, are a reliance on patient self reported information and lack of a placebo control group.The researchers recommend that future research should explore

the use of additional modes of electrical stimulation such as TENS, and direct current on acupuncture points (Galantino et al., 1999).

A retrospective case control study by (Henrickson, 2001), had three treatment groups namely massage alone, acupuncture alone and massage and acupuncture that were matched to subjects who were not receiving these therapies. The study reports improved clinical outcomes such as increased CD4 counts for the massage group when compared to the group receiving massage and acupuncture. In addition, the subjective experiences of the treatment and non-treatment group were sought in a portion of the sample and positive experiences of pain reduction, increased energy levels, improvement in sleep and reduced anxiety were reported. It is difficult to make any definite conclusions from this study as larger samples and attention to some of the limitations of this study needs to be undertaken. This study had large variability in the subjects, selection bias, the number of treatments and lack of standardization of treatments received because they were individually tailored. However, as the authors point out, to ensure a perfect design in the current HIV management model may be problematic. They explain that some of the challenges include the patient variability, due to the nature of the condition and the need for adherence to treatment and service delivery guidelines (Henrickson, 2001).

Despite challenges described in these studies and clinical experiences, some positive clinical effects were reported. However, the studies reviewed above, have not evaluated the impact of these modalities on function as well as carry-over effects and long term efficacy of the different approaches. The current models of rehabilitation and management of HIV and other chronic conditions, require that physiotherapists focus on the relationships between impairments, functional limitations and the person's ability to carry out everyday activities (Martin & Kessler, 2007). To apply these modalities and make an impact on the patients' functional ability physiotherapists need to understand service delivery models and how physiotherapy can make an impact.

2.7.1.3 **Service delivery models in HIV- entry points for physiotherapy**

South Africa is a developing country (Human Development Report 2006). In its HIV/AIDS strategy, the Department of Health has set goals addressing the pandemic comprehensively through a continuum of care. Strategies that address primary care needs for PLWH are:

- HIV testing and counselling
- Antiretroviral therapy for adults, adolescents and paediatric patients
- Treatment of sexually transmitted infections and opportunistic infections (Department of Health, 2007b). There is little mention of the management of patients with regard to the impacts of the conditions and the resultant impairments.

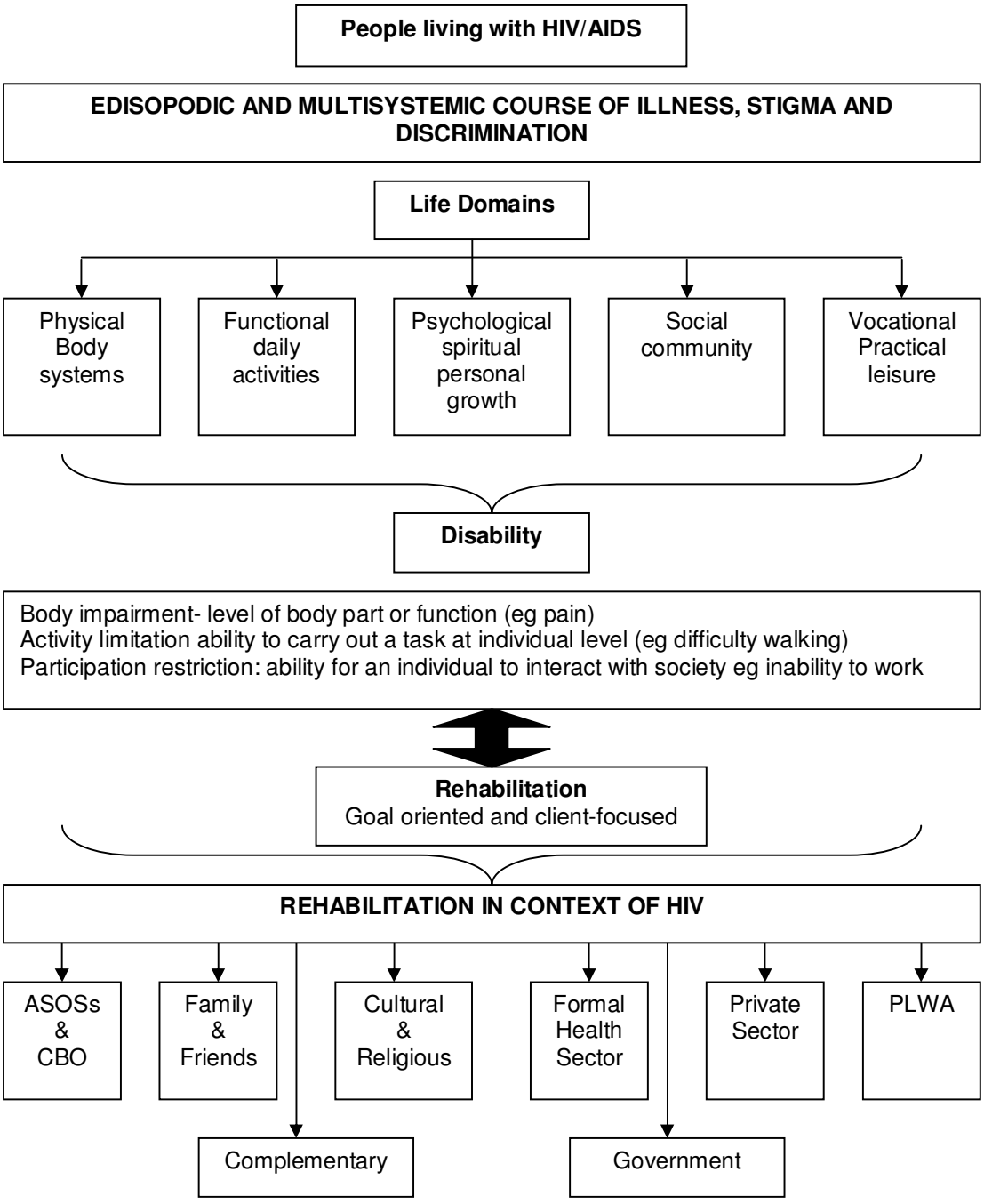
In countries and areas where there have been advances in disease monitoring and the introduction of ARVs and HAART, the approach to HIV management has shifted from services that focus on the management of impairments only, to dealing with the effects of HIV chronicity. In South Africa the ARV rollout as mentioned before has not reached optimal levels (Ndlovu & Daswa, 2006). Therefore a two-pronged approach to service delivery, which embraces HIV management that focuses on impairments and HIV as a chronic condition, is needed.

- The first approach should be short term, crisis oriented, focused on symptom management and palliative treatment.
- The second approach should shift focus to out-patient services and change health care services from hospital care to a more integrated delivery system that includes both acute and long-term community and home-based care (Uphold et al., 2007). Uphold (2007) in a review of the service utilization among PLWH notes that research has turned its attention from hospital and out-patient based utilisation patterns to the investigations of nursing home services, home health care, community based care and rehabilitative services (Uphold et al., 2007).

In South Africa rehabilitation and physiotherapy services are delivered in a variety of different ways, namely institutional, in and out-patient, outreach, community and home based care (Van Rooijen & Van der Spuy, 2000). Physiotherapists traditionally form part of most rehabilitation teams.

Once a physiotherapist is involved in these service delivery models, the role is expanded beyond dealing with impairments to responding to the person in a bio-psychosocial context as illustrated in the following framework (Figure 2.5) (Worthington et al., 2005). This framework, although reflecting the opinions and views of HIV providers in Canada, may be a useful starting point for the rehabilitation professional in other contexts. It links the broader context of HIV, the approach taken by rehabilitation professionals and their response to the life domains impacted on by HIV. The impact and outcomes of such influences are episodic

and will change from time to time depending on the patients' response to treatment and other external factors such as stigma and discrimination.



Worthington et al. 2005 (permission granted for reproduction August 2007)

Key: ASO- AIDS service organisations CBO- Community based organisation

Figure 2.5: HIV/AIDS Rehabilitation Framework

Expected outcomes of a physiotherapist's intervention are the improvement of independence in the home and the community as well as improvement in the person's HRQOL. Physiotherapists may identify risk factors in order to facilitate functioning and delay or stop the disablement process (American Physical Therapy Association (APTA), 1997; SASP, 2007).

Physiotherapists involvement in HIV within a particular context such as the community or special clinic may involve working with AIDS service organizations, community based organizations, family and all the key players outlined in the framework (Fig. 2.4). This implies the need to work with these important players and most critically, the person infected with HIV, and in the process educate and ensure the role of the physiotherapist is understood by all involved (Worthington et al., 2005).

In addition to understanding HIV within the context of rehabilitation, it would be incomplete and even grossly lacking, if the episodic nature of HIV did not transcend the understanding of the condition within the ICF concept. O' Brien (2007) presented results from a qualitative study on the episodic nature of HIV and highlighted the changing experience of the person living with HIV/AIDS (O'Brien et al., 2007). In the model of chronic illness developed by Corbin and Strauss (1992), they state that:

"The management of chronic conditions is more than just a matter of controlling symptoms, or living with disability or adapting to the psychological and social changes that long term incurable illness brings to the lives of afflicted individuals and their families. It is all these and more" (Strauss & Corbin, 1992).

Corbin and Strauss (1992) developed a trajectory model that proposes that chronic illnesses have a course that changes and are varied over time. The model recognises that the biographical needs and the performance of everyday activities may affect the choices made by patients about illness and this may eventually influence the direction and course of illness.

In this model, the term trajectory is used to explain the illness course and is used to connect all other concepts within the framework. The term trajectory has four subsets i.e:

- Trajectory - depicting the course that requires the efforts of the individual, family and health care professional to shape it.

- Trajectory phasing - different changes in status that the condition undergoes i.e. improvements and deteriorations as well as the daily fluctuations. These phases may be depicted by the terms pre-trajectory, trajectory onset, crisis, acute, stable unstable downward and dying.
- Trajectory projection - the vision of the illness depicted by questions on outcomes, how long, how far for both the individual and the health care professional.
- Trajectory scheme - plan to handle consequences of illness such as symptomatology, disability and overall illness course.

Two specific applications for health care professionals within this model have been proposed. The first one is that HIV should be viewed as a chronic disease. The second is an awareness of the two points of crisis for the patient i.e when one learns of their status and when they start showing symptoms. Due to the problems of stigma the health worker needs to be aware of the need for education to avoid alienation or hostility in and outside the home (Nokes, 1998).

2.8 DESCRIPTION of MEASUREMENT TOOLS

This section of the literature review looks at the literature concerned with the research tools that were used in collecting patient data.

2.8.1 Definition of Terms

In the management of HIV/AIDS, the focus of attention has moved toward symptom management and improving quality of life (Meynell & Barroso, 2005). It is for this reason that physiotherapists and other rehabilitation professionals should become more involved in the management of HIV and each define clearly what role they could play (Nixon & Cott, 2000; Zonta et al., 2005). A comprehensive framework from which rehabilitation theory and practice is currently approached is the International Classification of Function (ICF) (Stucki et al., 2002).

As a prerequisite to understanding the application of the ICF the terms rehabilitation, disability, ability and function, need to be reviewed to establish the current thinking around these terms:

2.8.1.1 Rehabilitation

A number of authors have defined the term rehabilitation (WHO 1981, Stucki et al., 2002, (Steiner et al., 2002). Stucki (2002) outlined rehabilitation as a process that involves the identification of problems and needs, and relates these problems to impaired body functions

and structure, personal factors and the environment (Stucki et al., 2002). Davis et al. (2006), also emphasised the process nature of rehabilitation saying it is an active, dynamic and continuous process concerned with the physical, social and psychological aspects of the individual (Davis, 2006). This cyclical process is supported by Steiner et al. (2002) who identified five stages of rehabilitation namely identifying problems and needs, relating problems to factors that are limiting, defining target problems, planning, implementing and coordinating interventions and assessing effects (Steiner et al., 2002).

2.8.1.2 **Disability**

The goal of rehabilitation will depend on the person's disability. The early definition of disability given by the WHO *(1980)* and recommended for common use is:

"Disability in the context of the health experience - a disability is a restriction or lack of ability, resulting from impairment, to perform an activity in the manner or within the range considered normal for a human being. Davis (2006), has discussed the term disability extensively, quoting a survey conducted by Baker et al. (1997) who outlined how disability is identified as being a dramatic change in life for the individual with the new needs being met by rehabilitation. Steiner et al. (2002) discusses the need to use appropriate language such as "persons with disability" as opposed to "the disabled" and concedes that this may be a contentious term as socio-cultural settings may influence the definitions and interpretations of terms such as disability or rehabilitation (Davis, 2006). However, the WHO (2001) gives a more definitive definition for disability: "*the umbrella term for impairments, activity limitations or participation restrictions"*. Though disability as a concept remains the same when dealing with HIV, it is important to establish the difference in its presentation in HIV.

2.8.2 **Dimensions of Disability in HIV/AIDS**

O' Brien (2007) defines a framework in which disability in HIV has been conceptualized to be episodic. In this framework, an individual defines health at baseline and then throughout the HIV disease stages may experience a series of episodes of disability. There are external and internal influences that can either exacerbate or alleviate these episodes. Some of these influences include: the level of support; stigma, and living strategies (social interaction; lifestyle; nutrition; sleep; a sense of purpose; maintaining a sense of control; planning for the future) and attitudes and beliefs. In addition to these are the non-modifiable characteristics such as age, gender and co-morbities (O'Brien et al., 2007). This conceptualisation is in line with the model for chronic illness management based on the trajectory framework proposed by Corbin and Strauss (1992). The framework is based on

the idea that chronic conditions have a course that varies and changes over time (Strauss & Corbin, 1992). The WHO (2001) proposes that non-problematic aspects of health and health-related states should be summarised under the term *functioning*. The link between impairments and functional disability has been illustrated in a number of models and theories described in the physiotherapy literature in section 2.5 (Cott et al., 1995), Hislop 1975, Harris and Dyrek 1989, Schenkman and Butler 1989). Some of the needs emanating from impairments experienced by PLWH and identified from the literature include pain and breathing difficulties. Health workers indicate that they manage patients with HIV experiencing breathing problems by using the routine of positioning, clearing the airways, oxygen and bronchodilatation (Uys, 2003). Care protocols for these symptoms are emerging. Ungavarski et al. (1999) describes the symptom management included in the long-term management and care progammes of HIV in the USA. Table 2.10 gives a summary of the symptoms that Ungavarski et al. (1999) have managed with the assistance of physiotherapists.

Table 2.10: Symptoms Managed with the Help of Physiotherapists

(Ungvarski et al., 1999)

Symptom	Aetiology	Assessment	Goals	Planning Care Health Teaching	Evaluation Tools
Fatigue	-Chronic HIV infection, secondary opportunistic infections, anaemia, malnutrition prolonged immobility metabolic disorders	-Subjective data for example -history of S&S treatment, -Objective data- for example exercise tolerance before and after activity	-Awareness of fatigue factors affecting exercise tolerance -Activity and rest plan -Life style- promoting activity and ADL	Non- pharmalogic intervention for example daily fatigue register & exercise. programme	-Symptom distress scale -Visual Analogue Scale to measure fatigue
Weight Loss	-Increased nutrient requirement from HIV &/secondary infections including intestinal infection primary and secondary -Decreased food intake	Anthropometrics (height, weight), biochemical, clinical nutrition screen - Nutrition screening tools -Economic/social	-Interventions to stimulate appetite, increase weight., preserve lean muscle mass and provide adequate levels of nutrition	-Non pharmacological intervention - for example nutritional change strategies. -Pharmacological and complementary interventions	-Chart for weight maintenance gain -Identification of sufficient and appropriate resources
Pain	-Localized pain in bone, nerve or organ possible causes: infection or tumor Arthralgia or myalgia, -Autoimmune response to HIV infection Pain related to other conditons for example diabetes	Subjective -Pain history -Opiod tolerance -Patient knowledge of pain management -Objective: heart rate, blood pressure, respiratory rate, ability and willingness to participate in ADL	-Reduce incidence and intensity of pain -Communicate with the patient regarding pain patterns and experience -Enhance comfort and satisfaction	-Identify activities that aggravate pain -Provision of comfort enhancing measures, for example pressure relief and support -Physiotherapy i.e. exercises ultrasound. therapeutic massage, use of TENs	
Dyspnoea	-Infections of the respiratory system as described under pulmonary disorders (PCP, neoplasms, lymphocytic interstitial pneumonitis, pneumonias and exercise intolerance)	-Subjective assessment including ADL -Objective assessment- respiratory and cardiovascular assessment. -Clients reponse to ADLs. pulse and or stress oximetry, pulmonary functional testing and chest Xray. -Situational assessment	Identification of factors precipitating dyspnoea - Identify strategies for prevention and control of dyspnoea -Develop a life style programme that encourages involvement in ADL, independence and social activity.	Teaching : - Physiologic therapies that control breathing pattern -Control of responses, for example coping with anxiety, support group participation -Patient education on pacing activities, prevention and cognitive therapies to restructure perception of dyspnoea	-Reduction in objective respiratory measures -Identification of contributory factors - Decrease in the experience of dyspnoea
Impaired Cognition	As result of HIV - induced conditions as outlined under neurological conditions	-Subjective assessment to include problems in memory and change in leisure activities. -Objective assessment outlined by Ungvarski et al. (1999) covers a full neurological assessment.	-Promotion of independence -Identification of factors that contribute to sensory perception -Provision of meaningful and sufficient sensory input -Minimize disorientation -Provide safety	-Assess and reduce causative factors in the institution and community. -Promote: cognitive stimulation and orientation - Independence and self-esteem. -Exercise and safety	The John Hopkins rating scale -Neurobehavioural rating scale -AIDS dementia rating scale

Having defined the terms disability and rehabilitation and the dimensions of disability in HIV the following paragraph discusses the ICF.

2.9 THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

The International Classification of Functioning, Disability and Health is a classification system and can be used in varying situations. Its uses are possibly as a tool for research, statistical, clinical, social policy and educational purposes (WHO, 2001). In line with the principles of classification, the ICF defines its universe, scope, units of classification, organization and how these elements are structured in relation to each other.
Universe - the ICF has a universal application in the broad context of health and does not cover circumstances that are not health-related for example socio-economic, religion or gender.

Scope of ICF - The ICF allows for a description of a situation concerning human functioning and its restriction and serves as a framework to organise this information. It also allows structuring of information in a meaningful, inter-related and easily accessible way (WHO, 2001).

2.9.1 Development of the ICF

The development of grand theory in relation to disablement has been ongoing through the use of the international classification of function (ICF). The preceding model i.e. the International Classification of Impairment Disability and Handicap (ICIDH) model and its terminology explores the relationship between the underlying condition, impairment and disability as a model for assessing the consequences of disease (Badley & Lee, 1987). This classification after a long process of consultation and field-testing was amended and is now the ICF (WHO, 2001) and its main aims are to:

- Provide a scientific basis for understanding and studying health and health-related states.
- Establish a common language among health workers and other stakeholders
- Permit comparison of data across different contexts
- Provide a systematic coding scheme for health information.

2.9.2 Uses of ICF

Therefore given these aims, the ICF does not classify people but describes the situation for each person within the array of health and health-related domains (WHO, 2001).

As a continuation of the ICIDH, the ICF (WHO, 2001) offers a useful framework for studying disablement and health-related consequences of diseases based on the following three concepts: Impairments, (problems with physiological and anatomical functioning at organ or limb level) activity limitations (difficulties in performing tasks) and participation (involvement in life situations). The ICF has been used to frame the manifestations and effects of a wide variety of conditions for example osteoarthritis, rheumatoid arthritis, osteoporosis, CVA , low back pain, depression, chronic wide spread pain, breast cancer, diabetes mellitus obstructive pulmonary disease (Cieza A, 2004) and childhood disability (Simeonsson et al., 2003).

Physiotherapists deal with different problems at various stages of any disease and the ICF (WHO, 2001) allows for a description of disablement through the stages of various diseases (Stucki, 2005 ; Stucki & Grimby, 2004a). Worthington et al. (2005) in developing a conceptual framework for rehabilitation in HIV/AIDS considered the ICF as an appropriate model to adapt as it uses the bio-psychosocial approach and captures several levels of impact of any condition and context. In addition, its universality is an added advantage.

2.9.3 Definition of Terms Used in the ICF

Components - Defined as:

"Being or serving as an element of something" (Random House college dictionary 1998). In the ICF each of its two parts, part one has two components i.e.:

- Part 1 Functioning and disability has components of:
  a) Body Function and Structure
  b) Activities and Participation; activities and participation give a complete range of domains denoting aspects of functioning from both an individual and societal perspective.
- Part 2 Contextual factors; environmental factors and personal factors.

Domain

The domains are a practical and meaningful set of related physiological functions, anatomical structures, actions, tasks or areas of life. Because the ICF considers these different levels, it integrates the two competing and contrasting models, the biomedical and social models of disability thereby making it a bio-psychosocial model (Stucki et al., 2003).

Examples of health domains are seeing, hearing, walking and health-related domains namely transportation, education and social interactions (WHO, 2001).

Two basic lists describe the domains from the perspective of the body, individual and society. They are: 1. Body function and structure

2. Activities and Participation.

The ICF systematically groups different domains for a person in a given health condition, for example what a person with a condition such as HIV or other conditions does or can do (Simeonsson et al., 2003; Stucki et al., 2003). However, the health condition is seen in relation to function and not in a unidirectional cause (Stucki, 2005).

Table 2.11 shows the two main parts of the ICF i.e. part - one dealing with functioning and disability and part - two contextual factors. The body component is classified into functions for body systems and the other body structures but both are organised according to body systems. A list of environmental factors organised from the immediate environment to the general environment is outlined in Table 2.11.

Table 2.11: An Overview of the ICF

<table>
<tr><th></th><th colspan="2">Part 1 functioning and disability</th><th colspan="2">Part 2: contextual factors</th></tr>
<tr><td>Components</td><td>Body functions and structures</td><td>Activities and participation</td><td>Environmental factors</td><td>Personal factors</td></tr>
<tr><td>Domains</td><td>Body functions body structures</td><td>Life areas (task, actions)</td><td>External influences on functioning and disability</td><td>Internal influences on functioning and disability</td></tr>
<tr><td>Constructs</td><td>Change in body functions Physiological

Change in body structures (anatomical)</td><td>Capacity executing tasks in a standard environment

Performance Executing tasks in the current environment</td><td>Facilitating or hindering impact of features of the physical, social and attitudinal world</td><td>Impact of attributes of the person</td></tr>
<tr><td rowspan="2">Positive aspect</td><td>Functional and structural integrity</td><td>Activities participation</td><td rowspan="2">Facilitators</td><td rowspan="2">Non applicable</td></tr>
<tr><td colspan="2">Functioning</td></tr>
<tr><td rowspan="2">Negative aspect</td><td>Impairment</td><td>Activity limitation participation restriction</td><td rowspan="2">Barriers/ hindrances</td><td rowspan="2">Non applicable</td></tr>
<tr><td colspan="2">Disability</td></tr>
</table>

(WHO, 2001), ICF pg 11)

Four distinct but related constructs are used to interpret the components of functioning and disability. By using qualifiers, one can quantify each construct.

The constructs for body structures and functions are described by anatomical and physiological changes in the body respectively. The change, when positive, is termed functional and structural integrity and when negative is termed impairment (WHO, 2001).

For activities and participation, the constructs of capacity and performance are used. Capacity refers to the ability of the individual to perform an activity in a standard environment while performance refers to the individuals' ability to perform activities in the current environment (WHO, 2001)pg 11). In this environment, the physical, social and attitudinal support is taken into account. The environmental component is viewed as external to the individual's health and functional performance and its constructs are explained either positively as facilitators or negatively as barriers as shown in Table 2.11.

2.9.4 The Development of Core Sets

It is very difficult to use the ICF in its entirety hence the development of ICF core sets. The core sets are developed to standardise what is to be measured (Stucki & Grimby, 2004a). In a paper describing the development of the ICF core sets, Stucki (2005) outlines the importance of the ICF as a powerful framework for use in the work towards reducing the burden or consequences associated with health conditions. He proposes the need to address the needs of clinicians and researchers concerned with specific conditions or people in care through the development of specific core sets. He argues that current rehabilitation studies have a wide, varying classification and authors may refer to function in a variety of ways such as physical function, physical functional disability, physical disability, disability, functional limitation or quality of life. Stucki (2005) asserts that the end points of rehabilitation research are often not clear to the reader, leaving the reader to interpret which impairments, activities or restrictions are targeted by an intervention and subsequently which changes in the intervention specifically contribute to the change in the study end point. In conclusion (Stucki, 2005 ; Stucki & Grimby, 2004a) argue for the use of the ICF especially core sets in planning studies to select candidate measures while taking into account content validity (Stucki, 2005 ; Stucki & Grimby, 2004a).

Theoretical Application of the ICF to Specific Conditions

Functioning and disability within the ICF are understood as a dynamic relationship between the condition, the environmental, personal and contextual factors. One of the aims of the ICF checklist is to assess the relationship between these factors. Figure 2.6 outlines this interaction.

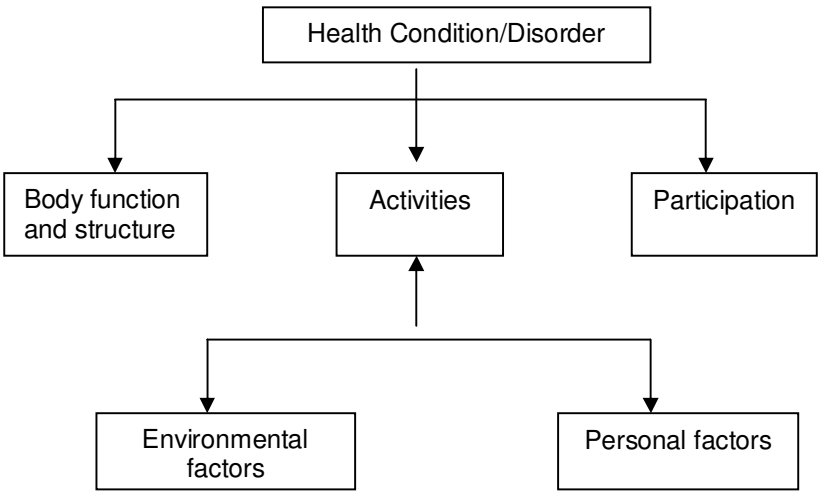


Figure 2.6: The Interaction between Health Disability and Function (WHO 2001)

Arathanat et al. (2004) in a comprehensive literature review on the ICF reviewed its application to cognitive disorders. Theoretically, Arathanat (2004), proposes that the ICF has the potential to classify and interpret cognitive deficits in a manner that allows the clinician to recognise the person's potential for rehabilitation and set realistic goals.
The application of the use of the ICF is demonstrated by analysing the kind of impairments and activity deficits outlined in other studies and demonstrating how they can be interpreted using the ICF. Arathanats (2004), review, demonstrates the use of the ICF using a case study, all other data is from studies done previously and cannot be considered to be truly representative of the application of the ICF. However, the authors do conclude that the true effectiveness can only be demonstrated through practical application (Arthanat et al., 2004).

Fransen et al. (2002), investigated the relationship between measures of impairments, activity limitations and participation restrictions in rheumatoid arthritis (RA). Using the SF 36 as a tool, they found associations between impairments and activity limitations for example pain and activity ($p<0.0001$) and activity limitations with participation restrictions. They found that there was low correlation between disease activity (rheumatoid arthritis) and joint damage and that only previous disease activity may be responsible for joint damage. However, activity limitation and pain were important causes of participation restriction This was a a large cross-sectional study using different tools to identify the impairments activity limitations and participation restrictions in a group of RA patients and it demonstrates the ability of the ICF to be used as a framework to understand the disease consequences of

RA. In this study the ICF is not used directly but the findings are placed in the ICF framework from an existing tool namely the SF36. This process is described as “cross walking”. The results can be considered robust for determining associations as they are based on a large cross-sectional sample (n-803) and validated tools used to cross walk data into the ICF framework (Cieza 2004).

Two studies assessed using the ICF specifically for people living with HIV. Hwang and Nochajski (2003) used a similar approach to Arathanat (2004). The illustration of the use of the ICF was based on a review of existing studies and literature such as Tagliati et al. (2000), Chrystal et al. (2000), O’Dell (1996) and Lopez (1998). A review of these studies, demonstrated how a number of ICF codes can be used to provide a systematic representation of disablement in HIV/AIDS. The results demonstrated the use of ICF codes in the components of body functions and chapters/domains of mental “b1” and neuromuscular and movement related functions “b7”. Furthermore, the uses of ICF codes were demonstrated in activity limitations in the areas of mobility “d4”, self-care “d5” domestic life d6 and major life areas d8. In the component of participation the domains of attitudes “e4”, services “e5” and systems and policies “e6” could be coded. Hwang and Nochajski (2003) concluded that the ICF conceptual framework could be used as a useful tool for identifying the nature and magnitude of health and social issues for those with HIV/AIDS.

The only literature found that tested the ICF checklist in South Africa was a small study by Jelsma et al. (2006). This pilot study examined the actual performance of the ICF in a resource-poor setting. Despite the data being collected on a small number of patients (n=12), it did demonstrate the usefulness of the ICF checklist in exploring the functional problems related to HIV. The study highlighted important areas of difficulty. It pointed to challenges with explanation of difficult concepts such as performance and capacity and the importance of using a translated version (Jelsma et al., 2006).

2.9.5 **Validity and Reliability of the ICF**

In the lead up process of developing the ICIDH 2, the predecessor to the ICF, experts revised the checklist and the most relevant domains were identified to form the ICIDH 2 checklist. International field tests focusing on reliability, utility and feasibility were conducted and the final ICF checklist was produced. The test-retest reliability showed a high Kappa value ranging from 0.7 to 1.0 for the ICIDH dimensions (Nixon & Cott, 2000; Ustun et al., 2003). A search of the literature on later studies on the test retest reliability of the ICF yielded only one study (Okochi et al., 2005). Okochi et al. (2005), tested the ICF checklist in selected codes on a sample of 742 elderly people. Using a weighted Kappa statistic, they

found a median rating of 0.46-0.55, which they concluded, was relatively low (Okochi et al., 2005). However, this study did report that the evaluators with more experience in the use of the ICF had better reliability. This suggested the importance of proper education on the use of the ICF and rigorous standardization (Okochi et al., 2005). Their study can be criticized for its use of a large number of evaluators i.e. 289. Although in the analysis, stratification was done to account for evaluator differences, this may have been a source of variability and may contribute to low reliability.

To use the ICF in rehabilitation one has to understand the organisation of the rehabilitation process. Based on a problem-solving approach, the rehabilitation process involves four steps, namely: assessment, assignment, intervention and evaluation (Stucki et al., 2003). The assessment step involves identifying the patients' problems and it is here that the ICF and ICF core sets are most useful.

Other scales have been used to classify the functional status of patients and one that is widely used is the Karnofsky scale. It is used as a quick method of classifying the immediate physical and functional capacity of patients (Karnofsky et al., 1948). The reliability of the Karnofsky scale Spearmans(r= 0.97) has been tested in cancer patients (Mor et al., 1984). The interrater reliability of the Karnofsky scale has also been examined in an HIV population and an overall score of (r=0.90) was found. Therefore it seems that the Karnofsky is a reliable indicator of gross function (O'Dell et al., 1995).

2.10 KARNOFSKY SCALE

Karnofsky index or scale is widely used in palliative care and in cancer patients to classify patients' functional status very broadly (Crooks et al., 1991; Hollen et al., 1994). The scale relates to physical ability and covers eleven points from normal health to death, and each point is presented as a percentage.

The scale is:		**%**
Normal health, no complaints no evidence of disease	:	100
Normal activity with minor symptoms	:	90
Normal activity with some effort, and some signs and symptoms	:	80
Unable to carry out normal activity or active work but able to care for oneself	:	70
Requires occasional help but able to care for most personal needs	:	60
Requires considerable assistance and frequent care, considered disabled	:	50
Requires considerable assistance and medical care, death not imminent	:	40
Severely disabled, very sick , active supportive treatment required in hospital	:	30
Very sick, active support needed	:	20
Moribund	:	10
Death	:	0

The lower the Karnofsky score the worse the survival for most serious illnesses.

2.11 CONCLUSION

From the literature review it is clear that HIV has a profound influence on the human body. HIV affects all body structures and systems from a cellular through to a societal level.

In this chapter literature concerning HIV was reviewed in an attempt to give an overview of the natural history of HIV, the current prevalence, its effect and impact on body systems with a particular focus on the systems that concern physiotherapists the most. The interrelatedness of the HIV effects on body systems was also reviewed. In this process, the impairments cited in the literature resulting from HIV infection were outlined as well as resulting function and quality of life. The literature review summarises and discusses underlying theories of physiotherapy and their link to current theory that influences the direction of physiotherapy and rehabilitation. These lead to a review of the ICF and its application to physiotherapy and HIV. The literature is examined for physiotherapy and rehabilitation interventions. In addition the link to physiotherapy of HIV is made in order to see the importance of this.

LITERATURE REVIEW - SECTION 2

2.12 HIV, CURRICULUM AND PHYSIOTHERAPY

This section of the literature reviews the literature on curriculum briefly and key elements of curriculum. Elements that may influence HIV and methods of presentation in a curriculum that have been examined in the literature are reviewed. Issues that may affect the response to HIV/AIDS in a physiotherapy curriculum are explored.

The overall aim of this thesis was to develop a model to mainstream HIV into the physiotherapy curriculum. Without a solid understanding of the key elements of curriculum, and its influences, the findings from the contributing studies such as referral patterns to physiotherapy and the patients' profile cannot be structured in a meaningful manner

2.13 CURRICULUM

Though a vast array of literature exists on curriculum, this review aims to inform those aspects of curriculum that support the need to review curriculum. In addition the work physiotherapy pertaining to HIV and the curriculum will be reviewed.

2.13.1 Definition of Curriculum

Curriculum and curriculum studies have their basis in the education sector in particular the schooling system. Kelly (1989), states that any definition of the curriculum must go beyond statements of knowledge content. She proposes that a curriculum must offer justification of the purposes of its transmission and discern the effects of exposing recipients to such knowledge (Kelly, 1989). In discussing the difficulties embraced in defining the term curriculum, Kelly points out that these lie in limiting the definition of curriculum to what has been planned and thus proposes a curriculum that goes beyond what has been planned to include the process of learning as well as the content. It is argued that for education to be a rational activity it must state its purpose (Kelly, 1989).

Curriculum is explained further by refinement of the definition of curriculum into the explicit, implicit and the null curriculum (Eisner 1994). The explicit curriculum is defined as what is officially taught (Eisner 1994). Eisner (1994) explains that the list of laws, rules, principles, definitions and steps that make up the explicit curriculum do not convey any message about how they came about. The main message in the explicit curriculum that is considered important is the desired end state however when one looks closer it is the larger matrix that

identifies and justifies the direction that curriculum takes. Furthermore Eisner (1994) suggests that changes to the explicit curricula do not have an effect on the implicit curriculum which is an integral part of the larger matrix. The implicit curriculum is explained as what the school teaches because of the kind of place it is. Everything from the structural set up, physical characteristics including the type of furniture and the surroundings are part of the implicit curriculum. What is not on the official curriculum and what educators exclude is considered part of the null curriculum.The Null curriculum is said to support the implicit curriculum. An important influence on all three aspects of curriculum described above is the ideology that influences the direction a particular curriculum takes.

Curriculum ideologies are defined as beliefs about what should be in schools, to what end and for what reasons. Therefore ideologies will influence what is taught. Six major ideologies are outlined in schooling systems namely Religious Orthodoxy, Rational Humanism (centres on content and teaching methods and based on the human being ability to reason); Progressivism (entrenched in the nature of human experience and in social reform); Critical Theory (an approach that strives to reveal the inferred values of an organisation.); Reconceptualism (that questions the status quo on educational development, existence and purpose and puts forward that the pupil should learn not only to earn a living but how to live) and Cognitive Plurism (this relates to the human beings ability to create and manipulate symbols and the plurality of knowledge with its different facets which influences the content of curriculum) (Eisner 1994).

Though the writings by Eisner were predominantly relating to the schooling system they are relevant to the health science curricula. Some of the ideologies have influenced the philosophies behind the approaches to curriculum. Such approaches as cognitive process (associated with critical thinking and building knowledge structures); technical rationality (associated with skill building); academic rationality and social adaptation (promoting social change) have been used in health sciences (Eisner 1994). Eisner concluded that in planning for curriculum and curriculum change it is what happens inside the classroom that matters and translates to curriculum change hence "***teachers ideology may be among the important changes that can be made in the field of education" (Eisner 1994 pg 83).***

2.13.2 Curriculum Planning

In order to undertake curriculum planning, Kelly (1989) proposes that curriculum planning has four dimensions i.e. objectives, content or subject matter, methods or procedures and evaluation and this process has not changed much in later literature (Iwasiw et al., 2005).

However, the linear nature of this model of curriculum planning excludes the required cyclical character which emphasises the inter-related nature of the dimensions. A more appropriate model of curriculum planning allows for regular modifications of the curriculum which is a process or developmental model. Kelly therefore proposes that any curriculum planning must start "***with a clear statement of the processes of development it is concerned to promote and therefore the principles that teachers day to day decisions are to be based upon"*** (Kelly, 1989).This is supported by the framework proposed by Iwasiw et al. (2005) in a framework proposed for the development of nursing curricula that states in its iterative process the need for change as well as establishing curriculum directions and outcomes.

2.13.3 Physiotherapy and Curriculum

In relation to physiotherapy Shepard and Jensen (2002) state that curriculum design includes the content organization of the basics of philosophy, goals, course work, clinical experiences and evaluation processes. They suggest that the actual curriculum receive input from different spheres of society such as regional and professional accreditation groups, state licensing agencies, professional associations, clinicians, faculty and administrators (Shepard & Jensen, 2002).

The prevalence of HIV and associated societal costs are high (Department of Health, 2007b) necessitating increased curricular focus on management of HIV from a physiotherapy perspective. The curriculum must therefore respond to the current physiotherapy developments and the changing environment and human health care needs (Shepard & Jensen, 2002). HIV is influencing health-care needs enormously as shown in Part one of the literature review.

2.13.4 Physiotherapy and Curriculum in the SA Context

As stated above the philosophy of the profession is part and parcel of a curriculum design.

In the models that guide curriculum planning and review, profession and programme philiosophies strongly influence the programme and educational goals (Shepard & Jensen, 2002). In nursing, clear principles emanating from the nursing philosophy and care principles gave guidance to clear curricula objectives for the content of HIV/AIDS into the curriculum (Iwasiw et al., 2005; Sarr, 1991). The Standards Generating Body (SGB) under the South African Qualifications Authority (SAQA) put forward standards based on the premise that physiotherapy as a profession prevents and addresses problems of disability, and promotes well-being through holistic health-care as part of the multi-disciplinary team. Through these efforts it contributes to a comprehensive health care delivery system. In the

Standards Generating Body document (Standards Generating Body (2007), the specific outcomes at each level demonstrate that physiotherapists must gain ability in knowledge and skills that encompass a bio-psychosocial approach for all conditions.The Standards Generating Body outlines a series of learning outcomes set out in the overarching and learning area statements (SGB, 2007). As seen in section one of this literature review, functional and quality of life are concerns for patients with HIV/AIDS. This approach can certainly be adapted within the curriculum to respond appropriately to HIV/AIDS.

The SAQA document states that the expected outcomes are developed in keeping with the WCPT published standards (SAQA, 2004). Related to this, the South African Physiotherapy Association released a position paper recognizing that the high prevalence of HIV in South Africa warrants focused attention by physiotherapists. One of the aims of the society is to ensure that members are kept abreast and educated on HIV management and remain involved in this condition of national priority (SASP, 2007).

2.13.5 HIV in Physiotherapy Curriculum and Practice

A review of the literature on HIV and physiotherapy training has revealed that much of the research is focused on establishing the current knowledge, attitudes and willingness to treat. Much of the literature is from the United States and Europe (or western world) bringing into question the generalisability to a South African context. Secondly, the effects of education on the student or qualified therapist‘s knowledge, attitude and practice have also been assessed (Held, 1993; Johnson & Sim, 1998; Oyeyemi et al., 2006; Powell & Single, 1996; Puckree et al., 2002; Sheen & Green, 1997). In addition a body of literature on methods of teaching HIV/AIDS content has began to emerge (Solomon et al., 2005; Solomon et al., 2002; Solomon et al., 2003b; Wyness et al., 2001).

Studies assessing the knowledge, attitude and practice among physiotherapists show varying results. Held (1993) found entry-level physiotherapy graduates lacked knowledge, had negative attitudes and were unwilling to treat people infected with HIV and having AIDS (Held, 1993).On the other hand, Sheen and Green (1997) in their study on UK chartered physiotherapists revealed positive attitudes (mean score of 79.64 out of 100). Another study by Johnson and Sim (1998) revealed that attitudes towards people with HIV/AIDS were moderately positive with 14% reporting negative attitudes. However, there were some knowledge gaps and the same study revealed a negative relationship between knowledge and attitudes (Johnson & Sim, 1998).

In the South African context Puckree (2002) reveals knowledge gaps among qualified physiotherapists and recommends the inclusion of HIV/AIDS content in the physiotherapy curriculum (Puckree et al., 2002). A similar study among undergraduates in South Africa

revealed students had a moderate to high level of knowledge that correlated with the number of lectures given (Puckree et al., 2004). It should be noted that the questionnaire did not test students' knowledge on a comprehensive basis and while giving a good indication of where South African students are it cannot be considered comprehensive for the state of knowledge, attitudes and practice with regard to HIV.

However, a study in West Africa was in variance with the studies reviewed above in that the results showed a low level of knowledge (mean 20.1 out of 34 ± 3.4) and poor attitudes (mean 103.6 ±19 out of 175) (Oyeyemi et al., 2006).

All studies used convenience samples but sampled from the total population of subjects. For example Puckree (2004) used all physiotherapy undergraduates of 2002. This strengthens the representativeness of this study and its generalisability. However, the disadvantages of using questionnaires were noted by the authors as informants may provide incorrect information. It may be argued though that the consistency in results within the regions may bear testimony to the effectiveness of the method.

Results from studies undertaken with other health care professionals in two of the focus areas of establishing knowledge attitudes and practice and assessing the impact of education programmes are comparable to those found among therapists (Andersen et al., 1997; Lohrmann et al., 2000; Seacat & Inglehart, 2003). In Seacats and Ingelharts study (2003), dental students had some areas of poor knowledge and their level of knowledge was negatively correlated with attitude. This result was also found at an undergraduate level where the improvement in knowledge correlated with the number of HIV- infected individuals personally known to the students (Anderson, et al.,1997). A factor that was pertinent to the student attitudes to HIV included knowing someone who is HIV positive on a personal level (Andersen et al., 1997; Lohrmann et al., 2000; Seacat & Inglehart, 2003). Lohrmann (2000) found that positive attitudes among nursing students correlated with a willingness to care for persons with AIDS and recommended that educational programmes capitalize on this willingness. In a study involving primary care physicians Fournier Baldor and Warfiels (1997) found that physicians had gaps in their knowledge, particularly those from areas with a low prevalence and a corresponding low HIV patient load.

Seacat and Ingelhart (2003) report that it is important to be aware of student knowledge and the factors that affect the acquisition of knowledge and skill of HIV. Knowledge is associated with professionalism, attitude, and attitude towards the patient. Professional attitudes will affect the health care provider's behaviour towards the patient. Therefore any deficiencies in professionalism or in HIV knowledge should be addressed in the curriculum (Seacat & Inglehart, 2003).

Recent work has begun to focus on examining educational approaches to imparting appropriate information and skills on HIV. Solomon et al. (2002) recommend that problem-based learning models seem more suited to education related to rehabilitation and HIV. In a qualitative intervention study, students were exposed to an eight week course that focused on rehabilitation in HIV. An analysis of the student journals and rating of the educational objectives gave insight into the extent and breadth of learning. Themes such as factual knowledge on signs and symptoms, social and ethical dimensions, knowledge of the roles of other health care disciplines, interprofessional learning, better insight into rehabilitation and gaining in confidence emerged form this study. Such detail was recognised by the authors as making a contribution to the body of knowledge on content and methods to be used in teaching about HIV as well us working in an interprofessional team (Solomon et al., 2002).

In the past two decades there has been a drive to moving from acute to primary care (Aberg et al., 2004), from training students in isolation to more inter-disciplinary training (Solomon et al., 2002) and from event based programming to mainstreaming (Verbrugenn, 2004)

"***Mainstreaming means sound understanding of the links between socio-economic and biophysical drivers of HIV/AIDS and in turn substantive reformation of sector and organizational activites to develop and elaborate effective interventions***" (Quinlan & Williams, 2006).

In education, Hunt et al. (1998) refer to mainstreaming as a method of taking a key goal of learning area from the periphery and placing into the centre and within the entire curriculum. Mainstreaming has been reported as a strategy that would help implement as well as address important aspects of programmes and curriculum, and help bring learning and awareness (Hunt et al., 1998; Verbrugenn, 2004).

2.14 MEASURING INSTRUMENTS

Methods that are used for the curriculum section are reviewed.

2.14.1 Focus Group Discussion

"Focus group discussion" (FGD) is methods used in health research to ensure discussion around a topic. The aim is to elicit details on peoples' interactions around a topic including their experiences and the beliefs behind the persons' actions, beliefs, perceptions and attitudes.

Focus groups are reported as useful in the elaboration of pertinent issues on a subject when the subject is complex and simultaneous use of additional data is required to ensure validity

and to concentrate on pertinent variables of a subject under study (Powell & Single, 1996). As a method it is useful in producing the details of people's experiences. Focus groups can be used where a researcher gathers 8-12 respondents and manages the discussion by allowing everyone a chance to speak. A second way of using the FGD is when the discussion is used to explore a particular topic in detail and access information that one would otherwise be unable to access (Babbie & Mouton, 2003).

The advantages of focus group discussions lie in the respondents having the ability to discuss issues that are pertinent to their experience that can be elicited from the broad questions asked by the researcher. In the discussion the researcher has the ability to observe the interaction of the group on a particular topic and can provide evidence on the participants' similarities and differences. Another advantage is the cost effectiveness of focus group discussions as a researcher can gain much information in one sitting (Babbie & Mouton, 2003).

2.14.2 **Delphi Technique**

The Delphi technique is reported to be a useful research tool that can be used to obtain consensus from a chosen group. Gupta and Clarke (1996) describe the primary purpose of Delphi technique to be ***"a method to obtain the most reliable consensus of opinion of a group of experts"***. The group should be selected for their recognised suitability in terms of expert knowledge and practical engagement with the issue under study (Raine, 2006). Appropriate selection of the group members contributes to the technique's face validity while consensus will contribute to the construct validity. High attrition rates affect the validity of the technique (Williams & Webb, 1994). Within the literature no guidance could be found on acceptable group sizes or attrition rates. A wide variety of group sizes have been reported (Raine, 2006). Smaller groups have been reported to achieve good results due to a low drop-out rate. Homogeneity of the group is also reported to contribute to good results (Ziglio, 1996).To determine if consensus has been achieved Deane et al. (2003) reported the range found in the literature to be between 60 and 80 percent (Deane et al., 2003). The steps for conducting a Delphi exercise outlined by Raine (2006) and Vazquez-Ramos et al. (2007) involve:

- Step 1: Selection:Identification, selection, invitation and recruitment of a panel of experts
- Step 2: Exploration: Construction of the statements based on the literature and/or generated within the first questionnaire. The collation and categorization of round one of results constitutes a content analysis that contributes to constructing the Delphi questionnaire. Love (1997) states that the first round of the Delphi can use a highly structured questionnaire or an open ended set of questions that will contribute to the development of the questionnaire in subsequent rounds.

- Step 3: Distribute second questionnaires. The assessment of items is through a Likert scale. The results are presented in terms of central tendency and measures of dispersion of the panels responses. Those items that fall below the chosen levels of central tendency and dispersion are included in the next round and constitute the content of the questionnaire for round three.
- The distribution of the questionnaires can be interspersed with controlled opinion feedback which is a process of informing the participants of the previous rounds results and allowing them to make their decision based on these results.
- Step 4: The results of round 2 are provided to the participants together with questionnaire 3. Participants are asked to reevaluate their responses based on their individual answers and the groups' response. Statistical analysis as in round two involves measures of central tendency and dispersion with those items that fall below the levels chosen being identified.
- Step 5: Final consensus - The items where consensus was reached are identified and a summary of the final results is compiled to constitute the instrument prototype. (Items that fall under the required central tendency and dispersion measures are included in the prototype though indicated as such).

Some of the advantages and disadvantages of the Delphi technique are that:
The technique allows a group of people with expertise in different locations to give their opinions and gain consensus on a particular problem in a manner that is free of bias while informed about other people's opinions (Vazquez-Ramos et al., 2007). Its disadvantages are that there is potential for poor execution through crudely designed questionnaires, Vazquez-Ramos et al. (2007) refer to the "so what" factor resulting from poorly designed questions. Other disadvantages are the poor selection of experts where a narrow perspective may be the result, unreliable result analysis, limited value of feedback and consensus and instability of responses in consecutive rounds (Gupta & Clarke, 1996). The methodological weakness influencing the integrity of the results is that the participants' answers will be influenced by the groups' results and this may result in a regression to the mean (Vazquez-Ramos et al., 2007). Other disadvatages that have been observed are that participating in a Delphi is time-consuming and may result in participants' fatigue (Gupta & Clarke, 1996; Vazquez-Ramos et al., 2007).

2.15 CONCLUSION

This literature review outlines the elements of a curriculum as content organization of the basics of philosophy, goals, course work, clinical experiences and evaluation processes implemented in an iterative process. A review of the literature on knowledge, attitude and practice among physiotherapists reveal varied levels of knowledge. The South African physiotherapists had gaps in knowledge. Another important aspect is awareness of student knowledge and the factors that affect the acquisition of knowledge and skill of HIV. Knowledge is associated with professionalism, attitude and attitude towards the patient. Professional attitudes will affect the health care provider's behaviour towards the patient. Related to the inclusion of HIV into the curriculum are issues of method of teaching with interprofessional education, inter-disciplinary approaches, mainstreaming emerging as important approaches.

CHAPTER 3

STUDY 1: ESTABLISHING THE REFERRAL PATTERNS TO PHYSIOTHERAPY

3.1 INTRODUCTION

The objective of this study was to establish the referral patterns to physiotherapy among HIV patients admitted into a tertiary hospital in South Africa.

The rate of admission into hospital for people living with AIDS remains high in South Africa, (Reid et al., 2005). People living with AIDS, present with multisystem disorders resulting in different diagnoses, a wide range of complications and problems. Some of the problems have been found to benefit from physiotherapy and other rehabilitation interventions. The problematic areas documented are respiratory, neurological, musculo-skeletal and painful syndromes (McClure, 1993). The specific roles played by physiotherapy within the HIV/AIDS pandemic in Africa have not been explored. In South Africa the range of diagnoses among people living with AIDS (PLWA) treated by physiotherapists is not documented. The Canadian working group on HIV and rehabilitation (Canadian Working Group on HIV and rehabilitation, 2002a) stated the importance of establishing what conditions are seen by physiotherapists as an important prerequisite to developing services (Canadian Working Group on HIV and rehabilitation, 2002a). No literature could be found to outline which conditions commonly seen in other countries are also seen by therapists in South Africa.

An accurate picture of the aetiology of disease that physiotherapists should understand could be constructed by examining patients already referred for rehabilitation. This option was explored at Chris Hani Baragwanath Hospital (CHBH) and it was found that patients presenting for treatment in the physiotherapy department did not always have their HIV status revealed. It is against this background that this study sought to establish how much interaction there is between physiotherapy and HIV positive patients in an in-patient setting as part of the larger study to establish the curricula needs of physiotherapy training in HIV. This study also sought to determine the range of conditions that present in patients admitted to hospital with HIV and how many were seen by physiotherapists. To that effect, this study reviewed the records of patients admitted into the medical unit at Chris Hani Baragwanath hospital (CHBH).

3.1.1 Objective

To establish the referral patterns to physiotherapy among HIV patients admitted into a tertiary hospital in South Africa.

3.1.2 Method

3.1.2.1 Sample

A retrospective record review was undertaken.

The study examined the total number of records from medical units in CHBH in a given period to establish which ones had a physiotherapy referral.

3.1.2.2 Procedure: Identification and Review of Records

Stage 1:

The records of patients who were referred to the medical units at CHBH between June 2004 and June 2005 were reviewed. The records office at Chris Hani Baragwanath hospital was approached. All records in chronological sequence according to assigned hospital numbers were identified physically by the records officer. Over 2000 records were reviewed to identify records of patients who were HIV positive. Two reviewers, the researcher and a research assistant (both qualified physiotherapists with clinical experience) identified files for patients who were HIV positive and had diagnoses that could be referred for physiotherapy. These files were categorized into five areas:

- HIV positive, but died
- Files with no information
- Files with other diagnoses, not HIV-related
- HIV positive with diagnoses that were suitable for physiotherapy
- HIV positive with diagnoses that were unsuitable for physiotherapy

A data sheet was designed for the review of the records containing the category of information required at each stage (see Appendix 3.2).

Stage 2:

Inclusion criteria for classifying, coding and ranking common diagnoses were established. This was done by examining the literature and from the clinical experience of the two reviewers. Lists of possible diagnoses that could be found in relation to HIV and whose symptomatology could be viewed as requiring physiotherapy were listed. After reading the notes and establishing the actual symptoms of the individual, the file was coded as requiring referral or not. Diagnoses that were found were pneumonia, post TB

bronchiectasis, TB with co-infection, neuromuscular conditions including Gullain Barre Syndrome, cerebral vascular accidents and polyneuropathies. Cases that were reviewed for potential physiotherapy referral were included if they met the following criteria:

- Age and gender of the patient were stated
- The diagnosis that was identified as suitable for physiotherapy,
- Whether the patient was referred to physiotherapy,
- Whether the common signs and symptoms (impairments) that are normally referred for physiotherapy such as. weakness of the musculo-skeletal system, state of ambulation and increased secretion production were present and
- The scope of tests that were conducted was described

Exclusion criteria

- Files without HIV status confirmation
- Diagnosis unsuitable for physiotherapy intervention and no indication of impairments that could be referred for physiotherapy
- Case files with single diagnosis unsuitable for physiotherapy such as gastroenteritis, renal disease TB without a productive cough or co-infection
- Retro viral disease (RVD) offered as a single diagnosis.

Ethical considerations

- Permission was sought from the hospital executive (see Appendix 3.2 permission letter)
- No names were captured while collecting the data
- Information collected was assigned a code.

3.1.2.3 **Data analysis**

Data were entered into an Excel spread sheet and descriptive statistics were used to identify the frequency of diagnoses and the referral rate to physiotherapy. Descriptive statistics were used to determine the distribution of the different impairment categories. Tables containing frequencies were used to present the distribution of demographic characteristics, diagnoses and referral status of patients.

3.2 RESULTS: STUDY ONE

Seven hundred and thirty two records at CHBH were identified for review in this study.

Table 3.1.1 shows how the files were distributed according to the allocated categories.

Table 3.1.1: Illustration of Distribution of Files According to Categories (n=732)

File Categories	% (n)
No information in files	5 (37)
HIV negative with other diagnosis	53 (388)
HIV positive but died	12 (88)
HIV positive with diagnosis unsuitable for physiotherapy referral	11 (80)
HIV positive with diagnosis for possible physiotherapy referral	16 (117)
Tuberculosis (TB) and HIV*	3 (22)

*TB was extracted as an additional category

Of the 732 patient records, 139 (19%) had diagnoses considered suitable for physiotherapy after the two reviewers examined the records as explained in section 3.1.2.2. These are the records that were further reviewed.

Demographic Characteristics

Of the 139 records that were considered potential candidates suitable for physiotherapy assessment, seven had undocumented information such as gender, age or clear HIV status in their files and were thus excluded from the study, reducing the sample to 132.

(a) **Gender and mean age**

Of the132 patients, 57% were females and 43% were males. The mean ages and standard deviation for the female and male patients were 34 (±9) and 38(±11) years respectively.

(b) **Distribution by age-group**

The age range was categorised into specific age groups as shown in Table 3.1.2 below with the number and percentage:

Table 3.1.2: Age-Group Distribution of Patients (n=132)

Age range	n (%)
15-19	5 (4)
20-24	12 (9)
25-29	25 (19)
30-34	29 (22)
35-39	19 (14)
40-44	15 (11)
45-49	15 (11)
50-54	7 (5)
55-72	6 (5)
Total	132 (100)

The majority of the patients were in the age group, 30-34.

Types of diagnoses

The most common diagnoses were ranked as shown in Table 3.1.3 below. The most common diagnoses were ranked as 1 while the least common was ranked as 8.

Table 3.1.3: Illustration of Diagnoses and Combinations Found in Patients' Records (n=132)

Rank	Diagnosis	n (%)
1	Pneumonia	39 (29)
2	Meningitis	34 (25)
3	Tuberculosis	27 (20)
4	Lower respiratory tract infection	26 (19)
5	Meningitis and cryptococcal meningitis	25 (18)
6	Lower motor neuron paralysis	11 (8)
7	Retro-Viral Disease (with no specific diagnosis)**	8 (6)
8	Thrombocytopenia(seen in combination with other conditions)	8 (6)
Total		178*

*The total exceeds 132 because some patients had more than one diagnosis

**Although this means a diagnosis of HIV, in the notes this was given as the patients' diagnosis when the patient was deconditioned with multiple non-specific impairments such as anaemia, and weight loss in combination with another diagnosis such as meningitis or pneumonia. This was confirmed by the head of the medical unit.

The two most frequent diagnoses were those with respiratory (ranked as 1, 3,&4) and neurological problems (ranked 2,5,6).

Some diagnoses presented as a single diagnosis or in combination with others. Table 3.1.4 shows the different combinations of diagnoses ranked in order of frequency as seen per patient.

Table 3.1.4: Ranking of Diagnosis and Diagnosis Combinations

Ranking	Diagnosis	n (%)
1	Pneumonia	22 (16)
2	Meningitis	11 (8)
3	PCP and TB	9 (7)
4	PCP	8 (6)
5	PCP and LRTI	7 (5)
6	TB and Pneumonia	5 (4)
8	Pneumonia and LRTI,LRTI and TB, lung abscess	3 (2)

Although twenty one different diagnoses were identified in total, this table shows the top eight conditions. Respiratory conditions such as pneumonia and other combinations of different respiratory conditions occurred most frequently. The other conditions that were present in this cohort but not ranked include post TB bronchiectasis, pleural effusion, pneumothorax, lower motor neuron paralysis, dementia, deep vein thrombosis (DVT), encephalitis, thrombocytopenia cancer (Ca) of the brain, asthma and congestive cardiac failure.

3.3 REFERRAL STATUS OF PATIENTS SUITABLE FOR PHYSIOTHERAPY

Only 2% (n=3) of the total number of patients further reviewed were referred and seen by physiotherapists while 98% (n=129) were not referred. Ten (7%) of the cases were discharged while non-ambulant. These ten patients had a mean age of 37 years (range 27-46), six were male, four were female. Two of them had been referred for physiotherapy. One was diagnosed with peripheral neuropathy and congestive cardiac failure (CCF) while

the other had a lung abscess. The third patient referred for physiotherapy had a lower respiratory tract infection and was ambulant.

The other eight non ambulant patients had the following diagnoses individually or in combination with other diagnoses:

Diagnosis	**Number of patients**
Hemiparesis	1
Meningitis/ cryptococcal meningitis	4
Lower motor neuron paralysis and polyneuropathy	2
Lower respiratory tract infection	3
Tuberculosis	1
Pneumonia and or PCP	2

3.4 DISCUSSION

As the nature of HIV changes from being a terminal to a chronic illness, it is important to examine some of the interventions traditionally included in the management of chronic illness. Rehabilitation and physiotherapy are among some of the key interventions for dealing with the disabling impacts of chronic illness or conditions (Worthington et al., 2005). However, differential diagnosis is seen by Lang (1993), in her experience with HIV, as essential for medical management and less so for rehabilitation (Lang, 1993). This sentiment is supported by Nixon and Cott (2000) who argued that the medical model lacks the conceptual framework to guide education, research or practice in rehabilitation. The literature on rehabilitation described earlier, and current medical practice, is grounded in this same medical model (O'Dell et al., 1996a; 1998; O'Dell et al., 1996b). Since there are no studies that have attempted to describe the population of HIV clients that may benefit from physiotherapy in the South African situation, this study was therefore considered an appropriate starting point in trying to establish what is being referred and seen by physiotherapists in spite of the paucity of information on functional and participation deficits.

The total number of HIV admissions to the hospital could not be obtained from the hospital information system at CHBH Hospital at the time of this study. However, 42% of the total records reviewed were of patients who were HIV positive. In this cohort there was a higher number of female patients 57 % (n = 76) with their mean age lower than that of males. This concurs with other literature (Rehle & Shisana, 2003) where within the affected population,

females are in the majority. This should be noted by therapists for appropriate age and gender sensitive interventions within the continuum of care model of prevention, treatment and care (UNAIDS, 2006b). Furthermore, the number of patients with HIV still remains higher in the productive age group between 25 and 49, the highest percentage being in the 30-34 age range. This is consistent with statistics released nationally (Rehle & Shisana, 2003)and internationally (WHO, 2006).

O'Dell (1993) in a retrospective study in a Philadelphia teaching hospital on medical records of persons hospitalised with complications of HIV referred to rehabilitation did not indicate the total number of records reviewed. Case notes reviewed showed a wide range of admitting diagnoses including similar ones found among the patient notes reviewed at CHBH. Two of the common diagnoses in both O' Dell's (1993) study and this study are pneumonia and cryptococcal meningitis. Furthermore, assessments of patients with HIV done by O'Connell and Levinson (1991) and O'Dell (1993) found different functional deficits and impairments among patients with HIV. Some of these deficits included: pain, physical deconditioning, proximal and distal muscle weakness, paresis and immobility. However, this study revealed other diagnoses including tuberculosis, lower respiratory tract infections and lower motor neuron paralysis. This result reflects the existence of a need for physiotherapy for PLWH. The range of diagnosis that were identified are commonly known to result in activity limitations that can be countered by physiotherapy and rehabilitation interventions (CSP, 2008a). In the cases reviewed by O'Dell (1993) 87 % were referred to occupational therapy and 80% to physiotherapy. In this study only 3 patients (2%) were referred for physiotherapy. In comparison with referral in western countries, this figure is very low perhaps indicating that there is no focus on the patient's physical and functional needs and subsequent quality of life. It is difficult though, to draw a firm conclusion from these results as HIV-related physical disability was not captured in the patient notes or on the discharge summary. Retrieving documentation was challenging in a hospital as large as Baragwaneth and undergoing many transitions. Retrospective data analysis is limiting especially where the records were not always standardised. The researcher minimised this limitation by ensuring the data collection forms were standardised.

Although the general impact of exercise, as a modality of treatment for HIV patients has been shown in a Cochrane review (O'Brien et al., 2005), to benefit people living with HIV, exercise is not considered as an option at CHBH as indicated by the low referral rate of patients to physiotherapy. This may be attributed to this sample of patients being in the advanced stages of HIV as information was obtained from the files of patients who present

themselves to the hospital and were deemed ill enough to be admitted. This was confirmed by the head of the medical unit at CHBH who revealed that most patients are admitted for medical stabilisation and are discharged as soon as this is achieved. All those who were reviewed for referral were discharged home with no functional assessment evident. It is difficult to draw firm conclusions on their need for rehabilitation if there is no detail of their impairment, physical and functional status other than laboratory markers and general status. If patients are not referred for further assessment and physiotherapy, it can be concluded that many patients with HIV-related complications who can benefit from physiotherapy are not receiving a comprehensive model of care due to this oversight.

For this study this sample was adequate to show the referral rate at a typical tertiary hospital. The researcher accepts that the direct need for physiotherapy cannot be determined from diagnosis alone however, known aetiology does give an indication of the impairments and subsequent disability. The use of the diagnosis may limit the accuracy to predict which conditions may need physiotherapy, but this is essentially the only common starting point that gives adequate overlap with the medical team's focus on the management of patients. To minimize this limitation the case notes were examined closely and isolated any impairment such as increased secretion production and alteration in muscle strength that would give an indication of the need to refer for assessment by a physiotherapist. Further research should endeavor to confirm the diagnosis, impairments and activity limitations**.**

As patients notes were selected from the medical units, many of the patients had advanced disease, as indicated by the head of the medical unit, and had low CD4 counts. Therefore this may give a skewed picture of the referral status. However, except for those who died and were excluded, all patients analysed for physiotherapy referral were discharged home. Other units such as neurology, surgery and paediatrics could be assessed for referral patterns to complete the picture. Information was retrospectively collected from the case notes whereas a prospective study could ensure more specific information. The notes were standard in structure but there were variations in the format and the information was given by different doctors thus leaving some room for inconsistency in reporting this data collected. The researcher acknowledges that a prospective or larger cross-sectional study examining functional deficits would build a better picture. However, establishing this clear picture of the current situation will contribute to a more appropriate education or intervention model.

3.5 CONCLUSION

Despite such a high proportion of HIV positive patients admitted to the medical wards at CHBH South Africa, very few patients living with AIDS are seen by rehabilitation professionals in the hospital setting. There is little or no referral of patients or first line contact with physiotherapy or other traditional rehabilitation professionals. These findings suggest that interaction between physiotherapists with PLWH is low in this context. This is in spite of a high number of patients experiencing impairments that could be addressed by physiotherapy. There is much to be explored and understood in the area of rehabilitation services for PLWH within the South African context. According to the literature, rehabilitation has the ability to impact on a number of domains across the full range of body function and structure, activity and participation and to contribute to better integrated care. The physiotherapists' role in increasing exercise tolerance, muscle strength, (O'Brien et al., 2005) improving general body conditioning (O'Dell, 1993) treating pain (Griswold et al., 2005) management strategies, improving function and activity and treating stress and anxiety related symptoms (Lang, 1993) is not fully exploited. This study did not investigate the underlying reasons for the lack of referral or the lack of active participation of rehabilitation professionals. However, it does suggest that perhaps the role of physiotherapists is not fully understood by the profession itself or by the rest of the medical team. Advocacy for appropriate referral is an important recommendation and to aid this and the physiotherapists' first line practitioner status it is important that a more accurate picture of the pertinent areas is gained. In order to do this, further research is needed to establish what functional deficits among PLWH exist and exactly where the needs lie.

3.6 SUMMARY

The purpose of study one was to determine what conditions were being referred to physiotherapy and to what extent physiotherapy was interacting with HIV patients. The study does show that the interaction of patients with HIV and physiotherapy is low despite the potential for the need for physiotherapy among HIV patients whose records were examined (139 patients identified with symptoms that could have been assisted by physiotherapy). As this was a medical unit, respiratory conditions were in the majority and as these patients need physiotherapy these results are consistent with those presented by McClure (1993) and O Dell (1993, 1996). Specific symptoms such as de-conditoning, fatigue, and dealing with specific neuromusculoskeletal effects of HIV were outlined in previous studies but were not a focus in this study. This study demonstrates that physiotherapists have not established a clear role in the management of HIV in the South African setting. Some of the conditions, such as pneumonias and tuberculosis, are

traditionally seen by physiotherapists with evidence to demonstrate treatment effectiveness (CSP, 2008a) and yet when they occur with HIV they are not treated. On this basis it may be necessary to examine the philosophical underpinnings that guide physiotherapists in the decision-making processes in the treatment of HIV. In addition in determining what to teach it is important to establish a comprehensive picture of the conditions and symptoms that affect PLWH within a conceptual framework to guide physiotherapists. The ICF is considered such a vehicle and in study two is used to obtain an overview of the functional and participation picture of people living with HIV.

CHAPTER 4

STUDY 2: THE FUNCTIONAL AND PARTICIPATION PICTURE OF PEOPLE LIVING WITH HIV

4.1 INTRODUCTION

Understanding the impairments, functional limitations and disabilities associated with HIV should be a prerequisite to rehabilitation interventions (Kietrys, 2002; Nixon & Cott, 2000). One of the ways of understanding the impairments, functional limitations and disabilities is to classify patients according to the ICF. The overall aim of the ICF is to provide a unified, standard language and framework for the description of health and health-related states, disability and their consequences (WHO, 2001).

In this study, the ICF checklist (a shortened version of the ICF) was used as the research tool. The checklist outlines two main components i.e. Part 1: body functions (BF) and structure, as well as activities and participation (AP). Part 2 consists of environmental factors (WHO, 2001). Each component has three domains, namely physiological, anatomical (Impairment), action and task (activity and participation and environmental factors) that are interrelated. The domains are divided into categories and subcategories (WHO, 2001). Through the concepts of impairment, activity and participation as well as environmental factors, the ICF offers a framework for the study of disablement and health-related consequences of disease.

It has been recognised that impairments and limitations due to any illness can be mitigated against by appropriate environmental support (Nixon & Renwick, 2003), and therefore understanding the scope of impairments and activity limitations may contribute to this. The ICF is a universal and widely used tool (Rusch M et al., 2004 ; Stucki & Grimby, 2004a) and provides a basis where data on the nature and magnitude of health and social issues can be compared for people living with HIV (Hwang & Nochajski, 2003). The ICF has been used in many studies as a framework to describe the function, disability and quality of life of people suffering from many diseases (Rusch M et al., 2004 ; Simeonsson et al., 2003; Stucki & Grimby, 2004a). The ICFs' usefulness in framing functional problems in an HIV population has been shown in a small pilot study by Jelsma et al. (2006). Apart from studies such as Rusch (2004) and Zonta (2005) who used the ICF explicitly to conceptualise HIV, no studies have been found that used the ICF directly for HIV.

The objective of this study was to obtain a relevant overview of the functional and participation picture of people living with HIV. To achieve the above objective, two studies were conducted: an in-patient group in a typical public health hospital was assessed and thereafter an out-patient group in a well resourced out-patient setting. Prior to these studies a separate pilot study was done to pilot the ICF. These settings represent a typical public health setting with patients from a wide geographical spread while the second setting allows for data to be collected in a setting where the patients are well supported and better resourced. As acknowledged before separate studies would be required to address the needs for adults and children. Due to the scope of work required to address both groups this study focused on adult needs.

Each of the categories within the domains of the ICF can be scored using available clinical results. The pilot study determined which laboratory results were to be used and standardised the wording of the questions used to elicit information from the patients. A separate pilot study was required to determine inter-rater reliability for muscle strength measurements using dynamometry. The methods undertaken within the pilot study are described in the methods section below

4.2 STUDY DESIGN OF MAIN STUDY

A cross-sectional descriptive design was used.

Aim: To obtain a relevant overview of the functional and participation picture of people living with HIV.

4.2.1 Methods of the Pilot Study and Main Study

In this study the ICF was used as a measuring tool. The intention was to collect and record data for the purpose of building a picture of the impairments, activity limitations and participation restrictions for people living with HIV.

4.2.1.1 Procedure for utilization of the ICF checklist

The full ICF checklist was utilized. The ICF can be used in a number of different ways and the interpretation is influenced by the purpose of the exercise. The steps taken in using the ICF and analysing the data for this study are outlined below and the procedure followed in rating the level of impairment, activity limitation and participation restriction is explained.

4.2.2.2 Step 1: Translation of ICF questionnaires

a) **Translation and Back Translation**

A professional translation company was contracted to translate the ICF check list into SeSotho and isiZulu, two local and commonly understood languages in the Gauteng province.

The process involved translation from English to the vernacular by a language expert. Following this a process of validation was conducted using physiotherapists who understood the languages to verify that the translation was accurate.

Thereafter back translation by a different language expert was carried out and a second process of validation as described above was undertaken to ensure the translation of terms was accurate. Six experienced physiotherapists (>10years) (the researcher and five research assistants) were involved in the validation process.

b) **Concepts that Proved Difficult to Express**

The two concepts (capacity and performance) that were difficult to express accurately in one word were explained in phrases. Under each variable there were not many terms that presented with difficulty. The few that were queried by the therapists who spoke the vernacular were discussed for clarity but ultimately none of the words suggested by the translation experts were changed by the team of indigenous physiotherapists who spoke isiZulu and Sesotho.

4.2.2.3 Step 2: Defining the Use of the ICF and Piloting the Checklist

The WHO ICF checklist was used as an interview schedule to collect the data through a structured interview and physical assessment. The researcher consulted with a WHO expert on the use of the ICF and advice and explanation were obtained. Three raters were involved namely the researcher, a primary research assistant and a second research assistant who was part of the clinical team. The second researcher obtained the initial consent and served as a translator during the interviews as she could speak both Zulu and Sesotho. Training of the research assistants was conducted by going through the checklist and determining how to complete each category using the available data. Three sources of data were determined i.e. from answers obtained from the patient interview, available clinical data such as laboratory results and patient observations recorded in the patient file, and observations and measurements conducted by the researcher and assistant.

Due to the high number of variables, the high variability, and multiple sources of data, inter-rater reliability and validation of the checklist itself was not carried out using the test-retest method. Only measurements of muscle strength were tested for inter and intrarater reliability as described in section 4.1.2.4.The WHO expert who was consulted suggested a process of piloting and standardization of the assessment procedure to ensure integrity of the results. An outline of the procedure is described below and Appendix 4.2 outlines the results of the piloting process to establish interrater reliability.

The full checklist was used with its codes and qualifiers. The training involved specifying how each area is coded and subsequently qualified. Two raters collected the data for this study namely the researcher and the primary research assistant described above.
The following section (1-5) outlines the general coding rules and how they were applied for this study (WHO, 2001).

1. **Selection of Codes**

   When using the ICF, it is recommended in the guidelines (WHO, 2001) that codes are selected to form an individual's profile. No core sets have been developed for HIV and therefore the entire checklist was used to collect data. [A core set is a defined set of variables derived from a process of determining which variables are pertinent to a given condition (Stucki & Grimby, 2004b)]. Doing this ensured that all components of the classification namely, body functions and structures, activities and participation and environmental factors were included.

2. **Coding of Relevant Information**

   The researchers ensured that information was coded in the context of the patients' health situations. In relation to this, difficulties arose when the patient indicated that they "had no problem with interpersonal relationships because they had not told their family or friends." In such instances the reason for no problem was noted on coding. Appendix 4.1 explains the coding terminology.

   (Definition of time: The patients were asked to report on their functioning in the previous month).

3. **Explicit Coding of Information**

   The rules for use of the ICF state that the user should not make inferences about the interrelationship between an impairment of body function, structure, activity limitation

and participation restriction. Therefore each category was coded after obtaining explicit information from the patient.

4. **Coding Conventions for Environmental Factors**

For this study convention one was chosen and this requires that environmental factors are coded alone, without relating these codes to body functions, body structures or activities and participation.

5. **Component Specific Coding Rules**

The coding of specific components i.e. body functions, structures and activities and participation was undertaken according to the guidelines given in the ICF coding guidelines (WHO, 2001) (see Appendix 2.1 and 2.1.2) for ICF checklist and guidelines) and these are:

- Once impairment is present it can be scaled in severity using the generic qualifier.

0	-	absence of impairment	
1	-	mild	(5-24%)
2	-	moderate	(25-49%)
3	-	severe	(50-95%)
4	-	complete	(96-100%)
8	-	not specified	(where there is insufficient information to determine the presence of impairment)
9	-	not applicable	(a situation where it is inappropriate to apply a particular code)

  - From the guidelines outlined, interrelationships may occur between impairments.
  - Impairments can be determined by direct observation, questioning the patient or assessed through standardised tests

- Body structure and function was coded using three qualifiers namely: the extent of the impairment, the nature of the impairment and location and then scaled as described above under the impairments.

- Activities and participation were coded using two qualifiers (performance and capacity) for the in-patient group. [Capacity refers to the ability of the individual to perform an activity in a standard environment, while performance refers to the individual's ability to perform activities in the current environment (WHO, 2001). When the first five patients were piloted, little or no difference was observed between the two qualifiers, capacity and performance, in the out-patient mining group. For this group only the performance qualifier was used -the same generic scaling method described for body function impairments was used.

- For coding environmental factors, two qualifiers exist, whether the environmental factor is a facilitator or a barrier. The following negative or positive scale signifies the extent to which an environmental factor acts as a facilitator or a barrier:
  - 0 no barrier no facilitator
  - 1 mild barrier mild facilitator
  - 2 moderate barrier moderate facilitator
  - 3 severe barrier substantial facilitator
  - 4 complete barrier complete facilitator
  - To obtain this the assessors asked whether the factor was present and if so, was it accessible (where applicable) and for both the facilitator and the barrier the extent to which it was a facilitator or barrier. The raters concentrated on establishing whether the factor was present or absent, and if so was it of a standard or quality acceptable to the individual. In this way it could be assigned as a "felt" barrier or facilitator. The severity or extent could then be assessed and a scale given using the generic qualifier of the range **"none to complete"** for both the facilitator and the barrier.

- After piloting, specific neutral questions were formulated as described below for each code:
- Do you have access to (food, transport, housing, social services, labour, health and employment services?)
- What is your experience with (health workers, family, friends, with regard to service and attitude?)

Patients tended to explain further and this information was used to rate the qualifier. Examples of comments given by patients that were used to code and scale are:

- **"I don't want to visit my friends because they stare"**

- **"I do not have problems with friends and family because I have not disclosed my status"**
- **"It is useless going to the council for housing as nothing ever comes of it",**
- **" I have never thought of applying for a house, I just accept the way I live and get on with it"**
- **"The health department is the only one doing something visible, they are just great", "and how can I have food if there is no income or money"**
- **"I have just stopped work and am moving in with my "mother"…."sister"…"friend"…")**

4.1.2.4 Step 3: Establishing Standardization and Reliability of Tests used in the Coding Process

The concept of "**cross walking"** was used to validate sections of the checklist. Cross walking uses components of validated research tools and outcome measures to ensure consistency of the measured phenomena (WHO, 2001). The following domains (categories) were assessed using the measures described below.

a. **Mental functions**

- Questions adapted from the Mini Mental Test (Folstein et al 1975) were used to determine the status of the patient in the mental functions domain. The questions were adapted for the areas of orientation, attention, memory and perception
- Orientation - What is the year/date/day and month and where are we?
- Attention/ Memory - count backwards by 7 (for patients who were not literate this did not work and their ability to calculate change when purchasing goods was used).
- Perceptual - recognition and naming three shapes (a square, a circle and a triangle).The patient was shown the shapes and asked either to name them or name an object they are aware of that has the same shape
- Pain - A verbal rating scale was used for assessing pain. Understanding the concept of pain on a continuum did not seem to be a problem for most patients. Patients who experienced pain were asked to rate their pain intensity on a scale of 1-10. At times the scale had to be explained by equating 1 to little pain and 10 to unbearable pain.

b. **Neuromusculoskeletal and movement related functions**

Dynamometry

Dynamometry is an objective measure of muscle strength using an objective measuring instrument (hand-held dynamometer) and was used in this study.

Table 4.1 summarises the positions used when testing muscle strength.

Table 4.1: Dynamometry positions

Muscle	Patient position	Placement of dynamometer
Elbow flexors	Supine	5cm proximal to the wrist crease
Hip flexors	Supine	5cm proximal to knee joint
Knee extensors	supine - in patient cohort sitting - mining cohort	5cm proximal to the ankle joint
Wrist extensors	Supine	1cm below carpo-metacarpal joints
Dorsi flexors	Supine	2cm below the tarso metatarsus joints

Problems experienced while conducting dynamometry

There were occasions in the in-patient group where dynamometry was not done. This occurred when the patient:

- complained of pain in the joint
- did not follow instructions or demonstration
- had oedema or pain due to drip site.
- in some cases the concept of applying resistance against the dynamometer was just not understood despite translation, demonstration or hand on hand guidance. This was despite the patient having answered the questionnaire fully and confusion having already been excluded.

To rate the muscle strength on the ICF checklist, the Oxford scale was used to determine the initial presence or absence of muscle contraction. Thereafter dynamometry measurements were taken. Dynamometry measurements that were taken from a group of control group of HIV positive ambulant subjects matched only for gender and age were used to determine if the measurement obtained for each participant in this study could be judged as no impairment or a mild, moderate or severe impairment on the impairment qualifier scale on the ICF check list.

c. **Method of testing intra and inter-rater reliability-dynamometry**

Aim - To test intra and inter-rater reliability of the researcher, and two research assistants when using a hand-held dynamometer. Ten percent of the total sample was recruited. Nine subjects of good health (18-60yrs) agreed to participate

Tool - FDK hand held dynamometer (Wagner instruments USA).

Muscles tested - Elbow flexors (biceps) and knee extensors (quadriceps)

Position

- The quadriceps muscle strength was tested in sitting with legs perpendicular to the floor and the knees flexed at 90º. The other leg was supported on a low stool and arms crossed in front for stability. The dynamometer was placed 5cm proximal to the ankle joint.
- The biceps muscle was tested with the subject in position lying. The dynamometer was placed 5cm proximal to the wrist crease with the elbow in extension.

Method for testing intrarater and interrater reliability

Each assessor familiarized themselves with the dynamometer. A short training session was held to ensure that the technique of body weight shift was similar between assessors and the placement of the dynamometer was in the same anatomical position for each test. Three separate testing sessions were conducted. The first two were 24 hours apart and the last one a week later. The first session was conducted with nine volunteers. The second and third sessions had only seven volunteers each as the other volunteers did not rerturn.

Each subject was tested three times on their dominant side by each assessor. There was a ten minute interval between tests. The “make test” was used. This consists of an application of force adequate enough to equate the maximum force given by the volunteer.

An ANOVA and Spearman’s correlation were undertaken to establish the association between and within the data sets for interrater and intrarater reliability. The Excel 2000 programme was used for data entry and the Stata Statistical package 9.0 for data analysis. The inter-rater reliability for raters 1 and 2 was very good for the biceps muscle and moderate for the quadriceps. Rater 1 was unable to participate in the data collection for study two. Reliability between rater 2 and 3 was

moderate for the quadriceps muscle (r=0.54-0.66) and low for the biceps between (r=0.21 - 0.57). (Shrout & Fleiss, 1979). Based on these results one rater was chosen to carry out all the dynamometry measurements during data collection of study 2. Appendix 4.2 outlines the inter and intrarater reliability results

d. **Goniometry**

Goniometry was used to ascertain joint range. The universal goniometer has been found to be more reliable than any other instruments assigned for joint motion measurement with a high correlation coefficient showing good reliability (Rothstein et al., 1983). Reliability of goniometry is found to be affected by complex joint motion; force applied using passive measurement, experience and accuracy of examiner as well as patient condition (oedema, adhesions, strength deficits, muscle hypertrophy).

Range of motion (ROM) was not assessed as after the first 10 patients were evaluated in study two, it was discovered that they all had full ROM and throughout the study it was ascertained that this was indeed the case.

e. **Functions of the cardiovascular, haematological, immunological and respiratory systems**

Use of Laboratory Markers

In order to assess the functions of the cardiovascular, haematological, respiratory, digestive, metabolic and endocrine systems, laboratory markers (see Table 4.2) were obtained when available and used to establish the severity of the impairment.

Table 4.2: Laboratory Markers used in Rating ICF Checklist

	Reference values	Interpretation
Haemoglobin	14.0-18.0 Males 12.0-16.0 Females	HIV can cause anaemia, neoplasms or other deficiencies
Glucose	1.1-2.75mmol/L male 0.2-0.88mmol/L female	Metabolic disturbances may result in glucose intolerance
White cell count	3600-10200 cells/cm^3 5-10^3 /uL	Increased in most infections Reduced with certain infections and drug therapies especially zidovidine, ganciclovir and sulfonamides)
Mean cell volume	86-98fl	As with haemoglobin
Potassium	3.5-5 mmol/L	Often affected by nutritional status and presence of diarrhoea or impaired kidney function
Sodium	135-148 mmol/L	As for potassium
Platelets	150000-400000 cells/cm^3 /ul	Reduced with HIV thrombocytopenia, infections and ARV drug therapies
Urea	3.6-7.1mmol/L	Elevated with kidney function impairment, drug toxicity. Reduced in low protein diets
Creatinine	0.9-1.3 mg/dl male 0.6-1.1 mg/dl female (Levine 1997) 7.6-30.6 umol/L	Elevated with kidney dysfunction Reduced with debilitation due to age and loss of muscle mass
CD4 lymphocytes	800-2000x 10^6/L	Suggests HIV infection
HIV - viral load (this was only available for the out-patient mining group		Indicates the presence of HIV

Ref (Levine, 1997) Clinical guides to laboratory tests Baragwanath Hospital laboratory reference values (NHLS 2007)

The latest blood test results available in the patients' hospital notes were used to score the haematological and immunological status. The current National Health Laboratory Standard used at Baragwanath hospital (NHLS) results were used as a guide to the interpretation of the blood results in the patients' notes. If they did not match the norms they were checked with a medical practitioner and subsequently coded. The results of the latest laboratory results are presented in Appendix 4.2

4.1.3 Description of the Use of the ICF in the Pilot and Main Study 2

An outline of what components of the full ICF checklist utilised is shown in Table 4.3. The full list of sub-categories (level 2) is not given. See Appendix 2.1 for the full ICF checklist used. Under the sub-category level 2, only examples are given here as there are too many to outline.

Table 4.3: Domains and categories of the ICF checklist used in our study

Domains	Sub-Category Level 1 (also referred to as sub-domains)	Sub-Category Level 2
Impairments of body function- b	b1-b9 b1 Mental functions, b2 Sensory functions, b3 Voice and speech, b4 Cardiovascular haematological and respiratory system, b5 Digestive system, b6 Genito-urinary b7 Neuromuscular skeletal	E.g. b2 Sensory functions b210 Seeing b230 Hearing b235 Vestibular b280 Pain
Impairments of body structure-s	s1-s7 s1 Nervous system, s2 Eye and ear, s3 Voice and speech, s4 Cardiovascular and respiratory, s5 Digestive, s6 Genito-urinary, s7 Movement	E.g. s1 Nervous system s110 Brain s120 Spinal cord and nerves
Activity limitation and participation restriction	d1-d9 d1 Learning and applying knowledge, d2 General tasks and demands, d3 Communication, d4 Mobility, d5 Self-care, d6 Domestic life, d7 Interpersonal relationships, d8 Major life areas, d9 Community and civic life First qualifier (fq)- extent of activity performance in normal environment Second qualifier (sq)- extent of activity without assistance	E.g. d4 d430 Lifting and carrying objects d440 Fine hand use d465 Moving around using equipment d470 Using transportation d475 Driving
Environmental factors	e1-e5 e1 Products and technology, e2 Natural environment, e3 Support and relationships, e4 Attitudes e5 Services systems and policies	E.g. e2 Natural environment and man made changes e225 Climate e240 Light e250 Sound

The lists below outline all the subcategory level one (sub-domains) and the number of subcategories used in the checklist that are referred to as codes. The full description of the sub-categories and the number of codes at level 2 is given in the ICF checklist (Appendix 2.1).

Eight body function domains were included:

- "Mental functions"-11 codes
- "Sensory functions and pain"- 5 codes
- "Voice and speech"- 1 code
- "Cardiovascular, haematological and respiratory systems" -5 codes
- "Function of the digestive metabolic and endocrine systems" - 4 codes
- "Genito-urinary and reproductive functions"- 2 codes
- "Neuromusculoskeletal and movement-related functions"- 4 codes
- "Functions of the skin and related structures"-1 code

Nine activity and participation domains were included:

- "Learning and applying knowledge" - 6 codes
- "General tasks and demands" - 2 codes
- "Communication" - 5 codes
- "Mobility" - 6codes
- "Self-care" - 6 codes
- "Domestic life" - 4 codes
- "Interpersonal interactions and relationships" -7 codes
- "Major life areas" - 6 codes
- "Community, social and civic life" - 5 codes

Five environmental factor domains

- "Products and technology" 6 - codes
- "Natural environment and human made changes to environment" 3 - codes
- "Support and relationships" 7- codes
- "Attitudes" 7- codes
- "Services, systems and policies" 9 - codes

The guidelines for completing the ICF were provided to the two research assistants (see Appendix 2.1.2). For the activity and participation section, the ICFs' recommended wording for the questions to elicit the person's capacity to undertake an activity was used (ICF Appendix 2.1.2).

4.1.4 Outcomes of the Pilot Study

- The first interview with a patient was conducted by all three assessors together. After the first three patients all assessors met and discussed their problems in using the ICF. This process was repeated for five more patients.
- Problems were experienced with the mental functions area, namely differentiating between impairments of body functions and body structures. Differentiating between performance and capacity qualifiers was initially found to be problematic. This was because the distinction between what the person could do without the help of different aspects of his environment and his own capacity was not easily understood. The question was simplified to. "***What can you do now without assistance from anyone or anything?" "What can you do in your normal living environment and how does this differ from what you can do on your own."*** Under the environmental domain the most difficult sub-category to explain was the "products and technology" and "services systems and policies". Attitudes were in most cases understood but getting differentiation between closely related concepts such as friends, acquaintances, health professionals and health-related professionals was difficult without making this concrete by naming a known type of health professional and health-related professional such as the community health worker or home-based carer.
- Specific questions were suggested after discussion between the researcher the research assistants and a telephonic consultation with the WHO expert. Once agreed upon, the specific questions and the guidelines for asking about capacity and performance qualifiers were followed strictly. This process was repeated three times until there was uniformity between the assessors. Subsequently the third assessor was used primarily as a translator. When there was clarity, data collection of the main study commenced.

4.2 DATA COLLECTION: STUDY TWO

There were two samples studied, namely an in-patient group from a large tertiary hospital with a large and varied cross-sectional catchment and a well resourced mining out-patient cohort

4.2.1 Sample Description

4.2.1.1 Study one: in-patient group

Patients admitted to the medical unit at Chris Hani Baragwanath Hospital between December 2005 and May 2006 were approached for participation in the study through the resident medical team after each admission intake. This was after patients had been

screened using the Karnofsky scale. This scale is a commonly used screening tool to ascertain a person's level of function in relation to their illness (O'Dell et al., 1995).

Inclusion criteria -

- HIV positive,
- Age range 18-75 years,
- Both employed and unemployed,
- Karnofsky score 30 and above.

Exclusion criteria

- Exclusion criteria: Karnofsky score below 30,
- Inability to answer questions and confusion

4.2.1.2 **Study two: out-patient group (Mining)**

Patients attending the Rustenburg Mine hospital Wellness Clinic and the Occupational Health Clinic in Rustenburg were approached for participation.

Inclusion criteria:

- HIV positive,
- Age range 18-75 years
- All mining employees or contract workers.

Exclusion criteria: Any confusion or inability to answer questions

Sample size

The cross-sectional sample size was determined by reviewing similar cross-sectional studies that sought to determine impairments, function and disability among people living with HIV.

(Levinson & O'Connell, 1991) - 51 patients

(O'Dell et al., 1991) - 37, (O'Dell, 1993) - 30 patients

(Powers et al., 2006) - 46 patients

(Zonta et al., 2003) - 74 patients

(Kohli et al., 2005) - 100 patients

The range was 30-100. The mean was determined to be 60 and the final number was set at 80 for the in-patient group.

In the second group 51 out-patients attending the wellness clinic in Rustenburg were rated.

In both groups patients were identified consecutively by the clinical team in the wards for the in-patient and in the out-patient clinic by the out-patient team. For the in-patient cohort the team screened the patients for suitability using the Karnofsky scale and all patients who scored 30 and below were excluded.

For the out-patient group the patients were approached for participation consecutively and categorized according to their HIV status and time since being on ARV treatment.

4.2.2 Ethical Considerations

- In addition to the institutional clearance shown in Appendix 1.
- Each patient was approached by a member of the clinical team to explain the purpose of the study before the researcher or the assistant, approached the patient.
- A clear explanation was given by the clinical team and an initial consent form signed by the patient.
- Thereafter the researcher explained the study to the patient again and a second consent form was signed by the patient Appendix 4.3.
- Anonymity was assured and all data collection tools were coded on entering data.

4.2.3 Statistical Analysis

Data were entered into a data base designed in Epi-Info 3.3.2. The data were analysed using SAS 9.1 and STATA 9.0 packages. Descriptive statistics were produced for all the demographic variables. For categorical variables frequency distribution tables were used to present the data while for continuous variables measures of central tendency (mean and standard deviations) were used. The Pearson's Chi-Square test was used to determine the associations between certain categorical variables (where appropriate Fischer's exact test was used). Statistical significance was ascertained at the 5% level.

Analysis was performed at both first and second domain level also sometimes referred to as chapter level [(WHO, 2001) ICF pg 14]. Each component was analysed in accordance with the ICF guidelines: What this meant is where a first domain level area such as mental functions had 11 subcategories namely consciousness, intellectual, energy and drive function, sleep ,attention, memory ,emotional functions, perceptual functions, higher level cognitive functions and language. Each of these subcategories was qualified for each patient. To obtain a score for mental functions it was decided that a mean would be taken of the two most frequently of occurring scores. So where 4 subcategories had a score of 2 and 3 had a score of 4 the mean of 3 would be assigned to mental functions. If only two qualifier scores were obtained the mean of these two scores were used. This happened if the patient had no problems in all but two subcategories.

Impairments - analysis was performed to indicate the presence and severity of impairment [(WHO, 2001),ICF pg 12 & 13].

Activity and participation - analysis was performed to indicate the presence or absence of activity limitation and a distinction is made between the performance and capacity qualifier [(WHO, 2001) ICF pg 14 & 15].
Performance qualifier: what the individual does in his/her current environment (lived experience).
Capacity qualifier: the individuals' ability to execute a task or action.

Contextual - environmental factors -The aim was to show the presence or absence of barriers in the patient's environment therefore analysis shows a distinction between environmental factors experienced as barriers and those experienced as facilitators [(WHO, 2001) ICF pg 17].

A logistic regression was done to determine the odds ratios of activity, limitation or participation restriction given certain levels of domains. That is, the odds of activity limitations at given body functions restrictions and in turn the odds ratio of activity limitations on social restriction were calculated. The same approach was also used to determine the odds ratios of impairments on social restriction as shown in Figure 4.1. Thus variables with multiple responses were dichotomised to enable logistic regression analysis to be undertaken. The two groups resulting from dichotomising the coded responses were (1to4) and (0) (see section 4.1.2.3 no 5 component specific coding rules). Those qualifiers indicating "not applicable" or "not specified" were excluded from the analysis.

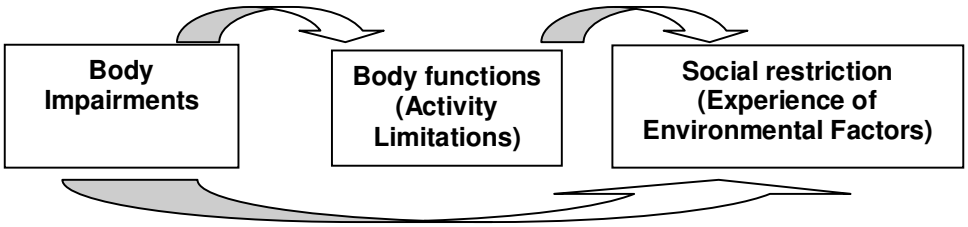


Figure 4.1: Associations Assessed by the Logistic Models

4.3 RESULTS: IN-PATIENT STUDY

The objective of this study was to obtain a relevant overview of the functional and participation picture of people living with HIV. To achieve this, results were analysed to determine the prevalence of impairments activity limitations and participation restrictions. In addition associations among the above mentioned domains were sought for this group of in-patients living with HIV and admitted to Chris Hani Baragwanath Hospital, Johannesburg, South Africa. The results are presented in the sections following.

Of the eighty eight (88) patients approached, eighty agreed to participate giving a response rate of 91%. Twenty nine percent (n=23) were male while 71% (n=57) were female. (In the South African National Health Survey the ratio of male to female is 49% male and 50% female) (SANHS,2005). Of the eighty patients assessed only 45 had CD4 counts available in their notes. The mean CD4 count was 118(±145) with a range of 2-570. However, 29 of the 45 patients had CD4 counts below 100. All patients were black Africans and the demographic characteristics of the in-patient group are seen in Table 4.4. below. With the exception of two patients, none of the patients could give dates since first confirmation of HIV status.

4.3.1 Demographic Characteristics of the In-Patient Group

Table 4.4 outlines the demographic characteristics of the in-patient group.

Table 4.4: Demographic characteristics of in-patient cohort

Variable	N	Proportion of sample (%)	Mean ± (standard deviation)
Age	80	100	37(±8.7)
Gender Male Female	 23 57	 29 71	
***Marital status** Never married Widowed Married	 61 12 3	 76.3 15.0 3.8	
***Years of formal education** no education 7 years and below 8-11 years 12-13 years	 6 23 47 2	 8 29 59 2	
Current occupation Employed Unemployed	 17 60	 21 75	
Karnofsky	80		60(±15)
ARV Ststus	90 %(n=72) could confirm they were on medication but only five confirmed ARV therapy		

*Does not add up to 100% because some patients' data were missing.

4.3.2 Prevalence of Impairments, Activity Limitations and Participation Restrictions in the In-Patient Cohort

Table 4.4.1a summarises the domains and the prevalence in each first level category.

Table 4.4.1a: Prevalence and Qualifiers of Impairments of Body Functions in the In-Patient Cohort (n=80)

First Level Domain	Prevalence		Qualifiers		
	No Problems n (%)	Mild to severe problems n (%)	Mild n (%)	Moderate n (%)	Severe n (%)
b1 Mental functions	22(27.5)	58(72.6)	21(26.3)	22(27.5)	15(18.8)
b2 Sensory functions	13(16.5)	66(83.5)	22(27.8)	29(36.7)	15(19.0)
b3 Voice and speech functions	63(78.8)	17(21.2)	9(11.3)	4(5.0)	3(3.8)
b4 Functions of the cardiovascular, haematological, immunological and respiratory systems	12(15.0)	65(82.5)	20(25)	34(42.5)	11(13.8)
b5 Functions of the digestive, metabolic and endocrine systems	13(16.3)	67(83.9)	15(18.8)	31(38.8)	21(26.3)
b6 Genito-urinary and reproductive functions	49(61.3)	31(38.7)	11(13.8)	13(16.3)	5(6.3)
b7 Neuromusculoskeletal and movement related functions	21(26.3)	59(73.8)	24(30.0)	22(27.5)	13(16.3)
b8 Skin and related structures and body functions	50(62.5)	30(37.5)	21(26.3)	4 (5.0)	4(5.0)

(Note: Percentages do not always add up to 100 because in some cases the assessment of particular impairments was not applicable therefore this would affect the total numbers of patients not adding up to 80 and the case of impairments and qualifiers not tallying)

Once the full data set was analysed, impairments were present in all domains. The five most common impairments were in the digestive, metabolic and endocrine system functions, sensory, haematological, immunological and respiratory functions, neuromusculoskeletal movement functions and mental functions.

The second level domains (chapters) are shown in Table 4.4.1b. These domains give detailed information of areas where most problems occurred in the first level domains

Table 4.4.1b: Second Level Domains of Impairments of Body Functions

First Level Domain	Second Level Domain	(n)%
Mental functions	energy and drive sleep emotional	(60) 75% (56) 71% (49) 62%
Sensory functions	pain	(66) 80 %
Digestive, metabolic and endocrine systems	weight maintenance	(61)76%
Haematological, immunological and respiratory systems	respiratory problems (shortness of breath) haematological problems	(57) 68% (46) 58%
Neuromuscular	muscle power	(60)75%

Under the haematological, immunological and respiratory systems problems with respiration were more prevalent 68% (n=57) as well as haematological problems 58% (n=46). The qualifier levels for second level domains are not graded but the levels are similar to those in Table 4.4.1a.

Table 4.4.2 illustrates the prevalence of impairments of body structure.

Table 4.4.2: Prevalence of Impairments of Body Structures in the In-Patient Cohort

Impairments of Body Structure	**(n) %**
Structure of nervous system	(39) 48.8%
Cardiovascular immunological and respiratory systems system	(47) 58.9%
Structures related to movement	(47) 58.8%

Structural changes that were noted in the nervous system included the spinal cord and peripheral nerves. Most patients 43% (n=34) reported qualitative changes such as changes in sensation or the absence of sensation. Differentiation with functional changes was therefore difficult. Under the category of cardiovascular, immunological and respiratory systems, 66% of patients (n=52) had problems associated with the structure of the respiratory system. Radiographic changes were evident and showed lung destruction and opacity. Muscle wasting was observed under structures of movement.

4.3.2.1 **Activity limitations and participation restrictions**

Table 4.4.3 outlines the prevalence of activity limitations reported in this in-patient group.

Definition of Qualifiers - Activity limitations

As explained in the method section a distinction was made between the first and second qualifier to distinguish between the person's performance i.e. first qualifier (Fq) - in their own environment with help and second qualifier (Sq) - patients own capacity to perform without help.

The difference between the capacity and performance qualifier depicts the number of people who could not cope without help from the environment. This was calculated by subtracting the total number of people who managed the activity in the second qualifier i.e. with help from the environment from those who managed on their own (capacity qualifier). The categories outlined below show the largest differences.

First Level Domains	**Differences**
D6 Domestic life	51.9% (41),
D2 General tasks and demands (e.g. making a cup of tea)	45.2% (37)
D4 Mobility	25.7% (26)

Table 4.4.3 gives the results of all the domains and their performance and capacity qualifiers.

Table 4.4.3: Prevalence of Activity Limitations and Participation Restrictions in the In-Patient Cohort

Sub-domain (Sub Category level1)	Performance qualifier**(with help) (individuals capacity in their usual environment) Degree of difficulty (NB related to qualifier defined above)			Capacity qualifier* (without help) (individuals capacity in a standardized environment) Degree of difficulty		
	Qualifiers			Qualifiers		
	Prevalence			Prevalence		
	No difficulty	Mild/ moderate	Severe/ Complete	No difficulty	Mild/ moderate	Severe/ complete
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
d1 Learning and applying knowledge	67(84.8)	12(15.2)		59(73.6)	13(16.3)	8(10)
d2 General tasks and demands	63(78.8)	13(16.3)	4(5.1)	26(32.6)	36(45.1)	18(21.5)
d3 Communication	69(86)	9(11.3)	2(2.5)	64(79.1)	13(16.3)	3(3.8)
d4 Mobility	35(43.8)	32(40.1)	3(16.3)	19(23.8)	31(38.8)	30(37.6)
d5 Self-care	47(58.8)	30(37.5)	5(6)	35(43.8)	33(41.3)	12(15)
d6 Domestic life	67(83.6)	6(6.6)	7(8.8)	26(32.5)	23(28.8)	31(38.8)
d7 Interpersonal interactions and relationships	50(62.6)	19(23.8)	11(13.8)	48(60.1)	17(21.3)	15(18.5)
d8 Major life areas	35(44.8)	21(26.9)	22(28.2)	25(32)	15(19.2)	38(38.8)
d9 Community social and civic life	40(50)	21(26.3)	19(23.8)	30(41)	25(31.3)	25(31.3)

***Individual capacity to cope *with* help in their usual environment**

** **Individual capacity to cope *without* help in their usual environment**

Patients gave reasons why they could not go out into the community, even when they have the mobility because of fear of stigma or even the inability to find a toilet quickly enough. A logistic regression was used to determine a) the odds ratios of body impairments on activity limitation; b) the odds ratios of activity limitation on social restrictions and c) the odds ratios of body impairments on the experience of the environment. Table 4.4.4 below outlines the odds ratios (point estimate and confidence intervals) and p-values. Only those results that were statistically significant are illustrated.

Table 4.4.4: Results of Univariate Analysis of Body Impairments on Activity Lmitations (CI set at 95%)

Body Impairments (Independent variable)	Outcome variable	OR (CI)	p values
b1Mental	d6 Domestic life fq e4 Obtaining products	0.23(0.07-0.79) 3.04(1.08-8.57)	p=0.02 p=0.04
b2 Sensory	d5 Self-care sq* d6 Domestic life sq*	4.90(1.37-17.84) 4.84(1.68-13.96)	p=0.05 p=0.004
b3 Voice and speech	d3 Communication fq* d3 Communication sq*	6.36(1.62-24.92) 6.75(1.97-23.08)	p=0.01 p=0.002
b4 Cardiovascular haematology respiratory	d2 General tasks* d4 Mobility	14.06(2.75-71.94) 5.40(1.41-20.66)	p=0.002 p=0.010
b5 Digestive, metabolic and endocrine systems	d2 General tasks* d4 Mobility sq d5 Self-care fq d5 Self-care sq d6 Domestic sq	20.43 (4.05-103.03) 5.83(1.64-20.73) 5.01(1.03-24.43) 9.85(2.02-48.17) 8.65(2.30-32.60)	p=0.0003 p=0.006 p=0.050 p=0.005 p=0.001
b6 Genito-urinary and reproductive functions	d3 Communication fq d5 Self-care fq d5 Self-care sq d7 Mobility fq	3.76(1.00-14.34) 2.53(1.00-6.49) 2.64 (1.01-6.90) 2.64(1.00-6.98)	p=0.05 p=0.050 p=0.050 p=0.050
b7 Neuromusculoskeletal and movement related functions	d2 General tasks sq d4 Mobility sq d5 Self-care fq d5 Self-care sq d6 Domestic life sq	6.23(2.10-18.45) 4.08(1.33-12.50) 3.09(1.00-9.57) 3.62(1.26-10.37) 3.67(1.24-10.84)	p=0.001 p=0.010 p=0.050 p=0.020 p=0.020

* Discussed below

Table 4.4.4 shows that patients with sensory problems were five times more likely to have problems in self-care than people without sensory problems. A similar pattern was noticed in patients with impairments in the digestive, genito-urinary and neuromuscular systems. That is, patients with problems in functions of the digestive system were found to be 20 times (4.05-103.03) ($p<0.01$) more likely to experience problems with general tasks than patients without problems. Patients with cardiovascular, haematological, immunological and respiratory systems problems were 14 times more likely to have problems with execution of general tasks (OR 14.06 (2.75-71.94), p=0.002).

Similarly patients with sensory problems were four times more likely to have problems with self-care without help from their environment and five times more likely to have problems with domestic life. Patients with voice and speech problems were six times more likely to have problems with communication in both the capacity (without help from the environment) and performance qualifiers (help from environment). Problems with neuromuscular skeletal and movement related functions had an effect on activities such as general tasks and demands in simple and multiple tasks, mobility, self-care and domestic life.

Table 4.4.5 summarises the prevalence of the in-patients' experience of the environmental factors.

Table 4.4.5: In-Patients' Experience of Environmental Factors

	Barriers			**Facilitators**		
	No barrier n%	**Mild/ moderate Barrier n%**	**Severe/ Complete n%**	**No facilitator n%**	**Mild /moderate facilitator n%**	**substantial complete n%**
e1-Products and Technology	63(78.8)	11(13.8)	6(7.6)	56(70.1)	15(18.8)	9(11.3)
e2-Natural environment and human made Changes to environment	(38)47.5%	30(37.5)	11(15.1)	78(97.5)	(n=1)	(n=1)
e3-Support and relationships	54(67.5)	11(13.8)	15(18.8)	16(20)	18(22.6)	46(57.5)
e4-Attitudes	39(48.8)	16(20.1)	25(31.3)	18(22.5)	18(22.6)	44(55)
e5-Services, systems and Policies	25(31.3)	23(28.8)	31(40)	37(46.3)	23(28.8)	20(25)

Patients reported different aspects of barriers and facilitators. The totals show a summation of the barriers and facilitators with facilitatory experiences in the domains of support and relationships and attitudes, particularly among health workers. Many patients explained how they felt health workers were more helpful and accommodating than any other system they had to deal with. Of note are the less facilitatory experiences with friends and acquaintances, systems, services and policies. Fifty three percent of the patients had mild to severe problems with the natural environment, in particular light and sound. From the subcategories of light and sound under the natural environment, 30% (n=24) experienced problems with light while 34%(n=27) had problems with sound.

4.2.2.2 **Association of impairments and activity limitations on social restriction**

When testing if impairments could have an effect on social restriction problems, only neuromuscular skeletal impairments (b7) were found to have a significant effect on social restrictions. Table 4.4.6 shows the results of the relationships between the activity limitations and experience of environmental factors.

Table 4.4.6: Association of Activity Limitation and the Experience on Environmental Barriers and Facilitators (n=80)

Independent variable	Outcome variable	OR	p value
d2 General tasks sq	e1B Products and technology	9.68(1.20-77.92)	0.03
d7 Interpersonal interactions and relationships sq		3.62(1.09-12.00)	0.04
d6 Domestic life fq		3.97(1.12-14.16)	0.03
d9 Community social and civic life fq		4.13(1.05-16.20)	0.04
d9 Community social and civic life fq	e4F Attitudes	0.19(0.04-0.92) less likely	0.04

When testing if activities had an effect on social restriction, difficulties with general tasks and demands (OR-9.68(1.20-77.92)), interpersonal relationships (OR-3.62(1.09-12.00)), domestic life (OR-3.97) and in community, social and civic life (OR-4.13(1.05-16.20)) were found to be closely associated with barriers in obtaining products for personal use and technology. For most patients difficulties were in the area of acquiring medicines, food and products for personal use. Difficulties experienced within community, social and civic life were less likely to predict attitudes in the community and could not be considered to have an effect on problems with perceived attitudes.

Demographic variables were added to form a multiple regression equation using variables that were found to be significant at the 5% level. From the above only marital status and gender were found to be closely associated with activity limitations and social restrictions. Table 4.4.7 summarises these findings.

Table 4.4.7: The Effect of Body Impairments on Activity Limitations and Social Restrictions when Adjusted for Sex and Marital Status

Independent variable (with level of significance)	**Outcome variable**	**Adjusted OR**
b2 Sensory p=0.004	D6 domestic sq	0.23(0.07-0.77) (p=0.02) gender
b7 Neuromusculoskeletal p=0.009	D4 mobility sq	0.30(0.09-0.99) (p= 0.05) - gender
B7 neuromuscular skeletal	E1F Products	4.17(1.36-12.75) (p=0.01) marital status

Men with sensory problems (B2) were less likely to have domestic problems as indicated by the adjusted OR = 0.23(CI 0.07-0.77) and although they had neuromuscular skeletal problems, they were also less likely to have mobility problems [OR = 0.30(0.09-0.99)] when compared with women. When adjusted for gender, neuromusculoskeletal problems became a stronger predictor of the ability to obtain products in the community (code - E4F) [OR = 4.17 (1.36-12.75) p=0.01 (see Table 4.4. for baseline results)]. Married patients with neuromuscular problems were less likely to have problems in obtaining products for daily use than single patients.

4.4 RESULTS: OUT-PATIENT (MINING GROUP) STUDY

4.4.1 Demographic Results of the Out-Patient Mining Group

Table 4.5.1 shows the demographic characteristics of the out-patient mining group.

Table 4.5.1: Demographic characteristics of the out-patient (mining group)

Variable	n	Proportion of sample (%)	Mean (± standard deviation)
Age	51	100	44.5 (±6.8)
Gender			
Male	50	98	
Female	1	2	
Marital status			
Never married	4	8	
Widowed	3	6	
Married	37	74	
Divorced/separated	14	7	
Cohabiting	2	4	
Years of formal education			
no education	10	20	
7 years and below	23	46	
8-11 years	14	28	
12-13 years	3	6	
Current occupation			
Employed	51	100	
ARV therapy			
On ARVs	44	88	
1 month duration	3	6	
2-6months duration	15	29	
7-12months	19	37	
13-24months	7	14	
Not on ARVs	7	14	

This group consisted of male patients only with the exception of one woman, the majority of whom were on antiretroviral therapy [(44)88% and married [(37)74%]. More than half the subjects had not been to school for more than seven years. Table 4.5.2a outlines the body impairments found in the out-patient mining group. The mean Karnofsky score for the group was 90(±7).

The results shown in the following Tables 4.5.2a – 4.5.4 indicate the domains in which patients experienced impairments, activity limitations and participation restrictions. In some cases the totals do not add up to the sample total because not all variables would be found on every patient. In other words the ICF checklist sought to identify the problems experienced by the patients and it would not follow that every patient will experience every problem. Table 4.4.5 shows the results from the univariate logistic regressions performed on the variables.

In a similar manner to the inpatient group the results are presented at the first level domain . Second level domains are presented where the number of people experiencing the problem

was high. Where for example a first domain level area such as mental functions had 11 subcategories namely consciousness, intellectual, energy and drive function, sleep ,attention, memory ,emotional functions, perceptual functions, higher level cognitive functions and language. Each of these subcategories was qualified for each patient. To obtain a score for mental functions it was decided that a mean would be taken of the two most frequently of occurring scores. So where 4 subcategories had a score of 2 and 3 had a score of 4 the mean of 3 would be assigned to mental functions. If only two qualifier scores were obtained the mean of these two scores were used. This happened if the patient had no problems in all but two subcategories

4.4.2 Prevalence of Impairments, Activity Limitations and Participation Restrictions in the Out-Patient (Mining Group)

Table 4.5.2a: Impairments of Body Functions in the Out-Patient (Mining Group) (n=51)

Domain - Impairments of body functions					
Sub category	**Prevalence no problems**	**Prevalence mild to severe problems**	**Qualifier mild n (%)**	**Qualifier moderate n (%)**	**Qualifier Severe n (%)**
b1 Mental functions	22(44)	29(40)	12(23.5)	14(27.5)	3(5.9)
b2 Sensory functions	18(35.3)	11(21.6)	15(29.4)	4(7.8)	3(5.9)
b3 Voice and speech functions	48(94.1)	3(5.9)	3(5.9)	0	0
b4 Functions of the cardiovascular, haematological, immunological and respiratory systems	24(47)	27(53)	21(41)	6(12)	0
b5 Functions of the digestive, metabolic and endocrine systems	18(35.3)	33(64.7)	19(37.3)	10(19.6)	4(7.8)
b6 Genito-urinary and reproductive functions	39(76.5)	12(29.6)	3(5.9)	6(11.8)	3(5.9)
b7 Neuromusculoskeletal and movement related functions	37(72.5)	14(27.5	10(19.7)	4(7.8)	0
b8 Skin and related structures and body functions	40(81.6)	9(18.3)	7(14.3)	1(2)	1(2)

Impairments were present in all domains with the most prevalent subcategories being the mental, sensory, cardiovascular, haematological, immunological, respiratory, digestive, metabolic and endocrine systems.

Table 4.5.2b outlines the components under the main subcategories outlined in Table 4.5.2a that were found to be problematic**.**

Table 4.5.2b: Components where Patients Experienced Problems in the Out-Patient (Mining Group) (n-51)

Main Subcategory/Domain	**Component**	**n(%)**
Mental functions	Domain memory	11(22)
	Energy and drive	18(36)
	Sleep	12(24)]
	Emotional	14(28)
Sensory domain	Seeing	17(32)
	Hearing	14(28)
	Vestibular)	14 (28)
	Pain)	28 (55)
Cardiovascular, haematological and respiratory	Blood pressure problems	10(20)
	Breathing problems	12(22)
Digestive system	Diarrhoea	8(16)
	Weight maintenance	32(63)
Reproductive and sexual	Sexual functions (of note reduction in libido)	11(22).
Muscular skeletal system,	Muscle power	12(24)

Table 4.5.3 shows the activity limitations and participation restrictions in their usual environment. This table therefore shows only the performance qualifier. Pain, energy and drive and weight maintenance were the areas where patients had the most problems.

Table 4.5.3: Activity Limitations and Participation Restrictions in the Out-Patient (Mining Group) (n=51)

Sub Category	Performance qualifier(with help) (individuals capacity in their usual environment) Degree of difficulty		
	Qualifiers		
	No difficulty	Mild/ Moderate	Severe/ complete
	(n)%	(n)%	(n)%
d1 Learning and applying Knowledge	4(80.4)	10(19.6)	0
d2 General tasks and demands	49(96.1)	2(3.9)	
d3 Communication	51(100)	0	0
d4 Mobility	39(76.5)	5(9.8)	7(13.7)
d5 Self-care	50(98)	1(2)	0
d6 Domestic life	48(94.1)	3(6)	0
d7 Interpersonal interactions and relationships	46(90.2)	1(2)	3(6)
d8 Major life areas	40(78.4)	5(9.8)	1(2)
d9 Community social and civic life	47(92.2)	4(7.9)	0

Activity limitation in this group was present in a small number of subjects. Twenty percent reported problems in learning and applying knowledge [n = 10 (20%)], and 24% reported problems with mobility (n = 12).

Table 4.5.4 outlines the experience of the environment as reported by the out-patient mining group.

Table 4.5.4: Environmental Factors in the Out-Patient (Mining Group) (n=51)

(Where patients felt this was not applicable to them it was scored N/A)

Qualifier	Barriers			Facilitators		
	No barrier	Mild/ moderate barrier	Severe/ complete	No facilitator	Mild/ moderate facilitator	substantial complete
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
e1-Products and technology	48(96)	1(2)	1(2)	20(39.2)	2(4)	29(56.8)
e2-Natural environment and Human made changes to environment	29(58)	14(28)	7(14)	5098)	0	1(2)
e3-Support and relationships	45(92)	3(6)	0 (3-n/a)	21(47.1)	1(2)	26 (53.1) 3-n/a)
e4-Attitudes	46(92)	0	3(6)	24(47.1	0	25(49) 2(n/a)
e5-Services, systems and policies	37(84.1)	1(2)	6(12)	18(38.3)	1(2.7)	28(59.5) 6(n/a)

The out-patient mining group reported fewer barriers in their experience of the environment. Those who reported barriers in obtaining products for their use in the community were predominantly living in informal settlements as opposed to company provided housing.

- The products included food and telecommunications. Environmental barriers were reported as hypersensitivity to light and sound.
- Patients reported a facilitatory experience in the domain of support and relationships predominantly from health workers. Very few reported on support from friends, work acquaintances, neighbours or family as they had not disclosed their status in these relationships.
- In the domain of services, systems and policy the experience was predominantly facilitatory as shown by the numbers reported in subcategories under this domain:
- Housing 32(63%), communication 29(57%), transport 31(57%), social security (37(75%) and health 42(84%).

4.4.2.1 **Association of impairments onactivity limitation and social restriction**

Table 4.5.5: The Effect of Body Impairments on Activity Limitations and Social Restrictions in the Out-Patient (Mining Group) (n=51)

Independent Variable	Outcome Variable	p-values	OR (CI)
b2 Sensory	e F Products	p=0.02	4.90(1.365-17.84)
b4 Functions of the cardiovascular, haematological, immunological and respiratory systems	e2 B Natural e4 FAttitudes	p=0.02 p-0.02	4.09(1.2 - 13.69) 4.05(1.2-13.53)
b6 Genito-urinary & Reproductive Functions	e3F support e5 B services	p=0.03 p=0.05	11.77 (1.37-101.49) 5.71(1.04-31.54)
b7 Neuromusculoskeletal & Movement Related Functions	d1SQ learning d4SQ mobility d8sq major life	p=0.02 p=0.01 p=0.04	6.89 (1.08-43.91) 6.4(1.56-26.19) 6.8(1.08-43.91)
d8 Major life	e4B attitudes	p=0.03	18.50(1.36-252.27)

Patients with sensory problems were less likely to have a facilitatory experience with the acquisition and utilization of products and technology.

Patients with problems with the functions of the cardiovascular, haematological, immunological and respiratory systems were four times more likely to have problems in the natural environment. The same group was less likely to have facilitatory experience with their encounter with attitudes. Patients with problems in the genito-urinary and reproductive system are eleven times more likely to experience support and better relationships from family and/or friends and in this case health workers and five times more likely to experience barriers with services.

Problems with neuromusculoskeletal and movement related functions were over six times more likely to experience problems in the areas of learning, mobility and community and social services.

When adjusted for demographic variables (gender, age marital status and length on antiretroviral medication) in a multiple logistic regression model, with backward elimination, the odds ratios produced were smaller and the confidence intervals narrowed. Only length of treatment was found weakly significant in the multiple models. (People who had problems

with major life areas had an average of 0.13 more months on treatment compared to those who did not have problems with major life areas).

4.5 DISCUSSION OF RESULTS OBTAINED FROM IN-PATIENT AND OUT-PATIENT GROUPS

The objective of this study was to obtain a relevant overview of the functional and participation picture of people living with HIV. The discussion will focus on the profile obtained in terms of demographic data impairments, activity limitations and participation restrictions and is combined for both sets of patients i.e. the in-patient and out-patient (mining group). In doing this part of objective one is also covered where the description of HIV/AIDS disease in terms of the International Classification of Function (ICF) for physiotherapists in the South African context is done.

Patient Profiles

The in-patient group were all hospitalised and ill. They had a Karnofsky scale ranging from 30%-90% and a mean score of 60% indicating that most required occasional assistance for some activities but were able to care for their needs. In contrast the out-patient mining group was independent with a Karnofsky of 90 and had a higher mean age (44.5±6.8). Proportionally the out-patient mining group had lower levels of education and the majority was married. Their socio-economic status could be considered as more reliable, supported and robust. This could contribute to the reported higher levels of activity and function.

Impairments of Body Function

The in-patient group revealed a complex picture of high rates of impairments associated with activity limitations and participation restrictions. In comparison with the in-patient group the level of impairments found for the out-patient, mining group was lower but none the less present. This contributes to building an accurate picture of a cohort of a typical HIV infected out-patient group in a mining set up and an in-patient South African population.

The high rate, as well as the variation in impairments found in this in-patient group was also reported in other studies. (Anandan et al., 2006; Crystal et al., 2000; Rusch et al., 2004; Zonta et al., 2003 ; Zonta et al., 2005),. Both domains of physical and mental related functions had high rates of impairments with problems in muscle strength being most prevalent in the in-patient group and all patients in this group were classified clinically by the medical team as being at stage three or four of HIV disease (WHO clinical staging).

Consistent with the multi-organ involvement of the HI virus, (Danbauchi & Okpapi, 2001; Hinz et al., 2002), and the extensiveness of the ICF, each patient, in the in-patient group, reported problems in four or more body functions in clinical and self reported impairments. Although impairments reported in the out-patient mining group were lower, they were nevertheless still present (Table 4.5.2a). High impairments were evident or reported in the areas of mental and sensory functions, of the cardiovascular, haematological, immunological and respiratory systems. Specific problems highlighted under sub domains inform the rehabilitation professional of the problems that are likely to be related to functional deficits.

Those problems under sub-domains are discussed as well as where appropriate, their significance for rehabilitation and physiotherapy. Energy, drive, sleep and emotional functions were problematic and are supported by other studies that found mental health, fatigue, depression and memory problems to be problematic (Fields & Selwyn, 2003; Hwang & Nochajski, 2003; Kohli et al., 2005; Okochi et al., 2005; Rusch et al., 2004). Kohli (2005) reports a high level of sleep disturbances among people living with HIV that impact negatively on their health-related quality of life. Worthington et al. (2005) indicated that rehabilitation of psychologically related problems was important within the rehabilitation framework. Physiotherapists involved in the management of PLWH must be aware of this need in order to ensure a holistic approach to care.

Shortness of breath was a major complaint among both cohorts. Cogniscance is taken of the fact that out-patient mining groups have other risk factors such as dust and particle exposure (Ross and Murray 2004). The highest number of impairments in the out-patient mining group was in digestive, metabolic and endocrine function.

These results suggest the need to pay attention to impairments, such as pain, breathing problems and shortness of breath and how they influence activity levels and participation restrictions. In order to provide an appropriate and sensitive level of care, the physiotherapist needs to be aware that the breathing problems and specifically dyspnoea [71% (n=57) in the in-patient cohort and 53% (n=27) in the out-patient mining group] experienced by the person infected with HIV will in turn affect activity levels. Furthermore the underlying pathology may be a result of the direct effect of the HI virus on the pulmonary vascular system which results in a reduction in the diffusion capacity (Diaz et al., 1999), lung damage after infection or possibly the effect of anaemia. In addition to this, recent evidence points to the presence of pneumocysticis colonisation (PCP) being associated with

the development of COPD. This could contribute to the experience of breathlessness (Morris et al., 2008). Therefore physiotherapy should be involved in interventions to facilitate, control and manage of such symptoms.

There is a paucity of literature that explores self reported impairments such as muscle aches, muscle power, energy, fatigue and drive, sexual functions, memory loss and emotional functions prevalent in people with HIV and the individual's performance in activities of daily living and community participation/ social isolation (Anandan et al., 2006). In South Africa the documentation of functional problems has been in its relation to HRQOL studies (Hughes, 2004; Jelsma et al., 2006; O' Keefe & Wood, 1996). No literature on such data could be identified for the mining sector.

Such problems as pain, energy and weight maintenance have been identified in studies by O'Keefe et al. (1996), Cunningham et al. (1998), Zonta (2005), Hughes et al. (2004). A study by Anandan (2006), reported fatigue as the most severely experienced impairment, in the ICF; this was expressed as low energy and drive and in this study, where 76% (n-61) had problems. Fatigue has been reported previously as contributing to limitations in activities such as mobility, activities of daily living and communication (O 'Dell et al., 1996). Fifty nine percent (n-47) of the in-patients and 17% (n=9) of the out-patient mining group had low haemoglobin which, as outlined by Volberding (2003), may be a direct result of the HIV infection or indirect side effects of the medication and may contribute to a low energy drive. Impairments such as weight loss were common in this study but have been reported as not being accurate indicators of quality of life once a patient becomes symptomatic (Cunningham et al., 1998). However, the complexity of the effect of HIV on the different body systems is illustrated by associations found between body mass index and diffusion capacity (Diaz et al., 1999). In this study, weight maintenance was reported to be a major problem. The underlying mechanisms for loss of body weight are multifactorial with the literature reporting direct effects of HIV on protein metabolism, muscle bulk, nutritional deficiencies due to mal-absorption and gastrointestinal abnormalities, increased resting energy expenditure and infections (Macallan, 1999; Wanke, 2004).

Both groups, in and out-patient (mining), reported problems with pain. In both studies pain was associated with physical activity problems. Pain experienced by HIV patients can have multiple origins: firstly, the HIV infection itself or its consequences (infections, tumours); secondly, treatments for AIDS; or, thirdly, it can be unrelated to the disease and its treatment. HIV-related pain has been found to impair both functional and affective

components of daily life (Larue et al., 1997). Pain has been reported in numerous studies as a common manifestation as well as being associated with activity and role limitation. (Cunningham et al., 1998; Lindberg, 2006). Researchers have used many HIV-appropriate health-related quality of life measures to express that sensory and pain issues are prevalent among PLWH e.g. EuroQol-5D, Medical Outcomes Survey-HIV and Medical Outcomes Survey-Short Form-36 (Babbie & Mouton, 2003; Braitstein et al., 2005; Hughes et al., 2004; Ruiz Perez et al., 2005). Use of the ICF Checklist in this study also showed that sensory issues and pain are common amongst PLWH.

Physiotherapists already deal with pain relief and should be involved in intervention strategies to relieve pain as well as self management strategies (Lang, 1993). Studies could not be found that have looked at the clinical effect of exercise on the perception of pain in patients with HIV specifically. For pain management, beneficial effects using modalities such as massage (Posner et al. 2004 in a clinical trial), microcurrents in a prospective study, (Galantino et al., 1999) acupuncture effects studied in a case control study (Henrickson, 2001) use of aids and appliances and improvement of the level of activity in a case report (Harris-Love & Shrader, 2004) all at different levels of evidence.

Problems in genito-urinary, reproductive, neuromusculoskeletal and movement related functions, as well as the digestive, metabolic and endocrine systems significantly affected activities such as self-care, domestic life activities and mobility thus indicating the need to focus on these areas of function in order to improve the patient's level of functional activity and subsequent health-related quality of life. The underlying reasons for this association need to be explored in future research as they could be associated with personal, contextual and environmental influences. It may also indicate that the association between impairments, activity limitations and participation restrictions is not unidirectional. Patients who reported digestive problems complained of frequent toilet use and found they could not therefore venture out. This would indicate a contextual reason for poor participation. The results discussed above, where associations or relationships were found are consistent with those reported in the literature (Crystal et al., 2000; Zonta et al., 2005). From the clinical picture drawn there are possible implications for exercise prescription, training programmes and intersectoral collaboration in the management and resource allocation for PLWH.

For mine workers, problems in the neuromusculoskeletal and movement area had an effect on mobility, learning and major life areas all of which can be affected by lack of energy, weakness and associated mobility problems. In addition to significantly lower muscle

strength, mineworkers reported loss of stamina which affected their endurance when conducting heavy duties in their work place. Most mine workers reported facilitatory experiences and were satisfied with the service they received. They sought assistance for most impairments experienced. One can deduce that many of the problems experienced by the in-patient group were not as evident in the out-patient mining group due to the better support structure. To improve the HRQOL of people living with HIV some of these support structures could be emulated.

With the expansion of the anti-retroviral programme, (ARV) in South Africa, there is need to focus attention on the management of impairments that will have a profound bearing on the patients' functional status. The multi-organ involvement of HIV/AIDS has clinical implications that may affect patients' capacity for exercise and ability to continue with daily activities and ultimately their quality of life (Mars, 2004a). Consistent with other literature, activity limitations and functional deficits for the in-patient and out-patient mining groups were high and had an impact on the patients' functional capacity.

Functional Deficits and Activity Limitations

A contrasting picture emerged with regard to the functional deficits and activity limitations between the out-patient mining and in-patient groups. The out-patient mining group reported very few activity limitations and functional problems. One of the problems reported by 19 % (n=10) of the out-patient mining patients, was that of learning and applying new knowledge. This is unsurprising as cognitive deficits have been reported as a result of HIV. Patients would need the correct application of assessment tools to determine the impact of cognitive effects on a person's functioning. In-patients reported having one or more difficulties with activity. The difference in activity limitatiion in the out-patient mining group can be attributed to the difference in stage of illness, availability of ARVs and a better support structure.

Apart from delineating the amount of disability, the ICF allows for a differentiation between what the patient can do on his own and what he can do within his environment with his usual supportive measures in place. Supportive measures may include external help from people, aids and appliances or other helpful measures such as support groups. In the in-patient group, there were differences in the patients' execution of activities with help (performance) and without help (capacity) (Table 4.4.3). The activities where differences are evident are general tasks and demands, mobility and domestic life, between the capacity and performance qualifiers. This would imply that these patients are dependent for their activities on outside help because their capacity to carry out activities is low. For example

patients who reported the ability to cope with domestic chores with help from the environment were obtaining help from family or friends. When asked how they coped on their own, they could not manage. In the in-patient group immediate family are carrying the burden and results may indicate that factors beyond the patients' impairments alone are compounding the patients' disability experience. Factors such as uncertain living conditions, lack of education, social isolation should be noted (Anandan et al., 2006; Vidrine et al., 2003) Most in-patients did cite that they were in the process of moving from their current address to live with someone who could assist them. Among the mine workers problems were reported by those who lived in informal settlements and not in the accommodation provided.

The burden on families of PLWH may indicate the need for training of families in patient-based needs and exploring and analyzing the community situation. For example, in the area of mobility which would be a key area for physiotherapists there was a difference of performance with and without help (54% reported difficulties with help and 75% difficulties without help). Mobility is a major activity affected by many body impairments related to HIV/AIDS and these results are supported by similar studies which reported mobility, as part of physical functioning and health-related quality of life, to be an important problem amongst PLWH (Hughes, 2004; Webb & Norton, 2004; Williams & Webb, 1994). As mobility is an important part of physical function, it has an effect on participation in other activities such as self-care, domestic life and access to services. Self-care and domestic tasks were demonstrated to be important areas of dysfunction among in-patients and were not significantly affected by areas of body impairments as found by other studies (O'Dell et al., 1998; Rusch et al., 2004; Webb & Norton, 2004; Zonta et al., 2005). This would indicate that mobility needs to be an area where the patient requires his own competence and in this activity, training of the patient and dealing with underlying impairments such as weakness and pain should therefore be closely managed. This again highlights the importance of physiotherapy involvement in the care of PLWH.

Similar to the findings by Van As et al. (2008), the out-patient mining group, found that self-care and domestic problems were not associated with impairments present, but mobility was. Patients in the out-patient mining group were already receiving rehabilitation intervention and reported attending strengthening programmes, post any episodic illness. Previous studies have indicated the need to promote exercise and physical activity as a preventative measure for weakness and they contribute to overall good health (Zonta et al., 2003).The benefits of exercise for the population with HIV/AIDS have been extensively

researched as outlined in a Cochrane review by O'Brien et al. (2005) and other authors where exercise has been shown to increase muscle strength, endurance, improve body composition and led to improved mood and quality of life (Dudgeon et al., 2004; Stringer et al., 1997). It is interesting to note that patients in the out-patient mining group are tested for work fitness using a functional work fitness battery of tests that assesses their endurance, stamina and strength to cope with the work they are employed to do. If there should be a reduction in their capacity they are referred for exercise and any appropriate rehabilitation.

Results published by Rusch et al. (2004) and Anandan et al. (2006) on the domains of difficulty, although similar to this study, do not differentiate between how the patient copes with and without help from his family or the community, thus failing to indicate the true patient situation before the community, including the family, participates in patient care. In the in-patient group the needs in areas of self-care, general tasks and to a lesser extent mobility are being compensated for by community factors. In programme development and policy direction such information would be important. Activities undertaken without community assistance in the domains of general tasks and demands that involve undertaking simple tasks, interpersonal relationships and community and civic life were found to have a significant negative effect on patients' experience of their ability to obtain food, transport, housing and communication. Findings from other studies, (Ruiz Perez et al., 2005) where the absence of social support was found to be associated with a worse quality of life support these findings. Understanding these types of community dynamics would influence rehabilitation management plans, the content of patient education, referral networks and the points and types of interventions on which community-based organisations and other health services dealing with HIV should focus their attention (Anandan et al., 2006; Rusch et al., 2004). It is important to note that the in-patient group still shows many activity limitations that are related to basic activities of daily living whereas the literature dealing with better resourced groups is concerned with instrumental ADL e.g. work role, function and wider community participation. For example, Crystal et al. (1996) found working at a job around the house or going to school were more prevalent than limitation in more specific physical tasks such as walking, climbing stairs and general small tasks as seen in this study (Crystal et al., 2000; Gielen et al., 2001).This difference explained above, may be in part due to the less uniform roll-out of the ARV programme in South Africa with many factors leading to patients not going on ARV (Nelson Mandela Foundation & Human Sciences Research Council, 2002).

Attempts to get an accurate picture of the in-patient group's ARV status were not successful as 90 %(n=72) could confirm they were on some sort of medication but only five confirmed ARV therapy. In contrast to the in-patient group the patients in the out-patient mining group are on ARVs and maintain a high level of function despite episodic deterioration.

Limitation in activity for the out-patient mining group pointed to limitations at work and not instrumental domestic chores. Greater limitation in activity has been reported to be associated with cognitive impairment (Benedict et al., 2000), older age, lower educational attainment, more advanced disease, and higher symptom burden (Crystal et al., 2000). Limitations in activity and participation restriction in the in-patient group in this study were associated with marital status and gender. However, a population based study may yield different results. This may be attributed to contextual issues such as culture. The position of women in society has been shown to be a strong influential factor in the coping and functioning of people living with AIDS (UNAIDS, 2006a). The out-patient mining group only had one female subject therefore this may contribute to the lesser burden of activity limitation. Cunningham et al. (2005) found an association between functional status, associated HRQOL and survival after controlling for socio demographic variables, CD4 count and HAART (Cunningham et al., 2005). Further analysis in the same study showed that body pain and physical functioning were uniquely associated with survival and could be considered prognostic indicators. In this study, both these domains were found to be high (Tables4.4.1a and 4.4.1b) as part of sensory impairments and should therefore be addressed through appropriate interventions.

In relation to the experience of the environment a mixed picture was found (Table 4.4.5). A high number of patients reported positive facilitatory experiences with health workers, however environmental barriers could be minimized among attitudes and support of friends and acquaintances. Community services could still be harnessed to ensure facilitatory and quality of life enhancing experiences for PLWH.

In-patients experienced hypersensitivity to light and sound. Jelsma et al. (2006), found the same experience in a group of out-patients within a natural environment where 53% of the patients had mild to severe problems with the natural environment, in particular light and sound.

4.5.1 **Challenges Experienced During Data Collection of this Study**

The results of this study helped to identify important areas of physical impairments, activity limitations and participation restriction in a South African in-patient cohort and an out-patient mining cohort. They also indicated the need for holistic assessment of the patients' physical

status and management of these challenges in order to positively affect the HRQOL of PLWH. However, certain challenges were experienced in conducting this study and they are:

- The ICF checklist is a very detailed tool and required the use of other measures to ensure reliability and validity of the process of completing the checklist as shown in Appendix 4.2. However, in transferring these data and assigning a score to the ICF qualifiers, reliability could possibly be negatively affected. The researcher minimized this by limiting the number of assessors to two and the two met frequently until there was congruence in the interpretation of answers given. In addition the data obtained from the validated data such as dynamometry and laboratory markers were assessed and scored by the researcher only.
- Lack of information in the in-patient group regarding the time since infection or diagnosis, CD4 counts and duration of ARV treatment was problematic.
- For better generalisability this study needs to be conducted among a wider range of patients in different contexts in order to get a more representative picture. In spite of this the study does give an indication of where the key problem areas are in an in- and out-patient group. The results do confirm what has been found in the literature and in a study by Van As et al. (2008) that used the ICF check list, with contextual differences taken into consideration.
- The use of the ICF gave a comprehensive overview, however the checklist is long and standardization of the variables proved to be a very long process. A list that is specific to HIV and shorter may be more suitable and easier to conduct.
- Generally, in some domains, wide confidence intervals and very high odds ratios were found. This can be attributed to the high variability in the nature of the data being self reported on activity limitations and participation restrictions.
- However generally the ICF check list is a good survey tool. It allows for more in-depth and a wide range of information to inform the HIV profile from a rehabilitation perspective than other available tools.

4.5.2 **Concluding Summary**

In summary this study provides an overall description of an HIV patient in two different settings. The type of problems these patients will have when described within a framework that physiotherapists understand and work with are outlined in a cohesive manner. The ICF gives detail of the levels and interactions between impairments, activities and participation that are closely related to function and subsequently influence participation in society in a

cohort of people infected with HIV. This in-patient group had high levels of impairments and activity limitations while a well resourced out-patient mining group had fewer problems. These results may contribute to care interventions and the contribution of rehabilitation which may in turn improve prognosis. The problems of pain, shortness of breath, reduced muscle strength, reduced energy and their subsequent effect on activity limitations should be considered in any programme development. All therapists dealing with people living with HIV should have an understanding of how the affected body systems evident in the impairments, domains ultimately influence activity and participation. This would facilitate a more comprehensive approach to the rehabilitation of PLWH. From the results of these two studies a patient profile can be derived for the in-patient and the well resourced out-patient group.

4.5.3 Patient Profiles

These profiles give a picture of what a typical HIV in-patient and out-patient in a well resourced set up experiences when assessed using the ICF checklist. In addition, results from Van As et al (2008)'s study were taken into consideration.

In-patient profile

Patients in a public health hospital in Gauteng, South Africa

Demographic profile

In-patients will be:

- Male or female
- Predominantly unmarried or cohabiting
- Will not have completed secondary education
- Employed

Impairments of body function

May present with problems of

- Muscle power
- Energy and drive,
- Disturbed sleep,
- Emotional problems
- Mild-severe pain
- Weight maintenance difficulties
- Diarrhoea

Impairments of body structure

May present with

- Changes in sensation or the absence of sensation.
- Lung destruction and opacity

They will have capacity problems in

- Domestic life
- General tasks and demands
- Mobility

Out-patient - mining Group profile

Demographic profile

- Male
- Married
- Will not have completed secondary education (7 years and below)
- Unemployed

Impairments of body function and structure

- Memory problems,
- Energy and drive functions,
- Sleep and emotional functions
- Seeing,
- Hearing,
- Vestibular and pain
- Blood pressure and
- Respiratory problems
- Weight maintenance
- Sexual functions
- Muscular power (proximal)

Activity limitations and participation restrictions

- Learning to read
- Walking and mobility (reduced endurance)

The principles of mainstreaming state that any programme that aims to mainstream HIV or any issue of importance should define a clear entry point. The results of the patient profiles may be the foundation of defining an entry point for physiotherapists to mainstream HIV into the curricula. Having described the patient profile it is possible for academics to translate this information into knowledge and practice needs within each body system.

CHAPTER 5

STUDY 3: ASSESSMENT OF THE CURRICULUM

5.1 INTRODUCTION

The overall aim of the study is to develop a model for mainstreaming HIV into the curriculum and practice of physiotherapy. So far the preceding studies (chapters 3 and 4) have sought firstly to establish how much physiotherapists are interacting with HIV by looking at the referral patterns and therefore seeing the type of patients with HIV that physiotherapists are interacting with. The second study sought to establish the profile of patients with regard to their impairments activity limitations and participation restrictions. This chapter comprises an audit of the written curricula of all eight universities offering physiotherapy training in South Africa. The purpose of auditing the universities curricular documents was to establish what is currently included in the curriculum. The results of this audit will contribute to understanding what physiotherapy education in South Africa has done so far in response to the HIV pandemic and will serve as a basis for developing conceptual framework and practice aims.The objective of this study was to assess the curricula at South African universities in terms of the HIV content related to the disease profile and referral patterns

5.2 METHOD

Procedure

Eight South African universities with physiotherapy degrees were asked to submit their full curricula and any information pertinent to HIV/AIDS within the curricula.

An audit of all the documents was conducted. Information was extracted to inform the following categories:

- Institution and year when the curriculum was developed
- Type of document provided for the audit
- Year of study in which the input is given
- Subject areas where HIV is covered
- Purpose of HIV input
- Expected outcomes
- Topics covered
- Content and assessment of the subject area

The audit was conducted and the current content on HIV was established for each university in as far as could be ascertained. Hence this was the tool used to collect and collate the information.

The results of the audit were sent back to each institution and they were asked to fill in any gaps that were evident from the first round in a second audit. A second audit was necessitated because there were gaps in the information supplied.

Upon receipt of all the curricula after the second round, the audit from seven universities was compiled (one did not respond) was undertaken. Specific areas were categorised and grouped within each of the components namely subject areas where HIV is reflected, the purpose of the course, its outcomes, topics and content.

5.3 RESULTS OF CURRICULA AUDIT

Out of the eight universities that offer physiotherapy training seven responded and sent their curricula for audit. Five of the universities sent a full curriculum and two gave extracted information. One university did not respond. The findings are shown in Tables 5.1 and 5.2.

5.3.1 Findings of Curricular Audit and Discussion

The subject areas are summarised collectively from all seven universities in the Table 5.1 below. Appendix 5.2 gives the outline of each universities input on HIV/AIDS.

Table 5.1: Initial Audit: Combined Results for all Universities

Subject area on HIV in physiotherapy curriculum	No of universities
HIV pathology, theory of HIV/AIDS and epidemiology	4
Specific opportunistic infections such as pneumocysticis carini pneumonae (PCP)	2
Paediatric manifestations and impact on child development	1
Impact of HIV in general	2
Philosophy of care	1
Infection control (one put HIV awareness for their own protection)	3
Professional approaches to HIV/AIDS	1
Relevancy of HIV in physiotherapists professional lives	1
Psychological impacts on patients	1
Implications for physiotherapy	1

Following the initial audit the results were sent back to each institution to verify that this was the information they were teaching with regard to HIV/AIDS. Additions were made by five of the seven universities and topics such as cardiopulmonary conditions related to HIV, impact and implications of HIV in spinal cord manifestations were added. The results are shown in Table 5.2.

Table 5.2: Results of the Combined First and Second Round Curriculum Audit

Subject /Areas where HIV/AIDS is reflected	Purpose of the course	Outcomes (what you want the student to be able to have learnt in that area i.e. Competency)	Topics	Content	Assessment
-Clinical physiotherapy	None noted	Knowledge empowerment so that expected outcomes are realistic	None noted	None noted	None noted
-Conditions medical/surgical	Empower students with knowledge	Clinical awareness	None noted	None noted	None noted
-Becoming a professional	Leadership and professional conduct	-Assess an adult with HIV functionally Plan and execute a daily plan -to ensure they are sensitized to the condition -Socially make informed decisions	HIV awareness for their own protection	-Basic relevancy of HIV in their professional lives	None noted
-Basic and applied neurosciences -Neurological manifestations of HIV -Spinal cord injuries	None noted	Understand HIV as one of the causes of SCI Apply the necessary precautions during treatment of an SCI patient with HIV	Neurological manifestations of HIV -Neurological changes -Spinal cord manifestations	-Neurological manifestations of HIV -Changes in the neurological system due to AIDS	None noted
-Paediatric - HIV and its impact on child development	None noted	None noted	Epidemiology,transmission,testing,TB Encephalopathy, developmental delay, PCP and LIP	None noted	None noted
-Theory of HIV/AIDS	None noted	None noted	-What is HIV -HIV History and epidemiology, signs and symptoms -Background pathology and epidemiology	-Pathology of the condition -Complication and opportunistic infections	None noted
Philosophy of care -Theory of HIV/AIDS	None noted	None noted	-Specific impacts of HIV -Implications for physiotherapy -To undertake training for home carers -Psychological impacts and intervention -Nutrition -Immunological disease -HIV/AIDS in philosophy of care -Underlying theory of HIV/AIDS -Transmission, infection, pathology, prevention, stages and treatment	-Social impact -Effect on the population -Policy of government matters -Positive effects of Nevirapine mother to child -The terminal sick patient Physiotherapy handling of complications -Effects of exercise Handling and contact with body fluids and needle stick injury -Training for home care -Psychological impact on the patient and family -Basic nutrition for patients with HIV	-Clinical block evaluations test

Table 5.2 continued

Subject /Areas where HIV/AIDS is reflected	Purpose of the course	Outcomes (what you want the student to be able to have learnt in that area i.e. competency)	Topics	Content	Assessment
Covered under -pulmonology, -othopaedics and PNF -Manual therapy -Women's health -Courses not taught as specific diagnosis " We teach according to problem based learning do not teach the disease on its own but teach basic principles and treatment modalities ***"(from one university***)	Awareness	Knowledge skill and attitude related to the course	-Gender implications, HIV/AIDS and law counselling, peer education and adherence -Emphasise safety precautions regarding HIV, TB hepatitis and other contagious diseases -Contra-indications and precautionary measures -Breastfeeding -Ethics professional development, leadership management	None noted	-Practical and clinical -Self assessment, -Peer assessment, -Practical tests applying skills, reflection exercises, small research exercises, -Assignments -Video tapes web based self tests
-Cardiopulmonary physiotherapy	None noted	-Confidence in handling patients -Confidence in physiotherapy treatment -Effective rehabilitation of patient -Discernment regarding involvement of physiotherapy i.e. indication s and contra-indications	Transmission, testing, role of physiotherapy in exercise rehabilitation for HIV/AIDS patients. Pathophysiology of PCP and the role of physiotherapy in the management of the PCP patient. Pathophysiology of TB and the role of physiotherapy in the management of TB	None noted	-Clinical placements and exams -Clinical placements/ exams -Theory test and exams
-Infection control	None noted	-Precautions -Safety measures patient handling	Testing how to handle a needle stick injury	Handling of hospital and intensive care Precautions for physiotherapists	None noted

The curricula were generally scanty on information regarding HIV/AIDS. According to the SAQA guidelines a curriculum unit standard should reflect the purpose, outcomes, assessment criteria, content, teaching and learning strategies, the level at which the subject unit is taught, topics and notional hours or credits (SAQA, 2000). SAQA summarises the purpose of the curriculum as that of dealing with standards setting, learning programme development and delivery, including its assessment and the assessment of its quality of input and student learning.

From the documents received two of the seven universities outlined all the above criteria with regard to the subject areas and where HIV was reflected. In general information on HIV in the curriculum was insufficient when compared to the information found in the literature

review in Chapter two and the results of the patient study in chapter 4. In four of the universities the curricula reflect that HIV is introduced in first and second year. Basic HIV pathophysiology and what some referred to as philosophy and epidemiology of HIV/AIDS are covered

Application and implication of HIV knowledge to physiotherapy is introduced in the third and fourth year. In all the documents received the purpose of the course was not evident and outcomes were outlined by one university only. There also seems to be a difference in the interpretation of what outcomes, topics and content is also evident.

According to SAQA, outcomes are important starting points for the curriculum. The results in Table 5.2, show that outcomes for the learning area of HIV/AIDS are clearly outlined for the topics related to clinical physiotherapy such as cardio pulmonary, infection control and to a lesser extent neuro sciences. The information on the topics covered does not tally well with the subject areas and can be judged as not explicit enough. The purpose of the course and the content is also not clearly outlined. When the curriculum input is viewed collectively for all eight universities, HIV is intergrated into some of the various physiotherapy specialization areas but not fully so. When compared to the areas outlined as a result of the literature review, the study of the patients and focus groups (described in chapter 6) with clinicians and academic staff, there are gaps, in particular:

- the types of conditions, influence of HIV on other body systems which are pertinent to the clinical reasoning process for the physiotherapist:
- the philosophy of care
- approach to management
- the physiotherapists role in HIV prevention treatment and care.

5.4 CONCLUSION

After assessing what each university made available to the researcher, the written curricula did not reflect all the criteria outlined by SAQA (2008) as essential in the description of a sub unit (Gaps evident in Appendix 5.2). A much more comprehensive picture is gained when the results of all eight universities were combined after the second round (Table 5.1). However, individually, the universities do not reflect a complete picture of the educational approach to HIV/AIDS. There are gaps in some of the institutions in areas such as cardiopulmonary, neurology, clear physiotherapy input, principles and philosophies of treatment. These gaps are reflected in Appendix 5.2 where each university's summary of

HIV input is shown in the table.To ensure that this lack of detailed information is reflective of the actual content delivered, all universities were asked to elaborate in the second round.

At this point in the study, the literature review within the ICF framework revealed topics for curricula content such as those related to the body systems and issues concerned with function, HRQOL, physiotherapy philosophy and topics perculiar to HIV. It was therefore necessary to collate all this information and verify it with the target group concerned. To do this, focus group discussions with clinicans and academics and a Delphi survey technique with academics was conducted.

CHAPTER 6

STUDY 4: FOCUS GROUP DISCUSSIONS, ACADEMIC INSTITUTIONS AND CLINICIANS

6.1 INTRODUCTION

The objective of this study was to determine the clinicians' and academics' perceptions regarding HIV curriculum and practice. The results were to be used in proposing an outline of the HIV content into a physiotherapy curriculum. In order to fulfil this objective, focus group discussions were conducted with physiotherapists from three academic and four clinical departments. Focus groups were chosen as the research method because of the ease with which the researcher could obtain information on the clinicians' and the academics' knowledge, experience, beliefs and perception on the issue. Focus group discussions (FGD) are recommended for exploring information on a topic (Babbie & Mouton, 2003).

Information obtained from clinicians and academics could verify what was found in the previous studies and gaps where important aspects had not been identified. Results from the literature review and studies, (in- and out-patient studies and the referral study), involving the patient with HIV/AIDS, indicated of where the focus for physiotherapists should be. However, before embarking on assessing the content of HIV physiotherapy curricula according to UN defined mainstreaming criteria, it was necessary to ensure that the information was informed by the practitioners' experience. Since a Delphi technique was also to be conducted to gain consensus on the areas found to be essential for a physiotherapist, the process of conducting focus group discussions FGDs were judged as suitable to integrate the results found so far. The purpose of the FGD was to verify, enrich the data and gain clinicians' and academics' insights and perceptions around HIV based on their clinical experience. In the academics case, their educational experience as well. Section 6.2 outlines the development of the tool used in the FGD and the process of validating the procedures.

6.2 RESEARCH DESIGN AND METHOD

6.2.1 Development of the Interview Guide

Questions were generated from the results of the literature review (Chapter 2), the study to determine the referral patterns (Chapter 3), the information derived from Chapters 4 which determined the profile of patients using the ICF and Chapter 5 the curricula audit results. Information from these studies was analysed and implications derived were used to determine the questions to be used in the focus group discussions. Key areas that were

seen as important for HIV as a subject for physiotherapists are presented in Figure 6.1 below.

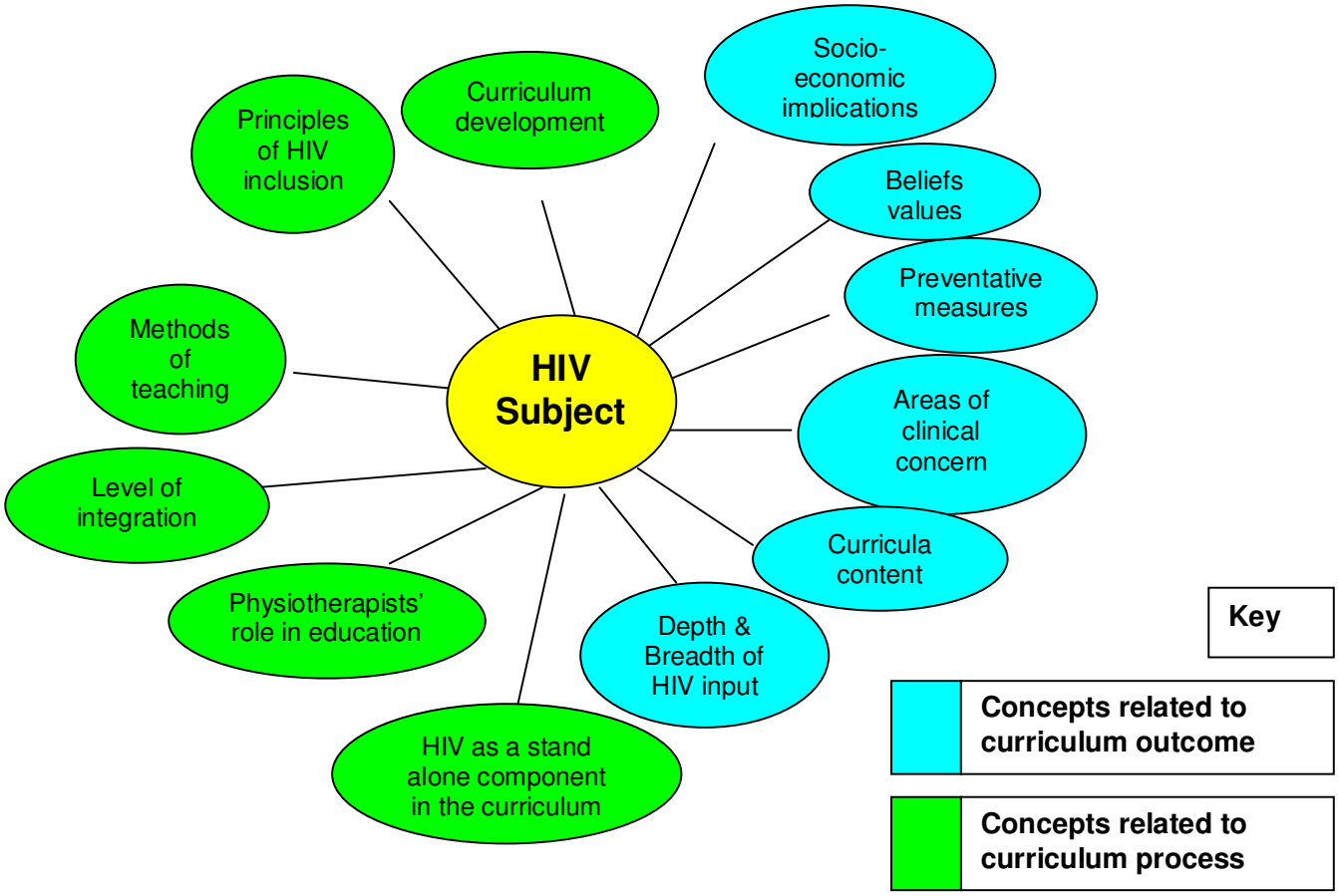


Figure 6.1: Reseach finding outcomes for HIV and Physiotherapy from Study 1-3

Table 6.1: Implications from Study 1 And 2 and 3, the Literature Review Informing Key Concepts and Questions for the Focus Group Discussion

Key finding/conclusions from the literature review and study 1,2,and 3	Concept	Questions
-Dynamics and determinants of the pandemic.	-Physiotherapists role in management of the patient -Preventative measures	-What preventative measures are taught?
-Low referral status to physiotherapy by health workers and medical practitioners -Knowledge gaps among qualified physiotherapists.	-Physiotherapists' role in education	-What do you think the physiotherapists role is in HIV management?
-Patients age range, marital and employment status. impact of these factors on their support structures.	- Physiotherapists role in management of the patient -Socio- economic implications	-Should large scale implications of HIV disease be included in physiotherapy education and practice?
-Pervasive nature of HIV- impact on all key body systems (pathophysiology) and problems (impairments) manifesting at impairment level- voice haematological, respiratory, digestive metabolic endocrine and musculoskeletal. -Subsequent association between impairments and activity limitations.	-Depth and breadth of input	-Would you consider HIV as a subject that should be taught on its own within physiotherapy curriculum? -Should HIV stand alone? -What considerations determine the depth and breath and input on HIV? -Are there any specific areas that should be taught that therapists are likely to encounter and treat in HIV positive patients?
-Any deficiencies (in professionalism or in HIV knowledge) in these areas that should be addressed in the curriculum (Seacat 2003).	-Current dificiencies -Level and type of Integration HIV as "stand alone"	-Should HIV be integrated into other areas such as paediatrics, neurology, orthopaedics public health and the community?
-Basics of philosophy, goals, course work, clinical experiences and evaluation processes influence curriculum (Shepherd and Jensen 2002).	-Beliefs, values, practices	-What beliefs, values, practices do you see as important for the delivery of prevention treatment and care?
-Physiotherapy philosophy promotes well-being through holistic health care as part of the multi-disciplinary team. Through these efforts it contributes to comprehensive health care delivery system. Association between impairments , activity limitations e.g. muscle strength affecting a persons activity level	-Principles underlying treatment	-What principles have you identified as being important for delivering prevention treatment and care in HIV specifically for physiotherapists?
-Basics of philosophy, goals, course work, clinical experiences and evaluation processes influence curriculum. Curriculum must respond to the current physiotherapy developments and the changing environment and human health care needs.	-Curricula content	-Are there any specific areas that should be taught that therapists are likely to encounter and treat in HIV positive patients?
-Teaching methods need due consideration (Shepherd and Jensen 2002) -A factor that was pertinent to the student attitudes to HIV included knowing someone who is HIV positive on a personal level (Seacat &Ingelhart 2003) -Problem based learning models (Solomon, Salvatori, Guenter 2002)	Methods of teaching	What methods of teaching could be utilised?

Efforts were made to keep the questions open-ended to allow for free generation of ideas. Questions that were formulated from the outcomes drawn up were sent to two physiotherapists with expertise in HIV for comments and validation. The final FGD interview guide is shown in Appendix 6.1.

6.2.2 **Sample**

- Purposive sampling was used to ensure representation from academic and clinical institutions.
- Three academic and four clinical departments were selected. The clinical departments were chosen based on the high numbers of HIV positive patients admitted and managed at the hospitals. Based on the curriculum audit, the academic departments were specifically chosen to represent a range of HIV input in their curriculum. One had an extensive course outlined, the second a fair amount and the last one very little.
- The clinical departments included Chris Hani Baragwanath Hospital (12 participants) 3.3(±2.8), George Mukhari hospital (8 participants mean number of years of experience) 5.8(±4.1) and Helen Joseph Hospital physiotherapy department (5 participants) mean number of years of experience 1.9(±1.1) and an in depth interview with the Themba Lethu HIV out-patient clinic (one medical doctor with more than 10 years of experience in HIV). These hospitals are large referral hospitals that see a large number of patients with HIV. With the exception of the HIV clinical expert, all the participants were qualified physiotherapists.
- For the academic staff, all participants were experienced lecturers with the exception of two who had just started lecturing; the rest had been involved in academic work for between five and twenty nine years
    - Medunsa (5 participants) (University of the Limpopo) (mean number of years of experience 11.9(±6.2).
    - University of the Free State (10 participants, mean number of years of experience 8.2(±6.6).
    - University of Pretoria (7 participants mean number of years of experience 14.5(±13.5).

6.2.3 Ethical Considerations

- Written permission was sought from the head of department of the hospitals and universities. A telephonic explanation was undertaken and the full research proposal and a copy of the ethical clearance certificate number availed before the appointment for the focus group discussions was made.
- Each participant was informed via the head of department about the proposed FGD and the need to sign a consent form.
- The consent form was sign before commencing the FGD. Within the consent the participant was informed of the need to record the session.

6.2.4 Data Collection

Focus group discussions were conducted. Each group was recorded using a digital recorder (speed link PDR3). Two physiotherapists, experienced in research, were invited to attend the first two FGD with two specific roles. They observed and critiqued the way the FGD was conducted and made suggestions on how the questions could be made clearer. A meeting was held with both of them after the focus group discussions to obtain feedback. The interviews were transcribed verbatim by a professional transcriber. An extract of the analysis of one of the six transcripts is given in Appendix 6.3. After the first round of analysis they were asked to verify that the data captured were an accurate representation of what had transpired.

6.2.5 Data Analysis

The general approach to data analysis was an interpretive content analysis using a constant comparison methods (Charmaz, 2000) .

Step 1

Each of the six transcribed focus groups was analysed vertically where each document had concepts identified separately. Tesch (1992) referred to this as decontextualising units of meaning that contain one idea. (Tesch 1992) and other authors refer to this stage of the analysis as open coding (Strauss & Corbin, 1990; Strauss & Corbin, 1992). During open coding data were placed into discrete components (concepts), examined, similarities isolated and differences and implications asked about the data. Strauss and Corbin (1990) recommend that in this process questions such as ***"what is this"*** and ***"what does it represent"*** be asked of self (i.e. the researcher). A constant process of comparing each item took place (Strauss & Corbin, 1990).This is also known as the constant comparison method (Charmaz, 2000; Merriam, 1998).

Step 2

These concepts were then amalgamated into one document from all seven focus groups. After closely examining the data, similar concepts were tallied around one phenomenon i.e. categorised and concepts that were repeated were tallied. The transcribed data were inspected again to ensure no concepts were missed.

Step 3

Clear categories or topics became evident and were documented. Two experienced researchers were given the list of concepts and were asked to produce a list of categories or topics. Their lists were compared to the researchers' list and eleven of the seventeen categories were congruent. Further discussion was undertaken to ensure that the categories were clear to all three researchers. Two of the researchers were observers in the first two FGDs and were asked to review the categories. Some of the categories that were not congruent were reworded and in some cases the concepts were amalgamated with other areas.

Step 4

Once the categories were finalised axial coding was conducted (Macallan, 1999). The researcher with the assistance of an experienced qualitative researcher, not involved in the data collection, discussed the links and the contextual associations of the categories. The categories were finally grouped. The data were treated independent of the original framework (Figure 6.2). A central theme emerged (physiotherapy content in the curriculum). Using numbers the categories were ranked and linkages identified. Finally themes emerged. (Appendix 6.2)

Step 5

Once step four was complete, transcripts were made available to an independent researcher, who analysed the data independently and identified concepts. The concepts identified by the independent researcher were compared with the concepts identified by the researcher. The differences that were found were either an omission or a difference in the amount of detail on a particular concept e.g. "Electrotherapy" versus "electrotherapy precautions, adverse effects and contra-indications" Omissions that were found in the independent researchers' concepts were included in the final results while the concepts with slight differences were noted where they enriched the data included in the concepts. The

results of agreement between concepts of the researcher and the independent researcher are shown in Table 6.2.

Table 6.2: Comparison of Focus Group Discussion Concepts

Focus group discussion site	Total concepts	Differences	Percentage agreement
Baragwanath- clinical staff	82	9	89%
Helen Joseph Hospital -clinical staff	80	11	86%
Helen Joseph expert clinician	67	7	90%
George Mukhari Teaching Hospital clinical staff	46	4	91%
University of Limpopo Physiotherapy Department academic staff	93	9	90%
Pretoria University Physiotherapy Department academic staff	100	8	92%
University of the Free State Physiotherapy Department academic staff	102	11	89%

6.2.6 Trustworthiness

The four strategies for trustworthiness were considered, namely transferability for applicability, credibility for truth value, dependability for consistency, and confirmability for ensuring neutrality (Lincoln & Guba, 1985).

Transferability

The researcher ensured transferability by means of purposive sampling of both clinicians and academic staff. A dense description of data collected also provides basic information to other researchers**.**

Credibility

Credibility was achieved through engagement in the focus group discussion (FGD), utilisation of the information from the preceding studies, peer examination of the conduct of FGDs and subsequent peer review and criticism allowing for improvement and clarity in the following focus group discussions. Based on the comments of the observers, four questions were added and one was clarified. Two of these questions were specifically for the academic group and the other two were asked of both groups. Appendix 6.1 shows the changes in italics. The observers felt clarity was needed on what currently informs curriculum and for clinicians it was advised that this be asked and the question: “was the HIV input in your curriculum adequate?” A question on practical beliefs, values and practices was also made clearer (Appendix 6.1 FGD interview schedule).

Member checking was done to ensure accuracy by sending the transcribed scripts with the concepts identified (Kielhofner, 2006), to the clinical and academic groups. Four of the groups responded and were in agreement with the transcripts. Two did not respond despite being reminded twice.They were asked to verify if the transcripts represented an accurate record of their contributions.

In addition to this, for validity the analysed transcriptions were discussed with an experienced researcher and therapist. In addition to that, transcripts were availed to an independent researcher not involved as part of the focus group and she undertook an independent process of analysis and coding.

Dependability

To ensure dependability a complete description of the methodology is given and the detailed description provided can be used to confirm truth and accuracy of the process and data derived.

6.3 RESULTS

The process of data analysis is described in detail under 6.2.5. Each of the themes was subjected to additional abstraction to identify further links. In this process similarities and relationships were discussed and concluded on. For example all the outputs that related to content and condition specific knowledge were grouped together as micro level issues. The literature on curriculum design was used to analyse the emerging themes presented in Appendix 6.2. These themes were assessed to determine whether they could belong to the micro, meso or macro environment (Shepard & Jensen, 2002). The micro level was considered as issues concerned with the actual content input, meso level issues were concerned with the immediate environment and macro level with the wider environment.

The following definitions of the macro meso and micro categorisation of the environment in relation to curriculum were found in the literature.

- The macro environment includes society, the health care environment, the higher education system and knowledge related to physiotherapy and therefore deals with large scale implications that influence a curriculum (Shepard and Jensen 2002).
- At meso level, Shepard and Jensen (2002), merge some of the aspects into the macro and others into the micro level. However, Akker Van Den (2003) does define the meso level as the level that deals with issues that would affect the implementation of curricula at an operational level (see Figure 6.2).
- According to Shepard and Jensen (2002), the micro level deals with aspects that have an effect on the students' clinical practice and reasoning.

Figure 6.2 below shows the relationships found.

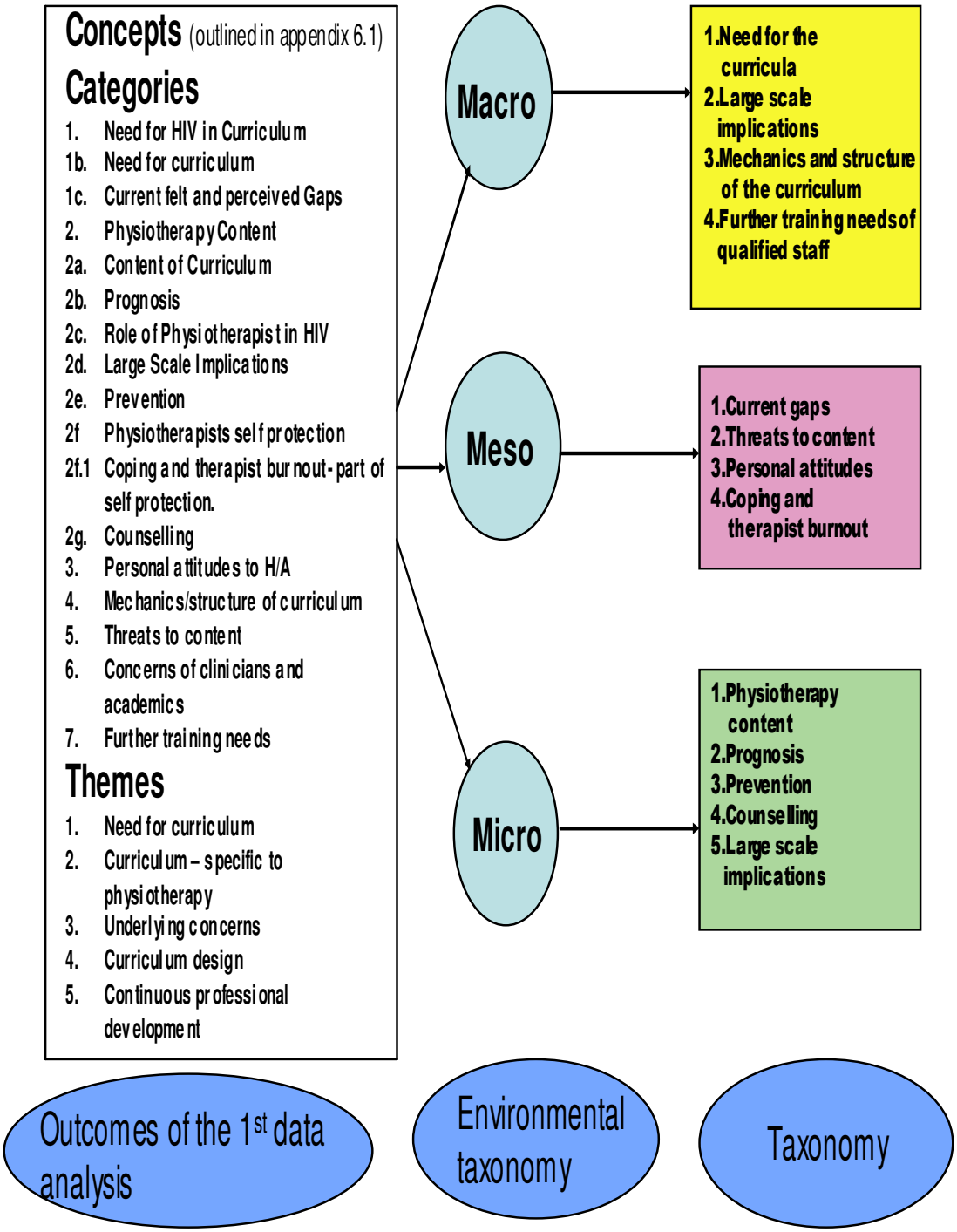


Figure 6.2: Schematic Presentation of HIV Curricula Taxonomy

Each of the categories from the first data analysis were further analysed to identify patterns and typologies (Le Compte, 2000). Furthermore, the needs identified from study 1 and 2 as well as the literature review, were assessed to identify what the clinicians and the academics did not express as felt or perceived curricula needs and are given in the tables as omissions. Tables 6.3 to 6.11 give the results of this further analysis. Table 6.3 outlines the content of what was grouped as micro level needs i.e. the actual content relating to HIV input. Meso and macro level issues are outlined in the tables that follow. Using constant comparison method, categories were regrouped into themes which resulted in a taxonomy which was collaborated by curriculum literature (micro, meso macro). This came out of successive analysis where participants, for example, expressed knowledge gaps in areas such as neurology and the need for emotional support these aspects were in the first analysis grouped under needs. A second analysis separated the needs that related to knowledge and those that related to coping strategies. Further categorisation separated these issues into micro and meso levels.

6.3.1 **Physiotherapy Content: Micro Level Needs**

Tables 6.3.1 and 6.3.2 outline the micro level needs which outline physiotherapy content.

Table 6.3.1: Micro Level Needs Part 1 - Physiotherapy Content

Micro level needs can be defined as needs that have a direct impact on the therapists clinical practice and reasoning processes.

Physiotherapy Content Knowledge	Categories	Themes	Omissions	Quotations
- Episodic nature/ recurrence of illness - Approach - good nutrition good drugs and mobility - Pathology and patient staging - relation to physiotherapy - ARVs o implication application o effectiveness/non effective o role o mechanisms o complications o programmes o MCTC/ children - HIV and breast feeding - Disclosure issues (challenge laws and charters).	-Approach to management of HIV	-Factual knowledge and information -Application of knowledge	-Determinants of the HIV disease and relationship to virology and HIV prevalence -HIV staging and classification used in SA -Activity Limitations and participation restrictions -HIV management approaches	"*We spend so much time with the patients… we're not, .., equipped to be able to say, ok, you're HIV positive, ... May be it's because we don't have this knowledge or we're not confident enough to say: from here, with a CD4 count of less than 10, you may not have very long to live,"*
- Case variation and common medical problems - Psychiatric conditions - Neurological conditions (sroke peripheral neuropathy) - Input into specific areas such as orthopaedics - Chest conditions - Coincidental co-morbidities - Depth of common conditions	-Conditions associated with HIV	-Factual knowledge and information -Application of knowledge	-Common Impairments such as pain, energy drive, dyspnoea, spectrum of mental effects, body mass. voice -How HIV causes impairment	*I think it's so vast and that it actually connects with so many other conditions that we could integrate it.* *"HIV is part of everything because HIV affects your pathology, your recovery, your rehab, whatever."* *"There's such emphasis on strokes and on paraplegia and all of that and you come here and so many of the patients you see have peripheral neuropathies…transverse myelitis and painful feet, peripheral neuropathy…myopathy"...*

Table 6.3.1 continued

Physiotherapy Content Knowledge	Categories	Themes	Omissions	Quotations

- HIV implications for physiotherapy and disease aetiology
- Physiotherapy specific input
- Physiotherapy as a dumping ground
- Rehabilitation role
- Palliative role
  ○ physiotherapy treatment techniques
  ○ approach
  ○ what is the practical role of physiotherapy
  ○ physiotherapy approach to the HIV patient
  ○ managing the very ill
	Identity for physiotherapists within HIV management	-Factual knowledge and information
		-Application of knowledge and philosophy
			Physiotherapy input into the management of impairments such as dyspnoea
			
			-HIV function and QOL
			
			-Screening of HIV patients
				." I think we can play a major role in the primary prevention, the secondary prevention and the tertiary prevention."
				", it's not just the CD4 counts, for us especially in terms of the patients' functionality. And perhaps use that in a way to advocate for better programmes for those patients."
				"I think is well understood or we're not there. We're not there in the community where the patient is, with a stroke, with HIV playing a major role in the physiology and pathology How to improve that with what happens to the patient from the research in communities where HIV is prevalent"
				"I think if the profession doesn't take the lead our hands are really tied because that's the problem"

Table 6.3.2: Micro Level Needs Part 2 – Physiotherapy Content

Physiotherapy management - CD4 vs. mobility/function - Effective physiotherapy interventions - Exercise, when to exercise - Dealing with general weakness	-Treatment approaches	Application		*' we don't teach a disease. We teach- we look at conditions, what they have in common, what special…precautionary measures and dangers there are,'* *"And it's strange like we have stroke classes, ?, we have back classes, ... I wouldn't say: do an HIV exercise class, I would say do a general exercise class or say, right, you know, just exercise in general."*
2.Role of Physiotherapist in HIV- - Clear roles in HIV - Management principles - Optimising patients health - Role of physiotherapy in the community lacking using generic module on role of teaching different disciplines	-Identity -Ethics /philosophy	-Thinking skills/ application		
- **2 b Prognosis-** - Treatment including medical treatment - Inform the therapist of the true prognosis - Prognostic changes – refer to ARV for secondary complications - Understanding overall management and treatment in relation to prognosis	-HIV aetiology	Information analysis and application		
- **2d Immediate community implications** - Grandparents - Orphans - General population response to HIV - Caregiver support and education - Gender victimization - Impact on the role of the family - Family structure and HIV	Public health implications	Information analysis and application		

Table 6.3.2: Micro Level Needs Part 2 – Physiotherapy Content - Continued

- **2e Prevention** - Primary prevention role of HW - Role & Influence of public	Primary prevention	Information and application	Only one group mentioned this as a possibility directly while with the other groups it was implied.	
- **2f Physiotherapy self protection** - Risk o to patient o to self - Universal precautions - Information on appropriate & correct use of precautions - Inappropriate precautions	Universal precautions	Application		*"Universal precautions..but I also think we should concentrate more on diverse things, like, we're now getting more patients on ARVs, so what now?"*
- **2g. Counselling** - Counselling skills - Patient communication - skills, approach, need - Creates openness about HIV - Encourages better response to patient - Important for physiotherapist/patient relationship	Counselling	Application		

6.3.2 Meso Level Issues that will Impact on the Curriculum

Each of the categories found in the initial data analysis was analysed further to identify patterns and links. Further categories emerged. Tables 6.4 to Table 6.7 outline issues that were considered as influencing the curriculum

Table 6.4: Meso Level Gaps Perceived in the Current Curriculum

Concepts	Category	Theme	Quotations
- Clinical picture - No practical application - Lack of clear picture of HIV staging - The need for numbers to quantify problem - Contact with people who are HIV positive in teaching	Clinical	Gaps perceived in the current curriculum	*"I think the most important thing is the number of patients we see because that will determine its importance"*
- Fragmented approach to HIV input (especially in adults)	Structural		"*When we were students and we did human behavioural sciences in sociology in first year, we did do quite a lot on HIV socio-economic implications, etc., etc. So I just felt that because we weren't in the situation we didn't realise the prevalence of HIV in South Africa and things like that. I mean, we had just come out of school, we were still in our own- you know, getting out of the home kind of thing, and getting into reality. So, I mean, the implications didn't really hit home until we got here,"*

Table 6.5:Meso Level Coping and Therapist Burn-Out

Concepts	Category	Theme	Quotation
Part of self protection: - Loss of hope - Loss of morale - Effect of HIV on personal level	Psychomotor needs	Coping and Therapist burn-out	*Suffering is a huge issue out here. We watch caregivers suffer as they try cope with their daughter who is going to die before them.*
- Staff overload - Other health workers - Physiotherapists	Structural effects		

Table 6.6: Meso Level Physiotherapist Personal Attitudes to HIV/AIDS

Concepts	Category	Theme	Quotations
- Death sentence - Judgmental - Beliefs	-Individual perceptions	Personal attitudes to H/A	*"it's not a good thing that I'm admitting, that sometimes I really do lose hope in my treatment, impact of HIV"*
- Avoidance pretend the patient has no AIDS	-Therapists responses to HIV/AIDS		
- Treat patient/person not condition - See person not disease - Stigma/destigmatisation - Need relaxed attitude to HIV	-Recommended approaches		

Table 6.7:Meso Level Physiotherapists Threats to Content

Concepts	Category	Theme	Quotations
- Need for non interference in undergraduate programme by inclusion of HIV	-Perceptual threats	-Threats to application of content	
- Patients HIV status unknown (disclosure) - Liberty to approach the subject with patients - Doctors determining content of HIV and depth - No presence of physiotherapists in out-patient HIV clinics	-Structural and organisational problems		*"The difficult part is that often the patient himself doesn't know that he's positive. They often find that out when they're- when he's already in hospital and you're not supposed to talk about it". "But it's a policy a national issue. I haven't come up with a plan to help tackle it. At this juncture we are a bit under pressure to follow regulations."* *"That we have not been able to take the bull by the horns because we're not allowed to get near the bull."* *"I also think it's going to depend on which area you lecture in. some areas are going to be much more important that other areas"*
- Misconceptions about prognosis - Perception of death sentence - Differences in understanding of HIV - Lack of understanding of HIV - Source of information from the media	Knowledge gaps		*"And I think the principles of therapy remain the same, really, as for any other condition. But I think they need to identify what goals at what stage of the disease are appropriate. And I think that's important because we are not teaching that at all"* *"we actually don't have any idea of how it works, who has access to it, what literature- you know, is there actually improvement in the patient's condition and functioning?"*

6.3.3 Macro Level Issues

The categories that emerged from the data analysis at a macro level are outlined in Tables 6.8, 6.9 and 6.10.

Table 6.8: Macro Level Mechanics/Structure of Curriculum

Concept	Category	Theme	Quotations
- Stand-alone initial phase /microbiology, clinical sciences - Coordinated input - Integrated approach - Focus on principles		-Mechanics /structure of curriculum	*"you do not teach the treatment of diseases but rather the principles applied to the management of conditions"* *"I wanted to say it's actually very difficult to make it a subject on its own because it's actually duplicating- it should be incorporated in each specific field,"*
- Increased HIV content - Increased depth and breadth - Comprehensive input - Avoid repetition	Content related		*"So I think it's quite a holistic approach, but it's on a basic level, it's not too involved…"* *"…but I also think we should concentrate more on diverse things, like, we're now getting more patients on ARVs, so what now? I think that's where we should be focusing on…"*
- Evidence based - Active learning - Problem-solving approach - Lecturers to have relaxed attitudes to HIV - Teaching methods - ward rounds, interactive, lively	Approach and methods		*"They have to read the evidence of the article content and the article has to have relevance to the patient. So you know, make them active learners,"* *We bring them to the water now they must drink"*

In Table 6.9 issues that pertained to large scale implications as part of the content and as influencing the inclusion of HIV into the curriculum are outlined.

Table 6.9: Macro Level -Large Scale Implications

Concepts	Category	Theme	Quotations
- Should be left to Dept of Education (DoE) - Political issue	Perception	Large scale implications	*"I think sometimes this whole HIV thing becomes almost like a way out,"*
- Refer to DoE input only - Challenge laws & charters			*I would definitely shy away from the bigger political issue, definitely. I don't think it belongs in a pre-graduate…"* *"We should look at the bigger picture in terms of the implications - it's actually the majority of the patients that we are actually dealing with are HIV positive, so the implications are huge in terms of our clinical practice"* *"And I also think that the students need to have a reflection of the bigger picture because they're going out into the bigger picture in the community service year"*

Table 6.10: Macro Level - Need for HIV Curriculum

Concepts	Category	Theme	Quotations
- HIV pervasive in all areas - More depth is required - Increased content required - HIV curriculum not responding to clinical picture - Need to respond to increasing prevalence - Lack of understanding among qualified therapists	-Clinically informed reasons	-Need for HIV curriculum	*"I think it's actually expected of us...it's a political issue"* *"I just wanted to add is that you must be careful about overkill."*
- An important subject in the country - HIV has a high prevalence - Situation needs to inform any curriculum - Changing prognosis of the curriculum - Difference in understanding of the management and approach to HIV	Environmental related reasons to include HIV in curriculum		

Table 6.11: Macro Level - -Continuous Training and Development Needs

6.4

Concepts	Category	Theme	Quotations
- Training needed for qualified staff - Qualified staff unaware of HIV/AIDS approaches	Training		*"I don't think we need to have, like, a very, very in-depth study into HIV, like with- I qualified quite a few years after Vanessa did, and we have a few lectures with HIV-related conditions, but not all of the HIV-related conditions that we see here at the hospital."* *"We sort of come from the old school where it wasn't really taught and I sometimes think we shy away from it because we ourselves are not knowledgeable enough in terms of what are the pathologies related to it and what do we actually teach the students."*

6.4 DISCUSSION

Defining what the physiotherapist, as a first line practitioner, should know with regard to HIV/AIDS in the context of their role is an important exercise. Clinicians and academics should, in practice, share their experiences to inform existing evidence and practice. Having done the curriculum document audit and identified the gaps, focus group discussions endeavoured to verify and further inform what had emerged from the literature and the preceding studies. In addition, the opinions of the clinicians and the academic staff potentially gave some indication of synchrony between the clinician and the academics experiences and the findings of the preceding studies. The results demonstrate the information on actual HIV input that clinicians and academics view as important to include in the curriculum. The results will be discussed under the headings of the environments' taxonomy that influences curriculum; macro, meso and micro issues (Shepard & Jensen, 2002) concerning HIV/AIDS in the curriculum (Figure 6.2). A secondary philosophical view is interwoven into the discussion.

6.4.1 Macro Level Issues of Curriculum Design

Shepherd and Jensen (2002) refer to the macro environment as including society, the health care environment, the higher education system and knowledge related to physiotherapy and therefore deals with large scale implications that influence a curriculum. The macro level themes that emerged covered aspects to do with mechanics and structure of the curriculum and the following categories namely, the debate on inclusion or not, content and issues related to approach and methods. These categories are discussed in the following paragraphs.

Inclusion of HIV in the curriculum

One of the issues discussed in the focus groups was whether HIV should be included in the physiotherapy curriculum at an undergraduate level. From the different discussions, all the participants felt that HIV should be integrated into the curriculum. Their responses were in line with Shepard and Jensen (2002) who state that, since a physiotherapy curriculum is part of a macro environment, it is prudent to make appropriate changes to the curriculum in response to changes in the environment. Some of the reasons given for the inclusion were the high numbers of patients on the wards who are HIV positive or who had HIV as an underlying cause of their diagnosed condition, political desirability and the obligation to know about HIV. These latter two reasons are expressed by some of the members of the group in the following manner.

"I think it's actually expected of us...it's a political issue" (academic).

Evidence for the high numbers of patients who are HIV positive is found both in the literature and the experience of the clinicians. One clinician said *"There are so many different presentations that often they come up with the strangest, newest, weirdest presentations that are unbelievable."* This statement is supported by some of the prevalence data (Department of Health, 2001; 2002; 2004; 2005) and the current literature on HIV. The disease profile in South African hospitals manifests this change in presentation with HIV accounting for a high number of admissions and changes in the conditions that are being admitted (Floyd et al., 1999).

One of the topics that was debated was the participants' perceptions on whether large scale implications should be included in the undergraduate curriculum. In theory, their perceptions relate closely to the concepts that were expressed i.e. HIV input being relevant and that appropriate HIV input after analysing large scale implications should be included. An example of the question of large scale implications is illustrated by the following example. When asked whether to include cross-cutting issues, such as socio economic implications seemed to have shown mixed positions. The academics seem to place responsibility elsewhere.

"*My opinion, I don't think it must be in the curriculum. Not necessarily in the curriculum but I think it must be part of the Department of Education's something - ?*"(academic)

Or even as one academic put it

"I would definitely shy away from the bigger political issue, definitely. I don't think it belongs in a pre-graduate curriculum."

This certainly does not give the impression of curriculum programmes responding to the changes in the macro environment. In turn the students would find it difficult to be appropriate if this disconnect was allowed. However, some participants support the inclusion of large scale implications strongly but with better coordination. One clinician said:

"We did human behavioural sciences in sociology in first year; we did do quite a lot on HIV socio-economic implications, etc., etc. So I just felt that because we weren't in the situation we didn't realise the prevalence of HIV in South Africa and things like that. I mean, we had just come out of school, we were still in our own- you know, getting out of the home kind of thing, and getting into reality. So, I mean, the implications didn't really hit home until we got here, we started working, things like that" (clinician)

However, for clinical application a participant said:

"Socio-economic is absolutely important for our students to know what is going on because that can have a lot of influence on your specificity of your patient." (academic)

Many of the issues raised illustrated that both practitioner and academic staff made a clear connection between their role as therapists and the greater impact of the large scale

implications but were in a state of confusion on how this plays out in the therapists' practical role in managing HIV. This may be due to some physiotherapists having little understanding of social determinants and being entrenched in the medical model.This difference in interpretation could also lie in the diverse emphasis in the implicit curriculum and the overarching ideology that colours the different curricular (Eisner, 1994). Phyiotherapy curriculum has been influenced traditionally by the philosophies of Cognitive Processes, Academic and Technical Rationality. HIV/AIDS profoundly affects all systems and has the the added difficulties of stigma and socio-economic implications. It therefore calls for professionals to fully embrace the biopsychosocial paradigm and perhaps the philosophy of social reconstruction. This approach would harness all the macro level components that influence the curriculum.

6.4.2 **Related HIV Content to be Included in the Curriculum**

Further to the debate of whether HIV should be included in the curriculum or not, was the question of where, how and how much HIV/AIDS information to include in the curriculum? From the results, mixed positions were evident. There was a general trend towards supporting an integrated topic versus teaching HIV as a stand alone. Some of the supporting views on why this should be the case are illustrated in the statements below:

"*When it stood on its own, I didn't understand the connections with the physiotherapy profession. I mean it was, like, Greek." (clinician)*

"I think in every single subject that we do, it should be HIV integrated, tell us what we can do, what we can't do, which conditions should physiotherapy help with … tell us what we're supposed to be doing."(clinician)

The pervasive nature of HIV shown by how it has the potential to affect every body system was also seen as a reason to integrate it into different aspects of the curriculum and not as a "stand-alone" Newly qualified clinicians said they were shocked at how many patients were HIV positive no matter what the diagnosis was.

"I think we should include it and it's actually the majority of the patients that we are actually dealing with are HIV positive, so the implications are huge in terms of our clinical practice"

The literature review in Chapter two outlines how HIV affects all major systems (including the haematological and immune system) and this is illustrated by the clinical experience of one participant:

"It seems to be creeping into all our patients; it doesn't matter whether they are in-patients neurological or OPD (out-patient) patients"

It can be argued that the issue of whether HIV inclusion should stand alone or be integrated relates closely to approach and curricular philosophy. In this context, participants emphasized the need to remember how pervasive HIV is and felt this will have an impact on content. No literature could be found that relates to the advantages or disadvantages of integrating a pervasive condition into an educational curriculum. However, the complexity of HIV/AIDS has been recognised through the need to address social, biological and ethical perspectives (Solomon et al., 2003b). As a condition HIV is transcendent in that its affecting all aspects of human life. It requires a comprehensive approach and therefore provides a model for educating undergraduates and postgraduates students.

When considering the depth and breadth of HIV input, there was concern with regard to keeping a balance between clinical sciences, behavioural sciences and clinical physiotherapy. The participants cautioned on the danger of "overkill" as one clinician said *"Careful about overkill. It mustn't- you mustn't be repeating the same thing. Even though it stood out in sections, you can't be saying the same thing in the same sections."* While an academic said *"I wanted to say it's actually very difficult to make it a subject on its own because it's actually duplicating- it should be incorporated in each specific field,"* However, reservations were also expressed on the possibility of overload and the need to remember the "core" physiotherapy curriculum. It is evident that there is also a level of misunderstanding of the connection between HIV and QOL as illustrated by this statement "*we are physiotherapists, we're not there to change the world. We're there to make their quality of life better, to get them walking, may be, but we can't change the disease, we're not there (you know) I mean, with the medicine and that. So I just feel we need to know our limitations*". This is not surprising or unusual as it is an expected reaction to change. Jones et al. (2001) in assessing the response to curricular change in medical schools report how change is compromised by resistance to radical change and the high degree of autonomy among faculty members. A different perspective but related to the issue of what to include is the changing focus of education for health workers where curricula are being encouraged to reduce the burden of factual information towards "learning through curiosity " Jones et al. (2001) and Solomon et al. (2003) are of the view that it is easier for students to acquire facts about HIV/AIDS, its aetiology and treatment than it is to explore the more affective domain issues such as attitude, that are important when therapists are treating PLWH.

Participants mentioned the need to cover ethical issues but also the need for clarity in how to apply them to specific HIV-related situations.

"I also think the ethical aspect is very important, that the physiotherapists will know what to do and what not to do; I think that's also quite a big issue currently."

Clinicians who had qualified recently (approximately two years and below) reported a slightly higher level of input on HIV but expressed their dissatisfaction with the coordination of the courses particularly the adult patient who was HIV positive. They felt that this lack of coordination resulted in repetitive messages not clearly related to the area of teaching and not well informed. Connected to this, qualified staff (more than five years) expressed the need for further training on HIV and expressed ineptness in dealing with HIV.

"..I think one of the big problems is our lack of knowledge as physiotherapists regarding HIV. We sort of come from the old school where it wasn't really taught and I sometimes think we shy away from it because we ourselves are not knowledgeable enough in terms of what are the pathologies related to it and what do we actually teach the students."

This calls for the need to encourage continuing education around topics like HIV among clinicians. O'Brien (2001) supports the need for physiotherapists to engage in appropriate continuing education and outlines some useful theories and approaches to ensuring updated practice.

6.4.3 Outcomes Relating to Curricular Philosophy, Theoretical Approach and Methods

Prior to this study, an audit of the physiotherapy academic departments' curricula was undertaken. The conclusion was an incomplete picture where some universities had evidence of HIV inclusion in their written curricula. In all but two of the universities (Chapter 5), the stated outcomes did not give the impression of an approach based on a sound philosophy. Some topics were mentioned in the curricula but were not comprehensive. All academic departments who took part in the focus group discussions, state that they were including HIV in the curricula. The discussions do show that efforts are being made to include HIV, with all universities represented, stating inclusion in the clinical sciences that are covered at first year level. Two academic departments reported that decisions on content in the clinical sciences section has however been left to the medical doctors to determine. Input specifically included for physiotherapy leaves the impression of being mixed, thinly defined, and with a lack of tangible principles, belief and value systems.

Perhaps re-examining and restating the important underlying theories and principles that underlie physiotherapy would help in giving clarity to the approach to HIV management for physiotherapists. The theories that have been proposed and developed in the past are discussed in section 2.5 in the literature review (Chapter 2). One conclusion that sums up

some of the underlying principles is "*an understanding of physiological functioning and the effects of pathology on the body, and second, an understanding that movement must be considered in both the individual social-psychological context and the larger physical and social contexts* ". Participants felt an integrated approach to HIV in physiotherapy was needed and must be defined clearly. This problem was not peculiar to physiotherapists as the HIV clinical expert interviewed recounted the same experience in the medical school:
", we saw the same thing with the education of medical students. That it was something that was kind of tacked on, that it didn't belong to anyone, it didn't belong to the lung people or whatever, and it has to change. So I'm very pleased with this idea."

Clinicians were calling for more knowledge and both groups proposed that the input should be delivered thorough active learning and problem-solving approaches. They emphasized that teaching methods should endeavour to be interactive lively, and utilise ward rounds. The use of evidence-based input was underscored. Jones et al.(2001) emphasize how learning has moved from a "know all" to "know how" concept and in assessing the methods each university will have to keep this position in mind. Integrated problem-based learning is not a new model but has been tested by Solomon et al. (2003) specific to HIV. Interprofessional learning is seen as an effective method of learning and incorporating a condition requiring multifaceted learning such as HIV but this did not emerge as a category from these discussions.

6.4.4 **Meso Level Aspects of Curriculum Design**

Shepard and Jensen (2002), merge some of the aspects of the meso level into the macro and others into the micro level. However, Akker Van Den (2003) does define the meso level as the level that deals with issues that would affect the implementation of curricula at an operational level (see Figure 6.2). At this level some of the concepts that emerged were the current gaps in knowledge, threats to content inclusion and application, therapists' personal attitudes and therapists' coping and burn-out. This is unsurprising as the inclusion of such a complex condition in the curriculum is not without reservation or difficulty. Participants expressed many challenges that were categorised into two sections that are clinically and structurally related. The clinical category could be divided into issues concerning the patient and those concerning the therapist, on a personal and professional level. The issues raised by the participants will impact on integrating HIV in the curricula as well as its practical application in the field.

Clinically, some practitioners felt that in some topics where they had had input on HIV it had been very theoretical leaving no clear picture of what to do practically. HIV staging for

example was cited as an area where better clarity could be given in a practical way. In general, efforts to include HIV have been undertaken but no clear thought has been given to how the input can interlink better and create a more unified picture for the student, so that the fragmented input does not result in the student not having a clear picture of how to approach HIV as a physiotherapist.

"HIV is so all-encompassing, it takes bits and pieces from so many different areas of physiotherapy: from neurology, the respiratory, when you get patients who end up with TB signs, all sorts of things. To draw everything together would be useful"

Coping and therapist burn-out, emerged as an important theme with both psychomotor and affective effects i.e. loss of hope and morale, "physiotherapy worth" and the effect of HIV on a personal level. In relation to dealing with so many patients who are admitted into the hospital with underlying HIV disease, one clinician commented on how difficult he has found the clinical decision-making process in relation to managing PLWH and hospitalisation. Difficulties arising with ethical issues and value judgements were evident.

"I think that's stumped us the most this year. I think in particular, … the prognosis and the rehab process of that because with HIV being a deteriorating process, how much work are we going to put to gain function if they are deteriorating anyway?"

"I must be honest, it's not a good thing that I'm admitting, that sometimes I really do lose hope in my treatment, I'll give you an example - one of the patients got referred to my ward , got pneumonia and I worked so hard on his chest …. 5 days, 2 hours of the day, everything, and I thought this guy's going to get off his bed he's going to get better. And then I found out that he was HIV positive and then I was like, ag, well I've done this, but how much difference have I really made because he's got a death sentence on his head anyway."

Lack of clarity of their role seems to result in a clinical dilemma where the practitioners' question how far they should go especially when it appears the medical team has given up. Clarity of the therapist's role is important for both their ability to advocate and place themselves in the management continuum of the condition as well as the confidence to market their professional contribution (Solomon et al., 2003a). It would appear that personal attitudes unsurprisingly, play an important role in influencing the management of PLWH.

As illustrated by the above quote therapists do battle with their own perceptions of HIV being a death sentence, with being judgemental and their own beliefs regarding HIV. The

perception was even that lecturers exhibit their own attitudes in the way they teach the subject.

"I think a lot of the time we actually get taught in a way that (whispers) [name] is HIV positive". You know, like, if we- if we just get told a bit more positively…"

From the challenges facing clinicians, coping mechanisms seem to have emerged, although on analysis, one wonders if these coping mechanisms are sufficient for therapists to cope. Some clinicians said they just got on with treating the condition and didn't focus on the HIV. This can be interpreted as "*avoidance behaviour*" in order to cope. Physiotherapists' responses to HIV can be enhanced by more sensitive training. All intervention studies to include HIV in the curriculum have shown that training diminishes negative attitudes, enhances willingness to treat, promotes appropriate practice behaviour and helps with becoming a more patient-centred health provider (Balogun et al., 1998) (Balogun et al., 1998; Seacat & Inglehart, 2003),(Held, 1993). Although these studies have been conducted in the west they are relevant to the African context in that most of the topics relate to personal decision issues.

Another issue was the feeling of inadequacy and self worth

"… The bulk have been HIV patients with general weakness I mean on our stats, HIV slash general weakness, …, we just have to mobilize out of bed. And you spend the whole day coming, taking patients, taking them to bed and thinking well this doesn't take much intellectual…I've studied four years of physiotherapy and my job is coming everyday to take a patient out of a bed into a chair. And that can take up a lot of our day and it frustrates me at times as a physiotherapist, knowing that I can have potential with a lot of patients that may not have had HIV in their condition. That's been frustrating me as well."

Clinicians reported coping with the high number of HIV patients they see, and the difficulties of disclosure by pretending the patient did not have AIDS and only dealing with the manifesting condition. That way they do not have to deal with issues of prevention and disclosure and anything else they considered complex. This unfortunately is unethical as the therapists may make clinical decisions that are not informed by the patients' true situation and therefore influences effective intervention. In this situation the therapist is not being wholly honest. No published studies could be found on HIV disclosure issues and HIV in relation to health workers. Most of the articles are on disclosure in relation to family, friends and colleagues (Petrak et al., 2001). Salati (2004) in her unpublished dissertation found that "state of non-**disclosure** may instil fear of infection into **physiotherapists**."

Therapists' strategy for coping may be one of avoidance due to existing structural difficulties such as a lack of liberty to approach patients, unclear physiotherapy roles and poor clinical communication. A lack of liberty resulted from the need to honour the patient's right to

privacy and choice in disclosure. In the clinical set-up the patient's status is known mainly to the medical practitioners and the sister or nurse in charge. The consequence is that these factors may limit the physiotherapists' role in health promotion, secondary and tertiary prevention of problems around HIV/AIDS. These factors become threats to the application of content. This is exacerbated by misconceptions about prognosis, the perception of HIV/AIDS being a death sentence, and differences as well as a lack of understanding of HIV by both practitioners and academics.

6.4.5 **Micro Level Aspects of Curriculum Design**

According to Shepard and Jensen (2002), the micro level deals with aspects that have an effect on the students' clinical practice and reasoning. From these study findings most of the information obtained could be categorised into information related to content on factual knowledge, information relating to practical skills and philosophical underpinnings. A full list can be found in Table 6.3 micro level needs. The topics that were listed are similar to those listed in the literature (Balogun et al., 1998; Puckree et al., 2004; Schlotfeldt & Potterton, 2002) , and are based on the participants' experience in the clinical setting. Some of the topics are physiotherapy content related, prognosis of HIV, prevention, counselling and large scale implications.

Other areas that could influence management of HIV included understanding HIV presentations such as its episodic nature, how ARV's affect presentation, staging and dealing with disclosure issues. This would involve exploring the Patients' Rights Charter, the Public Health Act and their relationship to disclosure of the patient's status to physiotherapists for clinical decision-making. This would give clarity and practise guidelines specifically for physiotherapists.

Practical application issues were articulated through the need for physiotherapist role definition and identity in comprehensive HIV prevention, treatment, care and preservation of health. As one participant shared

"*We had a patient, she had a lung abscess… she was sick. And the rest of the medical team had already given up on her but then they wanted physio and I was like,… why do I want to come and treat when the doctors have just said they're stopping all medication…"*

Given the high numbers of patients who are HIV positive and the fact that statistics in the clinical field should inform curricula, HIV is undoubtedly an important topic in the physiotherapy curriculum. However, physiotherapists in the clinical setting, who informed this study, did not want to feel that physiotherapy was a dumping ground when the medical

team gave up. Physiotherapists want to feel that they play an active part in the management of patients and people who are HIV infected and affected. This indicates the need for the curriculum to clearly define physiotherapy roles and ensure that practising physiotherapists are able to define what they are doing at each stage of this disease. Linked to this was an expressed need by the clinicians for clarity on the principles governing treatment of HIV patients and effective evidence-based interventions. The application of rehabilitation models to the management of HIV/AIDS is documented as an important aspect of defining HIV rehabilitation (Solomon et al., 2003a). Approaching the HIV patient for the physiotherapist should be based on sound principles of knowledge of HIV, approach, treatment and ethics. The HIV clinical expert sums this up when asked what her view was on the role of health workers:

"Uhm, - the way that I treat my patients is, I tell the truth as much as I possibly can. You know, I talk about the side effects, I talk about everything and I think if everybody was trained in that, if the physio sees a patient and thinks ag, this patient had a stroke, they're a goner, and I can't be bothered. But instead of saying look, the rehabilitation for you in terms of what I'm doing, and if you take the medicine and you put the two together. And just knowledge of the true prognosis of HIV would benefit our therapy"

The above statement reflects the need for a comprehensive approach to management of HIV patients including prevention, promotion treatment and a generally professional but empathetic disposition to PLWH. In relation to this, students in a study conducted by Puckree et al.(2004) suggested the need for more practical education on the physiotherapist's role and clinical practice on how to handle patients with HIV. One practical area where the participants seemed comfortable both from the academics' and clinicians' perspective was universal precautions. Input was clearly given in all universities and awareness was evident among clinicians. However, in practice, clinicians did report inappropriate application i.e. wearing gloves only when they became aware of an HIV positive result and yet not wearing gloves even in cases where there may even be a danger or more infective conditions such as hepatitis B. An interesting point raised by the clinical expert was that:

"In actual fact, most of the time we are more of a risk to our patients than vice-versa. If you go to work with a cold that you would normally fight off after a couple of days, and you transmit that to your patient, it's much more serious than the other way around."

Counselling was a practical area seen as important by both clinicians and academics. Clinicians who recognised their lack of knowledge enrolled for courses through the hospital

and found that this not only helped them with patients but with their own ability to deal with affective issues concerning HIV. These benefits of counselling are well documented in the literature (The Voluntary HIV 1 Counseling testing study group, 2000).

In relation to treatment, some academics mentioned the need to include exercise and its relation to HIV as a modality in the curriculum, and clinicians felt a clearer position on exercise and function was needed. While the clinicians did admit they had a duty to research their own evidence they felt some guiding principles as outlined in other conditions would have been useful. Several reviews and other recent research are available in the literature that give guidance to exercise as an effective modality in the management of various aspects of HIV (Dudgeon et al., 2004; Kietrys, 2002; Mutimura E et al., 2008a; Mutimura E et al., 2008b; Nixon et al., 2005; O'Brien et al., 2004; Stringer, 1999). However, the unclear link to clinical reasoning in areas such as function and mobilisation was pointed out by clinicians.

"Yes I have seen people with a CD4 of 150 are non-functional and other with a CD4 of 2 are up and about".

Two of the groups mentioned that physiotherapists play a role in the promotion of function and improvement of quality of life. There were no clear views beyond understanding factual knowledge relating to HIV and its application to the clinical setting. With regard to public health implications, there was a definite absence of understanding HIV in its complexity and relating this to the role of the physiotherapists in the wider context. One academic did say "*we are not there in the community*" and alluded to being unable to connect with the real issues that affect PLWH.

Both clinicians and academics mentioned topics that have direct public health implications for example the impact on the family and social support structures, impact of HIV/AIDS on the general population, gender and their role as a therapist. The mixed feelings by academics about whose responsibility it is to teach the students on large scale implications is a contrast to those felt needs and perceptions. However, the literature shows the need for health workers to have an understanding of the biological, psychological, social, economic and cultural aspects of HIV/AIDS (Worthington 2005).

For most therapists in the study, there seems to be a clear disconnect in linking the above-mentioned aspects in the management of HIV/AIDS. This could be attributed to the lack of a philosophical underpinning such as the ICF and recognising the need to shift the goals of treatment according to which part of the disease trajectory one is placing the patient. The episodic nature (O'Brien et al., 2007) of this condition requires that the therapist be aware of

this constant flux of management goals. Therefore the roles would also change and identification of which role such as those evident in the concepts (palliative, community role and treatment roles) would be less confusing.

An understanding of the true prognosis of HIV was seen as an important prerequisite to understanding HIV and was underscored as important by the clinical expert. This could have profound effects on the attitudes and affective consequences that are felt by therapists. These two statements were given by the HIV clinical specialist

"Ja, what I was going to say about HIV stigmatisation is that until relatively recently, people thought you got HIV positive, you got AIDS and you died. And the advent of ARVs has really changed that. And I saw amongst the doctors that they were really discouraged, I mean ultimately we become health care professionals because we don't want patients to get sick and die… And there was a lot of loss of morale amongst health workers" -

"I think that with the advent of antiretroviral therapy, our patients do get better. They go from really, really ill and if we could commence in time they get back to normal life, they can be 40 kilos skinny And if we can attack that from all sides, with good nutrition, good drugs obviously and help with mobility, it would help a lot of our patients."

6.4.6 **Reflection on the methodological approach**

A qualitative approach was used for this part of the study (Strauss & Corbin, 1990). The data analysis allowed the researcher to identify concepts that informed the knowledge areas required, as well as practice and attitudes related to HIV. The data analysis was informed by the literature in identifying concepts, decontextualising these concepts and finally recontextualising them to identify categories (Strauss & Corbin, 1990; Tesch, 1992). Through the constant comparison method, categories were identified and regrouped through successive levels of analysis resulting in a taxonomy that was confirmed by the curriculum literature (micro, meso macro) (Akker Van Den, 2003; Shepard & Jensen, 2002).

This qualitative approach used in this study captured some of the subtleties of the experiences of both clinicians and academic staff. A rich explanation is one of the strengths of qualitative research and through "quoting", the participants were able to speak directly about this topic. No qualitative studies relating to inclusion of HIV curriculum were found. Most of the previous studies have been confined to quantitative surveys on knowledge, attitudes and practice (Balogun et al., 1998; Puckree et al., 2004; Puckree et al., 2002) and

they missed describing the problems and misconceptions experienced when dealing with HIV as clinicians. In addition, the knowledge gaps and misconceptions were also evident among academic staff.

Finally, in qualitative research, the legitimacy of the topic adds strength to the study methods and outputs (Piercy et al., 1994). In the case of HIV/AIDS, the condition is at a pandemic level making it a pertinent topic. HIV impacts every level of society and this also adds weight to focussing research on it. As a profession, physiotherapists, must address the those impacts of HIV that physiotherapy modalities and approaches can influence (Piercy et al., 1994).

6.5 CONCLUSION

In 2002, the University of the Witwatersrand declared that as part of its holistic response to HIV, it would integrate HIV/AIDS into every student's studies and thereafter every discipline was to integrate HIV beyond this basic level (HIV/AIDS programme executive 2002). A full list of what the topics are beyond this basic level have emerged from this study and are presented in Appendix 6.4 and are the content of the conceptual framework

What the clinicians and academics felt was important for inclusion in the curriculum is well outlined. In all, it tallied well with what was found as important from the preceding studies and the literature. Gaps in practice outlined by the clinicians were; the detailed information of neurological conditions, practical application, unclear specific roles for physiotherapist, how to deal with challenges such as disclosure, what is effective treatment and when treatment should be commenced and decisions on how much treatment were proposed as needing expansion and clarity in the curriculum.

CHAPTER 7

STUDY 5: TOPICS FOR INCLUSION INTO THE PHYSIOTHERAPY CURRICULUM; CONSENSUS THROUGH THE DELPHI TECHNIQUE

7.1 INTRODUCTION

The objective of this study was to determine the level of consensus with regard to the curriculum topics among academic staff at eight South African universities

The Delphi technique was chosen as the appropriate method as it allows for consultation whilst eliminating geographical constraints. The purpose of a Delphi is to arrive at a consensus of professional opinion on a given topic in this case, HIV topics for inclusion in the physiotherapy curriculum (Deane et al., 2003; Ferguson et al., 2008)

The inclusion of HIV into the curriculum has been recommended for all health workers in many parts of the world where HIV is a problem and most especially South Africa where the prevalence of HIV is high (Andersen et al., 1997; Lohrmann et al., 2000; Puckree et al., 2004; Seacat & Inglehart, 2003). A preliminary list of themes and topics considered core to understanding HIV in physiotherapy and deemed necessary for inclusion in a mainstreamed manner was developed from the results of the preceding studies in this thesis. This list was developed into a questionnaire. Within physiotherapy, mainstreaming has been identified as a strategy that takes key goals and learning, practices such as learning, communication, thinking and analysis and places them at the centre and through out the curriculum (Hunt et al., 1998).

7.2 DEVELOPMENT AND PILOTING OF THE QUESTIONNAIRE

7.2.1 Development of the Questionnaire

The final list of topics that emerged from the results of the clinicians' and academics' perceptions and experiences with HIV as explained in Chapter 6 had been informed by the results of the proceeding studies namely the literature review (Chapter2), referral patterns study (Chapter 3) patient profile (Chapter4) and curriculum audit Chapter 5). The topics were then categorised under specific physiotherapy exit outcomes that were adapted from a study done in South Africa by Krause et al. (2006).The questionnaire was then piloted.

7.2.2 Piloting the Questionnaire

The questionnaire for use in the Delphi technique was piloted for feasibility and content validity by sending it to five lecturers from other institutions, with experience in HIV, curriculum and research. Based on the results the following changes were made before the final tool (Appendix 7.2) was sent out by email.

- The rating scale was changed to allow for those raters who feel they have inadequate knowledge on a particular topic to tick “don’t know”. This was kept separate from the Likert scale of strongly disagree to strongly agree.
- All topics were formatted to ensure categorisation under the most logical areas
- In addition to the academics’ opinion on inclusion in the curriculum, a survey component to determine how much was already being taught was expanded to include “not taught” and “don’t know”. Sections for comment were also given

7.3 SAMPLE SELECTION

In this study, the area of expertise was defined as “physiotherapy curriculum”. Therefore the person responsible for managing particular areas of the physiotherapy curriculum such as neurology, respiratory, musculoskeletal and or public health or community physiotherapy was seen as having the expertise to determine which aspects of HIV to integrate into the curriculum. For this reason, all lecturers’ at all South African universities involved on a full time or part time basis in teaching and education of student physiotherapists were invited to participate in this Delphi exercise as they were considered to have expertise in “physiotherapy curriculum”. Up-to-date lists of current staff were obtained from all eight South African universities that offer physiotherapy training.

7.4 DELPHI TECHNIQUE

7.4.1 Round One

A letter (Appendix 7.1) was written to all 68 identified lecturers employed at the eight South African universities that offer physiotherapy training inviting them to participate in the first round. The questionnaire was emailed upon receipt of a response to the invitation letter. Participants were asked to indicate their level of agreement to the suggested topics being included in the curriculum and then to indicate the status of teaching within their institution.

The level of agreement was determined through a four point Likert scale ranging from strongly disagrees to strongly agree. The status of teaching was established through a scale that determined input and the perceived level of detail i.e. taught but not in detail; taught

adequate detail and taught too much detail. An option of not sure and not taught was added after the pilot study.

7.4.2 Round Two

Individuals who responded to round one of the Delphi survey were invited to participate in round two. The questionnaire consisted of the items that did not obtain consensus in round one. The same Likert scale was used. Surveying what was taught and in what perceived detail was excluded as the information obtained in round one was deemed adequate.

7.4.3 Data Analysis

Descriptive statistics were used to determine the frequency of each response. To determine the statuses of agreement, the frequencies of strongly agree and agree were combined and similarly strongly disagree and disagree were combined in order to dichotomise the responses. For the status of teaching, three categories were reported i.e. taught with in-adequate detail, taught with adequate detail and not taught and not sure were combined

Responses of the first round were collated and summarised and the results were then sent to each participant. The level of consensus was targeted at 80%. No reference could be found to determine a standard level of agreement. Where consensus was not reached, participants were invited to rate the topics in round two using the same rating scales.

7.5 RESULTS

7.5.1 Results: Round One

A total of 68 lecturers were invited to participate in the Delphi using either the fax or email. Ten lecturers were on leave, off sick or away on sabbatical and were excluded from the total sample. The final population that was present at work was fifty eight (Table 7.1). Forty seven (47) responded to the first round of the Delphi giving a response rate of 81%. Shaw et al. (2005) reported a 33% response rate in the first round (Shaw et al., 2005) and a 66% response rate in the second round while (Sowell, 2000) reported a 45% response in the first round and 79% in the second round in their studies. The demographics of this sample are illustrated in Table 7.1.

7.5.2 Sample Demographics

Table 7.1: Number of Lecturers who Responded from Each University

Universities	No of lecturers present at the time of study	Non responders	Number of lecturers who responded from each university n (%)
1	8	2	6(12.8)
2	8	2	6(12.8)3
3	7	2	5(10.6)
4	6	1	5(10.6)
5	6	2	4(8.5)
6	8	2	6(12.8))
7	6	0	6(12.8)
8	9	0	9(19.1)
total	58	11	47(100)

Of the lecturers who responded, 17.1% (8) had bachelors degrees, 53.2% (25) masters degrees (MScs) or equivalent and 29.8% (14) had PhDs. The areas of specialisation or teaching are summarised in Table 7.2.

Tables 7.2: Lecturers' Areas of Specialisation

Area of specialisation/teaching	N (%)*
Orthopaedic	12 (26)
Neurology	8(17)
Public health/community physiotherapy	13(28)
Paediatrics	10(21)
Neuromusculoskeletal	14(30)
Cardiopulmonary	13(28)
Other(ethics management, research, ICU)	11(23)

* Percentage does not add to 100 because some lecturers teach in more than one area

7.5.3 Results of the First Round of the Delphi Questionnaire

Results showing the level of consensus in the first round are shown in Tables 7.3 to 7.9.

Each of the tables is placed under the physiotherapy learning outcomes identified and outlined in the questionnaire. The first three columns after the topic in the table outline the results of the level of agreement to the inclusion of the topic. In all topics the respondants were asked to complete all responses. The second three columns indicate their opinion of the level of current teaching. In some cases the respondants felt they could not respond to

this part as they did not have concrete knowledge and left it blank. Despite prompting via email some respondents felt without further research they could not respond truthfully. Therefore for level of teaching not all rows add up to 47.

7.5.3.1 **The ability to contribute to prevention of disease and promotion of health with due consideration for the impacts of HIV/AIDS**

Table 7.3.1: Basic Information on HIV: The Current Prevalence Global to Local

Topic	Don't know	Disagree n(%)	Agree n(%)	Taught inadequate detail	Taught adequate detail n(%)	Not taught/ unsure n(%)
Types of HIV	1(2)	1(2)	45(96)	15(33)	19(42)	2
Social determinants	1(2)	1(2)	45(96)	20(42)	15(31)	12(26)
Sex and sexuality	3(6)	6(13)	38(80)	16(34)	14(29)	17(36)
Mean			42(89)	17(36)	16(34)	10(20)

Consensus was attained for this topic. Sex and sexuality had a border-line level of consensus. Three participants felt they did not know enough on the topic of sex and sexuality to make a judgement. Eighty nine percent felt it was taught in adequate detail.

Table 7.3.2: Impact of HIV

Topic	Don't know	Disagree n (%)	Agree n(%)	Taught inadequate detail	Taught adequate detail n(%)	Not taught/ unsure n(%)
Clinical presentations of the patient		1(2)	46(98)	17(36)	22(46)	8(17)
Socio-economic implications of HIV/AIDS	1(2)	1(2)	45(96)	22(47)	17(36)	8(17)
Impact of HIV on the family and caregiver		1(2)	46(98)	22(46)	16(34)	9(19)
Mean			46(98)	(20) 43	18(38)	8(17)

All but one respondent agreed with the inclusion of topics covering the impact of HIV. Eighty one percent (total of both adequate and inadequately taught) of the lecturers felt that the content under basic HIV information was taught, however, just over a third (38 %) felt it was at an adequate level. The level of consensus on pathophysiology and the perception of what is taught is illustrated in table 7.4 below

7.5.3.2 **A well founded knowledge of HIV disease, pathology processes medical management as a basis for physiotherapy input to HIV/AIDS management**

Tables 7.4 to 7.5 outline consensus for inclusion and level of teaching for important basic knowledge for HIV/AIDS in pathophysiology and ARVs. Subsequent tables (7.6.1 to 7.6.4) under this same learning outcome, out line the results of HIV on the different body systems.

Table 7.4: Pathophysiology of HIV (n=47)

Topic	Don't know	Disagree n (%)	Agree n (%)	Taught inadequate detail n(%)	Taught adequate detail n(%)	Not taught/ unsure n (%)
HIV structure and factors influencing HIV proliferation		3(6)	44(94)	14(30)	11(23)	21(45)
Mechanism of HIV entry at cellular level	1(2)	6(13)	40(85)	12(26)	12(26)	23(49)
Key receptors of HIV in the cellular structure within the different body systems	2(4)	511)	40(85)	12(26)	12(26)	23(48)
Role of chemokines and cytokines in HIV (in view of their subsequent role in exercise)	2(4)	2(4)	43(92)	11(23)	7(15)	30(64)
Stages of HIV		0	47(100)	14(30)	16(34)	17(36)
Episodic nature of HIV/AIDS and the relation to the pathophysiology		1	46(98)	15(32)	9(19)	23(49)
HIV prognosis		0	47(100)	16(34)	15(32)	16(34)
HIV prognosis in relation to understanding overall management of HIV/AIDS		0	47(100)	16(34)	14(30)	17(36)
Relation of stages to clinical presentation, functional ability, general health and physiotherapy treatment decision		0	47(100)	13(28)	18(38)	16(34)
mean			45(96)	14(29)	13(27)	21(44)

A range of 85-100% consensus agreement was obtained for the topics under pathophysiology of HIV as seen in the column depicting agreement. The overall mean for the lecturers who felt the topics were taught in adequate detail was 27 %(13). Note-worthy is the lower figure attained for the topics of mechanism of HIV entry at cellular level, key receptors of HIV in the cellular structure within the different body systems and the role that chemokines and cytokines play. The level of consensus and perception of what is taught is illustrated in Table 7.5.

Table 7.5: Anti-Retroviral Therapy (ARVs)

Topic	Don't know	Disagree n (%)	Agree n(%)	Taught inadequate detail	Taught adequate detail n(%)	Not taught/ unsure n (%)
Implications of ARVs to physiotherapy management		1(2)	46(98)	15(32)	10(21)	22(47)
Effectiveness/non effectiveness of ARVs		1(2)	46(98)	14(30)	9(19)	24(51)
Role of ARVs in the overall management of HIV		1(2)	46(98)	16(34)	8(17)	23(49)
Mechanisms of how ARVs work	3(6)	1(2)	43(93)	13(28)	7(15)	27(57)
Complications of ARVs	1(2)	2(4)	44(94)	14(30)	8(17)	25(53)
Structure and organisation of ARV programmes	4(9)	2(4)	41(87)	14(30)	5(11)	28(60)
Mother-to-child transmission programmes	1(2)	4(9)	42(89)	12(26)	9(19)	28(60)
mean			44(94)	14(30)	8(17)	22(54)

A range of 87% to 98% agreement was obtained for the inclusion of information on ARVs as can be seen in the agreement column. Only a mean 8(17%) (range 5(11%)-10(21%) of participants reported that ARVs were taught in adequate detail.

HIV effects on body systems: direct and indirect effects on all systems

The following tables outline the results of consensus levels obtained under the topics concerning the impact of HIV on the different body systems

Table 7.6.1: HIV effects on the Haematological and Cardiopulmonary Systems and Common Conditions Related to HIV – Epidemiology, Aetiology and Signs and Symptoms

Topic	Don't know	Disagree n (%)	Agree n(%	Taught inadequate detail	Taught adequate detail n(%	Not taught/ unsure n (%)
Direct and indirect effects on the haematological system	3(6)	6(13)	36(76)	6(13)	8(17)	32(68)
Aetiology of anaemia in relation to HIV	2(4)	7(15)	38(80)	8(17)	3(6)	36(76)
Cardio/Pulmonary - HIV						
Effects on oxidative system		1(2)	46(98)	7(15)	8(17)	32(68)
Effects on diffusion capacity		1(2)	46(98)	7(15)	8(17)	32(68)
Effects on metabolic pathway		1(2)	46(98)	8(17)	7(15)	32(68)
Effects on cardiac system		1(2)	46(98)	7(15)	9(19)	31(66)
Pneumonias including interstitial lymphoid pneumonitis		1(2)	46(98)	15(32)	17(36)	15(32)
Tuberculosis		1(2)	46(98)	13(28)	21(45)	13(28)
Aerobic incapacity		1(2)	46(98)	11(23)	14(30)	22(47)
Fatigue		1(2)	46(98)	11(23)	16(34)	20(43)
Relation of the above conditions to physiotherapy management		1(2)	46(98))	11(23)	20(43)	16(34)
mean			40(85)	9(18)	12(25)	26(54)

Most of the respondents agreed with including the effects of HIV on the haematological and cardiopulmonary system. The range of agreement was from 36(76%) to 46(98%). Only one area did not obtain consensus i.e. the direct and indirect effects of the haematological system. Over 14(30%) (range14 (30%)-21(45%) of the lecturers felt pneumonia, TB, aerobic incapacity and fatigue were taught in adequate detail. (The range is taken from column indicating taught in adequate detail) Over 68% were unsure or felt the effects on diffusion metabolic pathway and oxidative system were not taught. This is drawn from the column depicting not taught/unsure. Table 7.6.2 illustrates the consensus obtained in the topics of metabolic system disorder in relation to HIV and the perceptions by academics of what is taught.

Table 7.6.2: HIV Effects on Metabolic System and Disorders in Relation to HIV

Topic	Don't know	Disagree n(%)	Agree n(%)	Taught inadequate detail	Taught adequate detail n(%)	Not taught/ unsure n(%)
Lipodystrophy	6(13)	6(13)	35(74)	8(17)	2(5)	36(76)
Lactic acid	5(11)	4(9)	38(80)	9(19)	3(6)	35(74)
Insulin resistance and intolerance	5(11)	2(4)	40(85)	8(17)	2(4)	36(76)
Weight loss	4(9)	1(2)	42(89)	13(28)	6(13)	28(60)
Relation to physiotherapy management	2(4)	2(4)	43(92)	11(23)	6(13)	29(62)
Mean			40(85)	10(21)	4(5)	33(70)

Some participants marked "I don't know" therefore the number of participants does not add up to 47.

Six participants reported that they did not know if lipodystrophy should be included and less than 80% felt it should be included. Lecturers also felt the effects of the metabolic system are not taught in adequate detail as shown in the column taught in adequate detail. Consensus on the HIV effects on neurological system and common conditions related to HIV epidemiology, aetiology and signs and symptoms and the academics' perceptions of what is taught are illustrated in Table 7.6.3.

Table 7.6.3: HIV Effects On Neurological System and Common Conditions Related to HIV Epidemiology, Aetiology and Signs and Symptoms

Topic	Don't know	Disagree n(%)	Agree n(%)	Taught inadequate detail	Taught adequate detail n(%)	Not taught/ unsure n(%)
Direct and indirect effect of HIV on neurological system		1(2)	46(98)	14(30)	19(40)	14(30)
Impact of ARVs on neurological systems		1(2)	46(98)	12(26)	13(28)	22(47)
HIV and stroke		1(2)	46(98)	12(26)	18(38)	17(36)
Global encephalopathy	3(6)	1(2)	43(92)	9(19)	12(26)	26(55)
Peripheral nerve dysfunction and peripheral neuropathy		1(2)	46(98))	11(23)	18 (38)	18(38)
Progressive multifocal leucoencephalopathy	3(6)	1(2)	43(92)	5(11)	12(26)	30(64)
AIDS dementia complex	2(4)	3(7)	42(89)	6(13)	13(28)	28(60)
Guillian Barré Syndrome	1(2)	2(4)	44(96)	10(21)	20(43)	20(43)
Spinal cord disorders	1(2)	1(2)	45(96)	10(22)	20(43)	17(36))
Meningitis	1(2)	1(2)	45(96)	10(23)	19(40)	17(36)
Relation to physiotherapy management		1(2)	46(98)	10(23)	21(44)	16(34)
Mean			45(96)	9(22)	16(34)	20(44)

Consensus was obtained for including the topic of HIV effects on the neurological system. The range was 92-98 % (n=42-46) and a mean of 96% (45). Between 26-44% (n=12-21) (mean34% (n=16) of lecturers felt this topic was taught in adequate detail. Consensus on HIV effects on the musculoskeletal system, common conditions, epidemiology, aetiology and signs and symptoms and the academics' perception of what is taught is illustrated in Table 7.6.4.

Table 7.6.4: HIV Effects on the Musculoskeletal System, Common Conditions Epidemiology, Aetiology and Signs and Symptoms

	Don't know	Disagree n(%)	Agree n(%	Taught inadequate detail	Taught adequate detail n(%)	Not taught unsure n (%)
Impact of HIV on fracture healing	1(2)	1(2)	45(96)	12(26)	10(21)	25(53)
Direct and indirect impact on muscles	1(2)	1(2)	45(96)	14(30)	9(19)	24(51)
Myopathies	3(6)	2(5)	42(89)	16(34)	6(13)	25(53)
Inflammatory arthropathies	3(6)	2(4)	42(89)	14(30)	5(11)	28(60)
Infectious musculoskeletal conditions	3(6)	2(4)	42(89)	13(28)	6(13)	28(60)
Relation to physiotherapy management	3(6)	2(4)	42(89)	12(26)	7(15)	28(60)
			43(92)	14(29)	7(15)	26(56)

Consensus of over 89% (mean 92% n=43) was achieved for HIV effects on the musculoskeletal system. However, a low percentage of these topics are taught in adequate detail as seen in the table above. Consensus on physiotherapeutic principles, philosophies and problem-solving with due consideration for the impact of HIV/AIDS inputs and the academics' perception of what is taught is illustrated in Table 7.7

7.5.3.3 **Physiotherapeutic principles, philosophies and problem-solving with due consideration for the impact of HIV/AIDS inputs**

Tables 7.7 and 7.7.1 outline the results of the topics under the learning outcome relating to physiotherapy principles and related topics.

Table 7.7: Physiotherapeutic Principles, Philosophies and Problem-Solving with due Consideration for the Impact of HIV/AIDS Inputs

Topic	Don't know	Disagree n (%)	Agree n(%)	Taught inadequate detail	Taught adequate detail n(%)	Not taught/ unsure n(%)
Understanding HIV management approaches		1(2)	46(98)	12(26)	14(30)	21(45)
Rehabilitation approaches and role in HIV management		1(2)	46(98)	12(26)	16(34)	19(40)
Role of the Physiotherapist in a community setting		1(2)	46(98)	12(26)	18(38)	17(36)
Palliative role for the physiotherapist		1(2)	46(98)	14(30)	15(32)	18(38)
Rehabilitation and physiotherapy theory and relation to HIV		1(2)	46(98)	13(28)	17(36)	17(36)
ICF and HIV uses and implications for the physiotherapist		1(2)	46(98)	13(28)	17(36)	17(36)
The role of the physiotherapist in managing common impairments		1(2)	46(98)	12(26)	19(40)	16(34)
Relationship of episodic HIV to physiotherapy	1(2)	1(2)	45(96)	15(32)	12(26)	20(43)
The role of the multi-disciplinary team in HIV management		1(2)	46(98)	11(23)	19(40)	16(34)
Physiotherapy treatment modalities evidence and current use, precautions and contra-indications in the treatment of HIV	1(2)	1(2)	45(96)	15(32)	16(34)	16(34)
Mean			46(98)	13(28)	16(34)	18(38)

Between 96-98% consensus on the topics under physiotherapy principles, philosophies and problem-solving was achieved. A mean of 34 %(n=16) felt these topics were taught in adequate detail. Consensus on HIV and concepts of disability, function and HRQOL and the perception of what is taught is illustrated in Table 7.7.1

Table 7.7.1: HIV and Concepts of Disability, Function, Exercise and HRQOL

Topic	Don't know	Disagree n(%)	Agree n(%)	Taught inadequate detail	Taught adequate detail n(%)	Not taught/ unsure n(%)
Concepts of disability and their relation to HIV		1(2)	46(98)	13(28)	14(30)	20(43)
HIV disability and function		1(2)	46(98)	15(32)	14(30)	18(38)
CD4 levels and the relation to function		1(2)	46(98)	16(34)	10(21)	21(45)
The relationship between disability and HRQOL	2(4)	1(2)	44(94)	9(19)	14(30)	24(51)
Effects impacts and evidence of exercise in HIV and disability		1(2)	46(98)	19(40)	9(19)	19(40)
mean			46(97)	14(31)	12(23)	20(43)

All topics under HIV and concepts of disability, function exercise and HRQOL had consensus agreement of 94-98 (mean 97% n=46). Only a mean of 23% (n=12) of lecturers felt the impact and evidence of exercise was taught in adequate detail. Consensus on appropriate attitudes and behaviour patterns for care in HIV/AIDS and application of social and behavioural sciences in the physiotherapy profession and academics of what is taught is illustrated in Table 7.8

7.5.3.4 **Appropriate attitudes and behaviour patterns for care in HIV/AIDS and application of social and behavioural sciences in the physiotherapy profession**

Under this learning outcome Table 7.8 outlines the consensus results for the specific topis and the perception of the adequacy with which they are taught.

Table 7.8: Appropriate Attitudes and Behaviour Patterns for Care in HIV/AIDS and Application of Social and Behavioural Sciences in the Physiotherapy Profession

Topic	Don't know n(%)	Disagree n(%)	Agree n(%)	Taught inadequate detail	Taught adequate detail n(%)	Not taught/ unsure n(%)
Counselling basic approaches to counselling	1(2)	1(2)	45(96)	17(36)	10(21)	20(43)
Self assessment of attitudes	1(2)	1(2)	45(96)	9(19)	9(19)	29(62)
Policies guiding HIV management	2(4)	2(4)	43(92)	9(19)	11(23)	26(57)
Appropriate approach to HIV patients	1(2)	1(2)	45 (96)	13(38)	17(36)	17(36)
Disclosure and patients charter public health act	2(4)	1(2)	44 (94)	9(19)	13(28)	25(53)
Role definition and marketing physiotherapy role	2(4)	3(7)	43(92)	12(26)	12(26)	25(53)
Application of Universal precautions	1(2)	1(2)	45(96)	7(16)	20(43)	20(43)
Clinical decision-making in HIV	2(4)	1(2)	44 (94)	12(25)	14(29)	21 (45)
Dealing with known threats (overcrowding, staff shortages, death, beliefs stigma)	2(4)	1(2)	44 (94)	11(23)	10(21)	25(53)
Mean			44(94)	11(23)	13(28)	23(49)

Consensus for inclusion was obtained for the topics applying social and behavioural sciences with a mean of 94% (n=44). Only universal precautions were considered to be taught in adequate detail (43% of respondents) while the other topics scored relatively low in the number of people who thought they were taught with adequate detail.This shows a low level of input in the area of application of social and behavioural sciences.

On completion of the analysis, the results of all the topics levels were presented to the respondents and they were invited to complete the second round

7.6 RESULTS OF ROUND TWO OF THE DELPHI SURVEY

A response rate of 91% was attained in round two with 43 of the 47 participants from round one responding in round two. Table 7.9 outlines the results of round two.

Table 7.9: Results of the Second Round Delphi Survey

	Level of Agreement		
Topic	**Don't know n (%)**	**Disagree n (%)**	**Agree n (%)**
Aetiology of haematological system and anaemia in relation to HIV	1(2)	7(16)	35(81)
Lipodystrophy	2(5)	6(14)	35(81)
Relation of anaemia and lipodystrophy to physiotherapy management	2(5)	3(7)	38(89)

Symmetry

The results of the first and second round were analysed for symmetry to test the change in opinion. The non-significant p value indicates random movement.

- Aetiology of anaemia p=0.5
- Lipodystrophy p=0.5
- Relation of anaemia and lipodystrophy to physiotherapy management p=0.3

These respondents showed random movement with no symmetrical opinion shift from one direction to another i.e. there was no consistent movement from disagreement to agreement or vice versa. For anaemia 9(21%) respondents shifted from strong agreement to agreement while for lypodystrophy 8(19%) shifted in the same manner

7.7 DISCUSSION

This study aimed to obtain consensus on the proposed topics for inclusion in the physiotherapy curriculum. The use of the Delphi technique allows for the structuring of group communication to identify group consensus (Raine, 2006). In this study consensus for inclusion of eighty (80) identified topics was obtained in all but two of the topics. When applying a Delphi technique it is important for the researcher to exercise caution on the meaning of consensus (Love, 1997). According to the Oxford Thesaurus consensus means a general agreement of opinion on an issue. Studies reviewed acknowledged the need for consensus but did not define it. (Williams & Webb, 1994) defined consensus as 100% agreement. Williams and Web (1994) also state that independent opinion can be considered

true the first time there is rating, after this the rater can be potentially influenced by the group results. The respondents' judgement can be questioned with regard to its validity, however, Lawshe (1975) states that there is no basis upon which to refute strong consensus.

When all respondents are in agreement with the given content, confidence is placed on given content being essential. Lawshe (1975) explains that when the strength of the consensus moves away from unity and approaches a fifty-fifty ratio, problems arise and make two assumptions:

1. "Any item performance which is perceived to be essential, by more than half of the panellists has some degree of content validity"

2. The more panellists beyond fifty percent who perceive the item as essential the greater the extent or degree of its content validity. Lawshe (1975) devised a formula to calculate a content validity ratio. The use of the content validity ratio (CVR) is to reject or retain items (Lawshe, 1975). In this study no items presented with a fifty- fifty ratio and therefore CVR was not calculated.

All academic staff from the eight universities in South Africa were considered as the total sample. Therefore the results of this study can be considered representative of the opinion of South African academic staff. The respondents of this study are seen as experts in physiotherapy education and therefore are in a position to make valid judgements on inclusion of new topics such as HIV. Only 17% of the respondents had a basic bachelors' degree. The remaining respondents had obtained a masters or PhD degree indicative of a higher level of expertise. Williams and Web (1994) suggest that homogeneity of the group, obtaining a high response rate and a high level of consensus suggest that the study demonstrates concurrent validity. The proposed HIV content tested for consensus was derived from results of a number of studies and can be judged as having construct validity (Lawshe, 1975).

This study started with a structured questionnaire outlining the topics considered important for physiotherapists to understand and apply in their management of HIV in the clinical setting. The importance of these topics was established and discussed in chapter 6. This Delphi exercise contributes to verifying and obtaining input on what should be included in the physiotherapy curriculum with regard to HIV content based on educators' clinical and academic experience. Similar studies have been conducted to establish content of other

topics (not necessarily HIV/AIDS) in given curricula (Cross, 2001; Iverson et al., 1979; Krause et al., 2006; Maxwell, 1995; Roskell, 1997; Williams et al., 2004).

7.7.1 Topics Included in the Curriculum

Topics were categorised around key outcome areas (Appendix 7.2) and will be discussed under these same areas.

Outcome 1: The ability to contribute to prevention of disease and promotion of health with due consideration for the impact of HIV/AIDS.

The experts were in agreement that topics outlined under this outcome area should be included. These topics had a high level of agreement as they inform the broad picture of HIV for students. Suggestions were made that these topics should be included in the clinical sciences and that the focus for lecturers should be on the implications for physiotherapy. In relation to this a respondent from the FGDs with clinicians and academics felt that "***If one doesn't know what is taught and therefore even if explaining the relation to physiotherapy is doing so without a clear basis of what knowledge is being built on***"(academic). Sex and sexuality presented with more disagreement and unsureness than any other topic in this section. One respondent commented that there is great uncertainty about what is meant by sex and sexuality and that there should be clear guidelines regarding what any curriculum should include under sex and sexuality. In spite of this over 50% strongly agreed with its inclusion. A few respondents commented that it was important to approach sex and sexuality in particular for physiotherapists as "targets" and physiotherapists as health care professionals. What is meant by "targets" is that physiotherapists also live in the community and are exposed to the same risks as the general population. This points to the importance of not forgetting that as human beings physiotherapists can be impacted on in their professional capacity and on a personal level. Not all lecturers felt this area was taught in adequate detail. It points to the need to assess what input is actually being given as this area together with the disease pathology processes forms the basis for all other input.

Outcome 2: A well-founded knowledge of HIV disease, pathology processes and medical management as a basis for physiotherapy input to HIV/AIDS management

The pathophysiology that was considered important was outlined under nine topics. A high level of consensus was obtained with 100% consensus for the topic on stages of HIV and relation of the stages to the clinical presentation. Lower levels of consensus were obtained for the mechanism of HIV entry, key receptors of HIV on cellular structure and the role of chemokines. Comments such as "***this is excessive detail"*** and that "***the undergraduate already has a lot learn"*** were made under this section. However, for the above mentioned topics, the content constitutes the fundamental background knowledge for understanding important physiotherapy content such as exercise and how HIV impacts on important body systems that physiotherapy deals with in particular the muscular, neurological and respiratory systems. In addition, as expressed by both the clinicians and academics who participated in the focus groups and the literature, the prevalence of HIV is high and newly qualified clinicians expressed shock at the number of patients they see either directly referred for treatment of a co-existing diagnosis or a diagnosis related to HIV. If physiotherapists are going to be relevant to current demands in the health care system they cannot view HIV as a **"*nice to know*"** or extra detail in "core" physiotherapy knowledge areas but must embrace the subject into the core of the curricula.

Overall the respondents were in agreement with the inclusion of the topics under pathophysiology but their perception and knowledge of what is being taught in adequate detail is relatively low. The majority of lecturers were unsure or felt the subject areas were not taught. This corroborates with the results found in Chapter 5 in the curriculum audit where the individual university curricula gave the impression of uncoordinated scattered and not well collaborated curricula. HIV should perhaps be treated in the same manner as input on clinical reasoning which impacts on every area and the outcomes of physiotherapy (Hunt et al., 1998). However, if basic scientists are teaching these in separate non-physiotherapy courses there will always be a disconnect

Antiretroviral therapy (ARVS)

A high level of consensus was obtained for including the topic ARVs'. ARVs are currently the most effective form of treatment for HIV and in some comments respondents felt little attention had been paid to this area. This was supported by the result of the low numbers of respondents who felt it was taught in adequate detail (Table 7.5). In the focus group discussions, clinicians expressed uncertainty in their knowledge of ARVs and realised how

many questions they were unable to answer when patients asked. Inclusion of this topic would equip physiotherapists with the knowledge to not only respond effectively to patients but to be more effective in particular in a trans-disciplinary setting. A therapist may not be effective if they have a poor or no understanding of the most important intervention in HIV management and are unable to relate this to the impact on impairments, activity limitations and participation restrictions and the patients' HRQOL.

HIV effects on haematological and cardiopulmonary systems

Similar to the other areas, a high level of consensus was obtained for the inclusion of the HIV effects on the haematological and cardiopulmonary systems. However, in the specific topic of direct and indirect effects of HIV on the haematological system input on HIV and anaemia respondents did not obtain consensus. Thirteen % (n=7) disagreed while four respondents did not know if this was important thereby affecting consensus. This may indicate a lack of understanding of the pervasive nature of HIV and how no body system is spared. As discussed in the literature review, the haematological system is affected directly and indirectly by HIV and this has implications for fatigue and exercise tolerance (Evans & Scadden, 2000; Mars, 2004b). Although in the second round 81% consensus was obtained, it was just above the chosen level of consensus. When the detail of what is taught was examined under this area, TB, pneumonias and aerobic incapacity were perceived as taught in adequate detail by a greater number of respondents (Table 7.6.1). There is some contradiction in this as aerobic capacity has much to do with the haematological system. This may point to both a lack of connection and perhaps a poor understanding of the impact of HIV also expressed in the focus groups and discussed in Chapter 6. A capacity building opportunity for educators may therefore be apparent.

HIV effects on the metabolic system and disorders

All components of this area had consensus in the first round, albeit lower than the other areas (80-91%), with the exception of lipodystrophy. Lipodystrophy is a relatively new phenomena emerging out of the effects of ARV treatment and this newness may contribute to the uncertainty expressed in the first round. As with anaemia, the second round marginally obtained consensus at 81%. In countries such as Rwanda where ARV treatment has been instituted for a longer time and with relatively fewer logistical problems, it has become evidently a problem warranting physiotherapy attention (Mutimura et al., 2008a; Mutimura et al., 2008b; Mutimura et al., 2008c; Mutimura et al., 2007). A possible explanation could be that the South African situation is different. ARV roll-out is not as

extensive (Dorrington et al., 2006) and therefore awareness of the impacts of ARV treatment may not yet be evident or widely known.

HIV effects on the neurological system

Many of the neurological conditions that are proposed are already taught in a physiotherapy curriculum (CSP 2008). Therefore neurological conditions obtained above 98% consensus except for global encephalopathy, AIDS dementia complex and progressive multifocal leucoencephalopathy that scored below 90%. This may be because these conditions result in more mental health manifestations than physical problems (Cherner, 2002, Manji and Miller, 2004). An awareness of neurological conditions that manifest in the patient who is undergoing antiretroviral treatment and one who is not is very important for a full understanding of the HIV patients' clinical picture (Burgoyne & Renwick, 2004; Montessori et al., 2004). Thirty four lecturers felt it was taught in adequate detail. This is a low figure and in the focus group discussions clinicians felt unprepared for all areas of neurology with the exception of stroke. In the case of stroke they felt they could transfer the same skills set but were unsure about aetiology and prognosis.

Musculoskeletal system

Consensus was obtained for HIV effects on the musculoskeletal system. As with the neurological system some respondents expressed a lack of knowledge on what the focus in this area should be. A high number felt the direct impact of HIV on fracture healing should be included. As with other areas the greater perception is that these topics are not taught and if taught they are done so in inadequate detail.

Outcome 3: An understanding of physiotherapeutic principles, philosophies and problem-solving with due consideration for the impact of HIV/AIDS

Understanding HIV within physiotherapeutic principles should be considered pertinent for the physiotherapist to be able to place themselves and their contribution within the prevention, treatment and care HIV management continuum. Although strong consensus (98%) was obtained for the topics that related to the role of the physiotherapist in HIV the connection was not always made between the topics that tied in together. This was evidenced by some respondents disagreeing with knowing the background knowledge of a topic but strongly agreeing with the need to understand the physiotherapeutic principles. This could mean respondents are not aware or have not given due consideration to the need to explicitly link the HIV content to its implications for physiotherapy principles,

philosophies, roles and practices. Thirty four percent felt this topic was adequately taught and this would imply that there is need to assess what is taught and how it is taught as it is an area that needs a coordinated approach.

Outcome 4: The ability to apply attitudes and behaviour patterns to ensure quality provision of physiotherapy management and care in HIV/AIDS needs and the ability to apply social and behavioural sciences in the physiotherapy profession

This final outcome covered topics that would prepare the student practically to cope with the challenges of HIV or any stressful situation. An indication of the current teaching indicated that twenty eight percent of academics' felt this area was adequately taught. From the results of the FGD discussed in chapter 6 it is evident that there are problems among clinicians with coping. Better focus on this area may counter some of the difficulties experienced. The respondents agreed with the inclusion of these topics into the curriculum.

7.8 CONCLUSION

Although consensus was not 100% for every topic, the level of consensus can be considered high as most topics attained above 90% consensus. Respondents in this study agreed with the topics that were put forward from studies done to establish important topics for inclusion of HIV in physiotherapy curricula. The level of detail was not explored for each topic as this was not the focus of this study. Cognisance is therefore taken of the fact that what the academic staff considered as adequate for teaching would be related to the level of detail set. The comprehensive list of topics that have emerged out of this study is a solid starting point for the inclusion of HIV into physiotherapy curricula in a mainstreamed manner.

CHAPTER 8

8.1 DISCUSSION

8.1.1 Introduction

The complexity of HIV/AIDS, both as a health and educational issue, necessitated this study to be conducted using four different studies and the results from all the studies show that HIV is a vast subject with large-scale implications on physiotherapy education and practice. This chapter will discuss the results of these studies and illustrate how they affect the physiotherapy curriculum. The discussion is framed around how this physiotherapy curriculum looks when the UNAIDS mainstreaming criteria (Verbrugenn, 2004) are applied. This chapter is in answer to objective seven which states that the curricula will be assessed according to the United Nations defined mainstreaming criteria.

Although the study used different approaches in ascertaining HIV curricula needs, the focus of this research was on mainstreaming HIV/AIDS into the physiotherapy curriculum. It is for this reason that mainstreaming as a concept and approach is used as a basis to collate information from all the studies so that it can have direct relevance to practice and application. The rationale for using this approach can be found in Verbrugenn (2004)'s outline of one of the main advantages of mainstreaming HIV, as bringing an issue to the fore and into the core business agenda, so that it becomes part and parcel of a programme. Similarly, in education, Hunt et al. (1998) refer to mainstreaming as a method of taking a key goal of a learning area from the periphery and placing it into the centre and within the entire curriculum (Hunt et al., 1998). Higgs (1998), acknowledges mainstreaming within the curriculum at subject level as an effective means of incorporating an important subject into the curriculum. This discussion is therefore structured around the key principles of mainstreaming HIV into a programme (UNAIDS, 2002).and these are;

1. Development of a clearly defined entry point for mainstreaming HIV/AIDS
2. Mainstreaming should take place within existing policies and frameworks and located within existing institutional structures.
3. Advocacy, sensitisation and capacity building to place health workers in a better position to undertake mainstreaming
4. Distinction between the external and internal domain
   Internal- staff risks and vulnerability
   External - An Institution should undertake interventions based on its mandate capacity in support of national and local strategic efforts

5. Highlights the importance of developing strategic partnerships based on comparative advantage, cost effectiveness and collaboration

Using the results of studies one to five, the next section uses mainstreaming principles as a basis to review and apply the major outcomes of all the studies. This is in answer to objective seven.

8.2 APPLYING MAINSTREAMING PRINCIPLES

This section discusses each of the mainstreaming principles separately; it applies the outcomes and results from the different studies in this thesis to each of the principles. The same results from each study may apply in more than one principle although the application may be different.

8.2.1 Principle 1: A Clearly Defined Entry Point

Defining an entry point for an issue that needs mainstreaming is a fundamental starting point in the process of mainstreaming. The entry point is seen as a position in the core business, at which one can start to include the matter to be mainstreamed. In this case, the physiotherapy curriculum is the core business.

Reviewing the literature on HIV and placing it into rehabilitation frameworks such as the ICF, creates several entry points within the different areas of specialisation in the practice of physiotherapy. The literature review includes explanations of the genesis of the disease, principal modes of transmission, evaluation of drug trials and other forms of treatment potentially used to slow down the degenerative process of HIV disease. HIV virology and subsequent staging, including the use of antiretroviral therapy, were found to be important and fundamental prerequisite knowledge on HIV/AIDS for any health worker including the physiotherapist. The literature explores the effect of HIV on the body systems and explores how HIV impacts on the body at an impairment level first. Subsequent impact on the patients' activity levels and quality of life is also ascertained. Common systems affected by HIV described in the literature are cardiopulmonary, haematological, metabolic, neurological and musculoskeletal. Experiences of clinicians and academics emphasise the need to include a number of these areas. Clinicians recommended the inclusion of the following; use of case variation and common medical problems such as psychiatric conditions, neurological conditions (stroke and peripheral neuropathy), input of the specific HIV effects into body systems such as musculoskeletal, cardiopulmonary, coincidental co-morbidities and increased depth of input on common conditions.

Impairments such as pain, fatigue and loss of body mass occur commonly. Physiotherapy curricula includes the basic structure, function and relevant pathogenesis within these systems (CSP, 2008b). How HIV impacts on these systems and the resultant conditions would not constitute major shifts or additions to the curriculum. Systematic inclusion of how each system is affected would help therapists understand downstream effects such as its impact on activity limitation and the patient's experience of the environment. Impacts of HIV on the socio-economic and socio-cultural environment of the patient must be considered. Previous information on the pattern of impairments and activity limitations among different groups (Van As et al., 2008; Zonta et al., 2003 ; Zonta et al., 2005) was also found in the clinical picture revealed in study 2 (Chapter 4) done to develop patient profiles.

The clinical picture revealed in study 2-Chapter 4, describes common impairments in the sensory and mental functions, digestive, metabolic and endocrine, cardiovascular, haematological, immunological, respiratory and neuromusculoskeletal movement systems. The specific impairments as shown in the data on patient cohorts in Chapter four (Tables 4.3.5 and 4.4.2, 4.3.7, 4.3.9-11, 4.4.3 and 4.4.4 to 4.4.5 4 are pertinent to a physiotherapist. These reveal impairments and aspects with which physiotherapists are already working under the different body systems. For example under sensory function, pain and balance are treated by physiotherapists using a range of interventions (Cross & Sim, 2000; Department of Health, 1998; Ungvarski et al., 1999). In the out-patient mining group memory problems, energy and drive functions, sleep and emotional functions, seeing, hearing, vestibular, pain, blood pressure and respiratory problems, weight maintenance, sexual functions and reduced proximal muscular power were frequently encountered. This agrees with Van As et al. (2008) 's findings of impairments in mental functions, sensory and pain, digestive, metabolic and neuromuscular functions. Over thirty percent of the group in Van As et al. (2008) 's study had activity limitations in general tasks and demands, major life areas, interpersonal relationships and mobility. These are similar to the in-patient group but when compared to the mining group, the picture shows a slightly different emphasis on the type of impairment. Results such as these guide the focus of a rehabilitation programme, where for example in all three groups, pain and mobility should have specific interventions. However, mobility for the in-patient group is at a basic ability level focussing on retraining movement. In the mining out-patient and the public health out-patient groups the focus may be on maintaining and improving parameters such as endurance. Assessing PLWH within the ICF framework gives the physiotherapist a good starting point and a clear indication of where the patient's problems lie. This location of problems helps in the management and

treatment programmes and with regard to curriculum it helps to focus the knowledge attitudes and practices to be emphasised.

Therefore, integrating HIV content into the curriculum would not pose great difficulty. One line of thought is that PLWH with a stroke (for example) are not much different pathologically speaking than any other stroke patients. Hence if we have the fundamental knowledge and skills to assess and treat stroke patients these will be transferable to PLWH. Therefore the transferability of an already existing skills base should potentially be tapped. Problems in cardiovascular, haematological and respiratory system are well researched in physiotherapy and therefore have a strong base of knowledge from which integration of HIV can take place within the curriculum (CSP, 2008b). Added information from the literature has the potential to enrich the knowledge base, which would add to curriculum content. For example, it would be necessary for physiotherapists to know that HIV patients maintain lung volumes but show lowered diffusion capacity (Diaz et al., 1999).
HIV illness is episodic in nature (O'Brien et al., 2007) suggesting that educators should emphasise this fluctuating nature in the curriculum. This would ensure the student realises they will apply their skills to the stages depending on whether the patient is in a period of relative illness or wellness.

Profiles of the in-patient and out-patient mining groups studied and outlined in Chapter 4 reveal that despite the contrasting contexts with in-patients coming from poorly resourced backgrounds and out-patient mining groups' supportive backgrounds, impairments, were present in both groups. Van As et al. (2008), found similar results of moderately high impairments, a moderate presence of participation restrictions and a low level of participation restrictions, in an out-patient group. Activity limitations were high in the in-patient group but very low in the out-patient group. The implication for curricula content is that when applying rehabilitation principles, HIV highlights the need for individually designed programmes. This is not new to physiotherapy but is underscored by the complex effects of HIV. Within the episodic pattern of HIV, physiotherapists need to keep in mind the presence of impairments thus relating to their role in health maintenance and wellness. Physiotherapists already use a bio-psychosocial approach in assessing patients and therefore the identification of activity limitations, participation restrictions within the patients' environment is an opportune entry point that exists for inclusion of HIV aspects within and throughout the physiotherapy curriculum. Throughout physiotherapy teaching the role of physiotherapy is highlighted for each area of teaching. The second objective of this thesis was to gain an understanding of the extent to which physiotherapy is already interacting

with HIV. The result of three percent referral illustrated a low level of interaction. Worthington et al. (2005) and the CWGHR (2004) noted that physiotherapists and other rehabilitation professionals should know how much and in what way they are interacting with HIV. Therefore, throughout all the areas of teaching under the various body systems the role of physiotherapy in HIV should be incorporated.

Other content issues are unique to HIV as illustrated by the presence of digestive system impairments and are outside of the traditional physiotherapy body systems covered in the curriculum. However, from the results, problems in the digestive system are associated with limitations in activity and participation restrictions. For example, in study 2, in-patient group, when patients were asked why they reported no community integration they attributed restriction in community integration to fear of not being able to find a toilet quickly enough, so that the patient had self-imposed restriction in movement and subsequent participation in community activity. With problems such as these, the physiotherapist would have to work in an effective team set-up in order to manage the patient well. The models of multi, inter and trans-disciplinary teams become more pertinent and should be emphasised in the curriculum (Davis, 2006). This is especially useful in the South African context where teams may not always be comprehensive. In such a situation, physiotherapists may find themselves requiring basic knowledge of all aspects of HIV management to apply the trans-disciplinary approach effectively.

Other aspects of HIV that would not pose great difficulty to integrate are specific impairments found in patient profiles in Chapter 4 such as pain, disturbed sleep, emotional problems and loss of body mass also found in the study by Van As et al. (2008). These impairments are relevant for physiotherapists as physiotherapy uses interventions such as exercise to counter the effects of such impairments on activity and function (Ungvarski et al., 1999). The full list of topics (Appendix 6.4) that emerged from the collation and interpretation of all the preceding studies also highlights how each of the topics identified could be grouped under the learning outcomes of physiotherapy (Krause et al., 2006). One example of the learning outcomes is that physiotherapists should obtain a well-founded knowledge of disease pathology, medical management and a basis for physiotherapy input. In this outcome, HIV input was clearly defined into pathophysiology, antiretroviral therapy, and the HIV effects on specific body systems. Within these systems areas pertaining to physiotherapy were explored to inform what the specific interventions are. These can also be considered entry points for mainstreaming HIV into the curriculum.

Specific rehabilitation and physiotherapy interventions including maintaining or increasing the level of physical activity and exercise were explored for their impact on PLWH and related physiology. Exercise, in particular, as part of behaviour modification and change in life style, has sufficient evidence for a positive contribution in the prevention and care of HIV manifestations (Nixon et al., 2005; Rusch et al., 2004). Some of the advantages for aerobic exercise primarily change the mitochondrial and cytosolic proteins while resisted exercise increases muscle protein (Zinna & Yarasheski, 2003). Other interventions such as electrotherapy, use of aids and massage are in the developmental stage for their effects on HIV (Fulk et al., 2004; Galantino et al., 1999; O'Dell et al., 1996b; Posner et al., 2004; Shor-Posner et al., 2004; Worthington et al., 2005). Some positive clinical effects have been reported, however, these studies are still challenged by small sample sizes, difficulties with blinding, standardisation and poor isolation of treatment due to the nature of treating HIV. Incorporation into teaching should therefore take cognisance of this status.

Important to note is that the patient may at different times experience periods of wellness or illness and could at any time present with a profile of high or low impairments, activity limitations and participation restrictions. The intervention points for the therapist will depend on the patient presentation and should be guided by rehabilitation models. As previously discussed, activity limitations and participation restrictions commonly found among HIV patients could be used as specific entry points when teaching the application of rehabilitation models and principles.

Existing rehabilitation frameworks such as the ICF and rehabilitation defined processes and approaches used for the management of chronic conditions and community based approaches within physiotherapy are very applicable to HIV (Hwang & Nochajski, 2003). Such approaches would be appropriate entry points for including and discussing HIV in the curricula. Successful application would need a functioning multi-disciplinary team that is either working in an inter-disciplinary or trans-disciplinary mode. The areas in the curriculum where working in teams is covered should be an opportune entry point for HIV inclusion (Canadian Working Group on HIV and Rehabilitation, 2002b). However, in adding important HIV-related content, it is important to take cognisance of the high demand on undergraduate time. While entry points are defined, the challenge for the lecturer is to keep a balance on equipping the graduate with the necessary knowledge and not making continuous additions to the curriculum. However, much of the identified content need not be addition of new lectures or significantly more time. Much of the information can be included to existing content and adding how HIV changes the picture, and in doing this, mainstream the content.

From the focus group discussions, some academic staff were concerned with the focus on HIV. They asked the question "*why the focus on HIV*?" What sets HIV apart is its pervasive nature, a high prevalence and the complexities it presents for the clinical situation as illustrated by both the literature review and the patient profiles. It has been said that HIV magnifies problems that exist in the health care delivery system (Piot, 2006).

Evidence suggests that problematic attitudes among health workers, as well as a lack of accurate information about HIV AIDS can make a significant negative impact on the health worker's approach to HIV. Training can improve knowledge skill, attitude and increase the level of comfort in dealing with those who are HIV infected (Kent et al., 2005). In the focus group discussions, clinicians expressed feeling ill-equipped and some academics and clinicians' contributions were evident of inadequacies in knowledge. Students and qualified therapists should be equipped with the necessary skill to apply known principles of physiotherapy and rehabilitation to HIV. To do this they need a basic level of knowledge on HIV (Puckree et al., 2004; Puckree et al., 2002; Ukwakwe, 2000). In addition to formal training, graduates need to use evaluation and self directed learning to extend their skills in managing HIV. This would augment their ability to manage HIV and should be actively encouraged (Hunt et al., 1998). Attitudinal and appropriate approaches would need a complex integration of knowledge and self-assessment of professional development of individual learners. It is important for academics and clinicians alike to realise that the knowledge on HIV is ever changing and it would be their responsibility to update their knowledge on the status of the disease.

A number of areas such as the different body systems, pain, function, activity limitation, the effect of the environment and social determinants where physiotherapists already work have been pointed out as entry points. Consensus for the inclusion of all the identified topics by academics from all the eight universities, offering physiotherapy training was obtained. In some cases this content has been incorporated but many topics remain unincorporated and if so, are taught at an inadequate level. Ensuring that HIV content is incorporated in these areas would successfully fulfil the application of the first mainstreaming principle. The level of detail and the process of learning should be determined by the educators themselves.

8.2.2 Principle 2: Mainstreaming should take Place within Existing Policies, Philosophies and Frameworks

The policies and frameworks are assessed at two levels. From the focus group discussions, issues that emerged as curricula concerns were categorised at macro, meso and micro levels. Under macro level issues, participants in the FGDs supported the need to include HIV because HIV is a national priority and has a high prevalence (Table 6.10). In response to the call for national responses and incorporation of HIV into all programmes by UNAIDS, the government called for all sectors to respond by incorporating HIV into their core business (Department of Health, 2007b). All eight universities have HIV policies that guide the implementation of response to infection and inclusion in subject matter. For example, the University of the Witwatersrand states that all university undergraduates must be exposed to basic knowledge of HIV and its mode of transmission. Thereafter all departments should identify specific areas within their courses where inclusion of HIV is pertinent. The list of contents that emanated from these studies (Appendix 6.4) and resulted in the Delphi tool (Appendix 7.2) could be a good starting point for physiotherapists as it outlines the key content areas within each learning outcome.

In addition, physiotherapy practice falls under the Department of Health and HIV/AIDS is a key area under the department. One of the key strategic goals is to provide comprehensive prevention treatment and care (Department of Health, 2007b). The South African National AIDS Council (SNAC, 2008) released a report on HIV/AIDS and disability in South Africa that outlines the concerns around HIV/AIDS and disability (SNAC, 2008). The report focuses on “disabled people” and their experiences with HIV and the risk of contracting HIV and only fleetingly refers to HIV as a cause of disability.

A broad understanding of the current policies and frameworks would be important for all health workers, including physiotherapists, to understand. This would help in defining their role and making informed management decisions. From the curricula audit, all but one of the seven universities did not reflect policies and frameworks. Certainly, a summary to ensure that undergraduate students have an understanding of the existing policies should be included in the curriculum as well as guide the curriculum development. In the focus group discussions, clinicians noted that when patients asked them about aspects of their ARV management they realised how ill equipped they were in understanding the overall approach of HIV management in relation to existing policy.

From the literature some new frameworks have emerged in response to the needs of HIV. An example is Worthington (2005)'s rehabilitation approach that accounts for disability in different life domains and these include the physical, functional, psychological, spiritual, social and vocational needs of an individual. Rehabilitation efforts should therefore be client-oriented and focus on the individual's need. In order to execute the service effectively, the participation of a wide range of community players such as AIDS service organizations, community based organizations, religious and church organizations, the formal health and private sector is essential. At the meso level, issues emanating from the FGDs participants expressed a fragmented and uncoordinated approach to HIV curricula input. This may be indicative of the lack of teaching around a framework that pulls the subject together. The ICF has been proposed as a broad framework.

The ICF with its bio-psychosocial approach is reported in many studies and reviews, as an appropriate model for framing rehabilitation approaches (Anandan et al., 2006; Hwang & Nochajski, 2003; Worthington et al., 2005). Therefore, most studies show how HIV influences function and quality of life with studies showing high impairments that impact on function or quality of life (Anandan et al., 2006; Benedict et al., 2000; Gielen et al., 2001; Low-Beer et al., 2000; Stringer et al., 1998; Vidrine et al., 2003; Zonta et al., 2005). Specific aspects of function and quality of life such as mobility, instrumental activities and self-care activities were covered. These are areas with which physiotherapy is concerned and the HIV perspective can easily be incorporated.

Related to the ICF and the bio-psychosocial approach are service delivery modes that have their philosophical underpinnings in the bio-psychosocial approach. One such approach that physiotherapists are familiar with is community based rehabilitation (CBR). CBR principles allow for the rehabilitation in a client and community focussed paradigm (Helander, 1994). An important link to the approach of CBR needs to be encouraged.

CBR is already well understood and taught to physiotherapists. Some of the principles, such as locating the person living with disability at the centre of their management and programme planning, is a practice encouraged by physiotherapists. Existing networks set up for community-based rehabilitation can be used to respond to the activity limitation, participation restrictions and experience of barriers and facilitators because of contextual aspects of the person's existence. Physiotherapists can work in HIV service delivery with what they already know and understand with regard to concepts and service delivery modes such as community based rehabilitation. To do this it would be important to include what is defined as disability in HIV, the concepts of participation (Myezwa & M'kumbuzi, 2003),

dealing with stigma and discrimination. Aspects that would facilitate prevention, treatment and care are advocacy for resource allocation, community and political mobilisation, community assessment and involvement (Helander, 1994; Vanneste, 2002). The DoH has focussed on how people with disability are affected by HIV and physiotherapists should remain sensitised to this in service delivery especially CBR. Bringing disability to the fore has always been a struggle that rehabilitation professionals deal with and these experiences can be re-energized and applied to managing HIV.

The range of impairments, activity limitations and participation restrictions that were found in this study add to understanding how HIV affects a person in the different domains. For each individual this experience is unique and therefore emphasis of the interaction between the three domains will assist the student in giving an appropriate assessment and subsequent intervention. It is also important to emphasize the need to assess how the individual patient interacts with his environment. The difficulties in the experience of the environment that were evident from this study are probably not peculiar to HIV patients but do show where efforts are needed. Most people with HIV in the in-patient cohort reported being in transition as far as their place of accommodation was concerned because of the episodic illness and loss of income. Other patients with chronic conditions may not experience this type of disturbance. The mining cohort, on the contrary, had fewer problems with accommodation or support structures but curiously reported sharing medication with spouses because the system did not support the spouse. They were also more concerned with attitudes of colleagues and work mates and therefore did not disclose their status. A full assessment by a therapist involved with the management of such a group would need to ensure these environmental aspects are taken into account to ensure effective management.

8.2.3 **Principle 3: Advocacy Sensitisation and Capacity Building**

Advocacy is a process of active support that involves acting as a go-between or canvassing for a particular cause to be considered for planning implementation or funding (Jacobs & Jacobs, 2004). Once HIV is recognised as a need, as it has been in most countries and programmes, it is necessary to get support from the people who are instrumental in implementation of intervention programmes. To do this one needs the facts to use as advocacy tools. In this case, the proposed curriculum content framework that has been developed from the results of all the studies in this thesis can be used as an advocacy tool.

In the curricular content, several main exit level outcomes that correspond to exit level outcomes developed by Krause et al. (2006), for training physiotherapists were used to

group the information from all the studies. The exit level outcomes correspond to those already used in physiotherapy education (Exit level outcomes - Chapter 7). For example, the role of physiotherapy in HIV falls within the outcome of understanding of physiotherapeutic principles, philosophies and problem-solving with due consideration for disease processes. Working from what is known to unknown is a known teaching and learning strategy (CSP, 2008b) and can be used for sensitisation and capacity building towards including the content that has been proposed from the HIV curricula framework that has been informed from patient assessment and the literature.

Another starting point is the result of the curriculum audit, which clearly shows the gaps for individual universities. Cognisance is taken of the written curricula not reflecting all that happens in the classroom and learning environment but certainly the curricula should reflect a well thought through process including the goals, objectives, content , learning experience and programme evaluation (Shepard & Jensen, 2002). A secondary advantage of doing the Delphi survey is that the process allows for sensitisation of its respondents and may even contribute to identifying capacity-building needs among the academic staff themselves.

Capacity-building needs could be extrapolated from the results of the curricula audit and the focus group discussions. Individually the universities written curricula did not display comprehensive HIV curricula input and could not be judged as being based on sound approaches and principles for HIV management. The picture was one of an ad-hoc and fragmented inclusion of the subject, perhaps dependent on interest of the respective lecturer and not on the policies and patient prevalence evident from the clinicians' experiences and patient numbers treated. Clinicians supported this interpretation, by stating their own input had been somewhat fragmented. In the FGDs, clinicians highlighted gaps in their knowledge and this was collaborated by the omissions found in the curricula audit. To effect change, advocacy would be needed to contribute towards change.

If gaps in knowledge exist for both the clinicians and the academic staff, the integration of HIV through a mainstreaming approach is threatened in its infancy. Therefore the need for capacity building to bridge knowledge gaps and ensure mainstreaming is facilitated, is essential. The literature on university education state that curricula need to move towards strategies for teaching clinical reasoning and knowledge, which reflect the reality of the work place and breadth of knowledge required for the workplace (Higgs, 1990).
In this study, gaps were evident in the explanation of the fluctuating illness and wellness, the prognostic changes and how this affects the role definition for the physiotherapist. Gaps

in specific underlying pathology for problems such as breathlessness, fatigue and poor exercise tolerance, encephalopathy, peripheral nerve dysfunction, myopathies and infectious musculoskeletal conditions were also evident. The effects of exercise on specific HIV conditions such as lipodystrophy (Mutimura et al., 2007) fatigue and body mass changes for example, were also evident gaps.

It is proposed that clinical reasoning should strive to consider the person as a whole, the social, political, cultural and historical contexts of practice (Shepard & Jensen, 2002). This generic approach has been within the physiotherapy curriculum for a number of decades and is constantly refined, with the current ICF seen as the gold standard giving a well-researched, comprehensive and integrated approach to analysing patient needs for subsequent interventions. Related to this, the clinicians felt inadequacies in defining their own role in HIV and in the curricula no evidence of an outcome to increase the understanding of physiotherapeutic principles , philosophies and problem-solving with due consideration for the impact of HIV/AIDS input was found. Some of the approaches to gaining a better understanding of the complexities of HIV management that are currently proposed are the use of problem-based learning, inter-professional education, the use of PLWH as facilitators of HIV education sessions and the development of trans-disciplinary management models (Canadian Working Group on HIV and Rehabilitation, 2002b; Solomon et al., 2003b).

The impression from the comments in the focus groups is that clinicians and academics are of the view that , *why then single out one condition if generic approaches are appropriate for a response to need and intervention*. Their approach to managing HIV-related conditions has been similar for debilitating conditions such as stroke (CVA), diabetes, spinal cord injuries and other conditions. However, the basic knowledge on these conditions is long established and the understanding of their epidemiology, pathology, aetiology and impacts of conventional physiotherapy and application of rehabilitation approaches is well understood and continues to develop a comprehensive evidence-based knowledge set. The emergence of HIV has affected the aetiology and morbidity of all the conditions traditionally treated and this is further complicated by problems of stigma, fear and the need for a very strong health and inter-sectoral support system.

The literature has until now described HIV/AIDS with particular emphasis on medical and pathophysiological effects. This study sought to build a picture of what in the literature has contributed to the rehabilitation perspective and these omissions have been explained under the first principle of defining entry points. Specific omissions such as the links to

function and participation and modalities used by physiotherapists in rehabilitation and physiotherapeutic approaches to HIV management were discussed. One of the omissions is assessing HIV within a rehabilitation framework such as the ICF paradigm. This would explain why physiotherapy clinicians seemed not to understand HIV/AIDS from a rehabilitation and physiotherapy perspective. Clinicians reported feeling overwhelmed by the number of patients and their own inability to define what their role is, as well as specific background knowledge. One of the problems clinicians expressed was the presence of co-morbities in the patients they see and their inability to deal with them. HIV is a condition fraught with major complications that influence the individual, irrespective of their being an academic, clinician or member of the public. Issues of stigma, disclosure and fear have been documented as almost paralysing people into inaction (Vance & Denham, 2008).

8.2.4 **Principle 4: The Distinction between the Internal and External Domains**

The internal domains refer to staff risks and vulnerability and the external domains refer to the institutional efforts in support of national, local and strategic efforts.

It was not the intention of this study to explore what would threaten management and mainstreaming of HIV, however, some results point to these aspects. In terms of the external domain all academic staff are aware of the need to include HIV as it is a call at national and international level (Department of Education, 1999; Department of Health, 2007b; UNAIDS, 2006a). Participants of the FGD supported the inclusion and integration of HIV in response to the clinical picture, the increased prevalence and the change in the type of conditions that they are seeing in the hospitals. Academics and clinicians, in theory embraced the policies and theories guiding input in relation to HIV, but input at a curricula and practice level was not reflective of this.

With regard to the internal domain, many staff risks emerged from the focus group discussions. Knowledge gaps expressed by the clinicians and academics were evident. Inappropriate attitudes and perceptions that would not support appropriate HIV management or education were also present. These gaps in knowledge, attitude and perceptions would need to be addressed through the undergraduate programme and in continuous development for qualified staff. These knowledge gaps and attitude problems may, more than likely, impact on clinical decision-making and educational input. The impact on such fundamental educational activities may be a risk to the implementation of mainstreaming HIV/AIDS.

Internal domain aspects that staff reported as having a direct impact on their ability to assimilate and apply knowledge on HIV relate to their lecturers in their training and other staff attitudes and beliefs. Clinicians in particular reported how the demeanour of the lecturer gave them their impressions of HIV. They recommended that lecturers should adopt a more relaxed attitude to the subject, which does not give a perception of stigma and instils the correct attitude in students. This perception, on the part of students, resulting from the lecturers' attitude and disposition supports the notion put forward by Eisner (1994) that the impact of the implicit and null curriculum does influence what students learn. There is a need for capacity development to equip staff with appropriate coping and management strategies. Loss of hope, loss of morale, staff overload affected therapists on a personal level. These responses are in no way peculiar to qualified therapists and it would be expected that students are affected in the same way. Preparation for these anticipated impacts of loss of hope and morale necessitate inclusion of appropriate content into the curriculum. Counselling, knowledge of HIV on the health system and a better understanding of the nature of HIV would help with minimising such effects.

Participants in the focus group discussions, referred to clinicians needing positive and informed mind-sets as a prerequisite to ensuring an appropriate response to HIV/AIDS. In particular, treating the person and not the condition, avoiding being judgemental and viewing HIV, as a death sentence were problems that clinicians discussed. The clinical expert interviewed did point out that until clinicians understand that the prognosis has truly changed with the advent of ARVs and that opportunistic infections can be managed through an intervention of life-style change they may approach the management of HIV completely negatively.

Problems such as actual gaps perceived in HIV curriculum content discussed under principle one that refers to the definition of an entry point and principle three that involves advocating, sensitising and capacity building all contribute to both internal and external domain impacts. In addition, problems within the hospital and management of HIV that are of a structural nature have a negative impact on staff, both personally and professionally. For example, the need for confidentiality and the paradox it creates in the therapists being unable to deal with problems arising directly from HIV infection status. This arises when the doctor or medical team does not disclose the HIV status and yet for decision-making on clinical matters and advice to the patient the status may be pertinent. Physiotherapists referred to increases in patient load and working in areas where the workload is affecting staff morale. Similar findings have been reported among nurses (Ukwakwe, 2000). From the categories identified in the focus group, discussions, mechanics and structure referred to

how recent graduates and academics viewed the way HIV was included in the current curricula. The current mechanics and structure of the curriculum were problematic and this would indicate the institutions have not looked comprehensively at the issues of HIV content, mode of delivery and integration of HIV-related aspects. The lack of coordination is evident in both the scanty picture displayed in the curricula audit and the experience of the clinicians who reported an uncoordinated approach in the teaching of HIV input. It is therefore important for academics to assess their response to both the internal and external domains when considering the HIV content and input within their respective curricula.

8.2.5 **Principle 5: Importance of Developing Strategic Partnerships**

The range and complexity of problems found when patients were assessed using the ICF checklist show that, in order to be effective in managing HIV patients using rehabilitation frameworks, therapists need to work with other sectors. For example, the problems seen across the impairments, activity limitations and participation restrictions show that solutions do not lie with rehabilitation or health alone. The multivariate logistic regression showed that marital status and gender have a bearing on the experience of the environment. Patients who need extra support require participation from different community based organisations and sectors such as Department of Education (DoE) and social services to enhance their rehabilitation outcomes and QOL. Though a causal link was not established, the results showed that the out-patient mining group received support from different sectors within the support systems and they do not experience the same level of barriers and activity limitations as the in-patient group.

The curricula input should ensure physiotherapists are clear on their own roles in order to share this information with other professionals, PLWH and the general community. Clarity of roles will also allow for medical personal and nurses to refer appropriately and include physiotherapists in the management of patients, as they are often the first contact for patients in the hospital and community setting.

The role of the physiotherapist will be fluid depending on whether they are in the hospital, out-patient setting or community setting. It is important for the therapists to realise that their skills set may change in each setting. The hospital setting may call predominantly for their clinical skills and working within a multi-disciplinary team. Some of these clinical skills may be in response to impairments such as those found in the in-patient group and therapists may need to respond to acute problems such as neurological, respiratory or neuromuscular problems with co-morbidities. Specific areas requiring focus of the physiotherapist may be in

neuromuscular integrity, mobility and subsequent participation. Palliative approaches may also be required (Uwimana & Louw, 2007).

In the out-patient setting the therapist may be required to use a wellness approach that needs the patient with HIV to focus on managing their risks and maintaining their health (O'Brien et al., 2007). Impairments shown as common in Chapter 4 in the mining cohort and the similar impairments found by Van As et al., (2008) can be contained by using secondary prevention principles. Depending on the model adopted for HIV management by the service delivery institution, the physiotherapist may work in a multi-disciplinary team but may also be required to understand and work in a trans-disciplinary setting. In the community environment the therapist may more than likely work in a trans-disciplinary setting which will require a skill set beyond that needed to respond at an impairment level.

Disparities evident in the university content as outlined in the curricula audit (Chapter 5) and discussed under the first principle of mainstreaming demonstrate the need for forging planned partnerships between universities in order to maximize on expertise and experience. These partnerships could be forged around themes that would address some of the challenges outlined within the internal and external domains. Strategic partnerships that ensure that mainstreaming and integration of HIV is done efficiently and with some level of quality assurance will also require partnerships at the level of the regulatory and supportive bodies such as other academics, the Health Professions Council of South Africa (HPCSA) and the South African Society of Physiotherapy (SASP). The internal and external domain problems discussed under principle four, point to the need to also strengthen the collaboration between hospitals and other healthcare delivery institutions in order to define the problem of HIV better and to respond through evidence based and expertise informed knowledge, practice and experience (Canadian Working Group on HIV and rehabilitation, 2002a). The Canadians recognised this type of strategic partnership is required and they formed a group to bring expertise together across sectors and within rehabilitation. Again, one could argue why specifically this grouping for HIV and the lack of clarity on the HIV and the answer is that physiotherapy thus far would benefit from an organised multi-disciplinary and subsequently multisectoral effort to address rehabilitation needs among people living with HIV within the South African context.

8.3 CONCLUSION

The curriculum content at all micro, meso and macro levels identified in Chapters 6 and verified by consensus in Chapter 7 is outlined and mainstreaming principles have been applied to them. This assists in formulating a curriculum that has been approached in a mainstreamed manner. Each area of teaching such as neurology and respiratory would have to examine its input and identify where HIV has an impact and therefore where it should be included. The ICF as a philosophical base is also an entry point and also a tool to use in framing the content in each area of teaching. The use of the ICF, in part answers the response to the second principle. However, other philosophical frameworks and policies at all levels should be examined to ensure that every aspect that HIV affects is covered. A pervasive condition like HIV requires support and acceptance from all those involved. For inclusion in the curriculum, academics and practitioners need to be sensitised to what is involved and trained in areas where gaps in knowledge, practice and inappropriate attitudes exist. Mainstreaming principle four, encourages focus on internal and external domains that can threaten mainstreaming in the curricula. In this study internal domain risks were identified that would directly affect curricula activities, namely academic and clinicians' knowledge gaps, mind sets, attitudes, loss of hope and low morale. External domain issues involved policies and frameworks. Academics and clinicians in theory embraced the theories, but the content in relation to HIV was not reflective of this. The final principle concerns strategic partnerships. To ensure HIV is mainstreamed into curricula and practice, it is necessary for partnerships to be developed at the operational level with other universities, practice areas such as hospitals and communities, patient organisations and regulatory bodies.

CHAPTER 9

9.1 CONCLUSION

The purpose of this final chapter is to describe and draw conclusions on the relevant outcomes that have emerged from this thesis.. The primary aim was to develop a conceptual framework and practice aims that will inform physiotherapy education in South Africa as stated in objective 8.

In addition the objectives included:

1. To describe HIV/AIDS disease in terms of the International Classification of Function (ICF) for physiotherapists in the South African context.
2. To establish the referral patterns to physiotherapy among HIV patients admitted into a tertiary hospital in South Africa.
3. To obtain a relevant overview of the functional and participation picture of people living with HIV.
4. To assess the curricula at South African universities in terms of the HIV content in relation to the disease profile and referral patterns.
5. To determine the clinicians' and academics' perceptions regarding HIV curriculum and practice
6. To determine the level of consensus with regard to the curriculum topics among academic staff
7. To assess the curricula according to the United Nations defined mainstreaming criteria.

Objectives one to seven have been discussed in each chapter within the main body of the thesis and a summary of the major outcomes pertinent to the development and outline of a cohesive conceptual framework for mainstreaming HIV into physiotherapy curricula and practice are reviewed below. A summary of the major outcomes of each of the studies and an interpretation of how they contribute to objective eight is given in the following section. Objective eight aimed to develop a conceptual framework for mainstreaming HIV into physiotherapy curricula.

9.1.1 Study Conclusions

The first objective of the study was to place the literature on HIV/AIDS within an ICF framework and in doing this identify important subject areas that help the physiotherapist to gain an appropriate and comprehensive understanding of HIV/AIDS. One of the main conclusions from this literature review was the importance of understanding HIV in its

entirety in order to be efficacious as a member of the health team. The most important finding of this was that the respiratory, orthopaedic, neurological, haematological metabolic and musculoskeletal body systems are important systems to examine, for the effects of HIV and that these effects will subsequently determine the HIV curricula content for physiotherapists.

In addition, the results from the study that developed the patient profile (study 2) link the effects of these body systems to health and health-related states of the PLWH. Study 2 aimed at obtaining a relevant overview of the functional and participation picture of people living with HIV. For each individual patient these links should be explored during clinical assessment and management. Within the context of a bio-pyschosocial approach physiotherapists need to understand that these influences are not unidirectional. Other results from Study 2 enrich this picture and strengthen the need for a bio-psychosocial approach. The two study groups reveal a picture of body systems where impairments, their associated activity limitations and the experience of the social environment are prevalent among PLWH. In-patients who were from a poor public health context showed more problems with impairments, activity limitations and participation restrictions than the out-patients in a mining context did. The level of activity limitations and participation restrictions found in the mining group was similar to an out-patient group studied in the public sector (Van As et al. 2008). What this implies is that therapists dealing with people living with HIV should have an understanding of how the affected body systems evident in the impairments domains ultimately influence activity and participation. This will facilitate a more comprehensive approach to the rehabilitation of PLWH. The principles of mainstreaming state that any programme that aims to mainstream HIV or any issue of importance should define a clear entry point. The results from the patient groups, the literature review and the referral patterns, are proposed as the foundation of defining an entry point for physiotherapists to mainstream HIV into the curricula.

The study in answer to objective 2 that aimed to establish the referral patterns to physiotherapy among HIV patients admitted into a tertiary hospital in South Africa concludes that there is a low referral rate to physiotherapy. This indicates that the role of physiotherapy is not understood fully by the health team. The outcomes of objectives four and five relate to this finding as they reveal that the curricula input of HIV is scanty and inadequate. The curricula on HIV are also seen as not coordinated or drawn together by a philosophical base. From the results of the literature review the ICF is proposed both in the literature and from this thesis as an appropriate philosophical approach to HIV practice and education.

Another conclusion that is drawn from the studies done in answer to objective four and five is that the role of physiotherapy in HIV is not only unclear to other health workers but to the physiotherapists themselves. In addition, the clinicians and academics seem to imply that other health workers should determine their input. From the literature review it is evident that all physiotherapy interventions, except for HIV, are in the developmental stage. Exercise has a strong base of evidence showing important clinical effects and positive impacts on function. The SASP position paper of 2008 makes a statement on the issue of the physiotherapist having first-line status and professional autonomy (SASP, 2008). One can therefore conclude that the role of physiotherapists in HIV needs to be more strongly outlined in-order for clarity in education and practice.

The list of topics that emerged from the focus group discussions held to answer objective five are given in Appendix 6.4 The suggested content that results from this thesis has been informed by: concrete findings in the literature, the needs of PLWH, curricula gaps, clinician and academic experiences and perceptions of physiotherapy input to HIV. From the Delphi technique study done in answer to objective six, one deduces that academics view the proposed content as essential or useful. The content outline can therefore be used to contribute to an appropriately informed HIV curriculum. Some of the concrete recommended areas of input where gaps existed in practice outlined by the clinicians were: the detailed information of neurological conditions, practical application, unclear specific roles for physiotherapists, how to deal with challenges such as disclosure, what is effective treatment, when treatment should be commenced and decisions on how much treatment was needed were proposed as needing expansion and clarity in the curriculum.
Linked to this is an important conclusion that as a profession, physiotherapists should build into the curriculum framework concrete ways of dealing with the threats that result from the complex implications of HIV. Some of the issues that were expressed by clinicians and academic staff were stigma, fear, attitudes and their ability to cope. There are also challenges related to the mismatch between what the ideal approaches should be and what actually happens in practice, such as the need for clinical information against the backdrop of disclosure issues.

Examination and application of the mainstreaming principles show the need for including facilitatory elements such as advocacy, and strategic partnerships. These elements underpin the acquisition of knowledge as well as the actual inclusion of HIV as a subject. This is important because HIV affects every aspect of the patient's life and therefore its

management requires a well coordinated management approach that is understood by clinicians. Some of the areas that will need advocacy and strategic partnerships are in areas where the results show that not all practicing academics and clinicians are equipped to deal with HIV. For example, at a clinical level not all problems experienced by patients can be dealt with by physiotherapists. Conversely, the health system does not have a full complementary team, so at times the health worker may need to work in a multi, trans or inter-disciplinary mode therefore requiring strong strategic partnerships.

All these conclusions are now illustrated in a conceptual framework that could facilitate the inclusion of HIV into a physiotherapy curriculum. The proposed framework is shown in Figure 9.1.

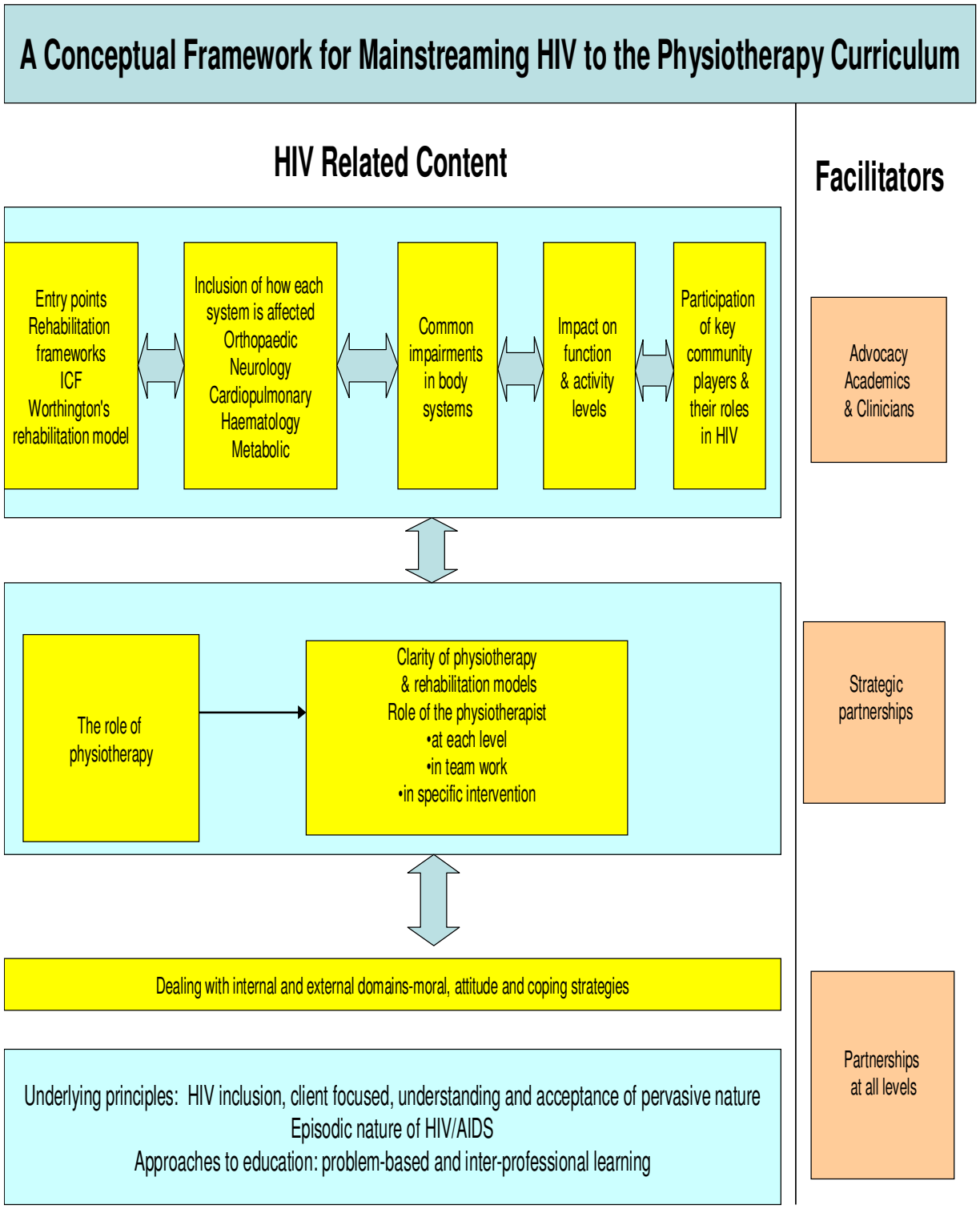


Figure 9.1: Framework for Mainstreaming HIV into Physiotherapy Education

This framework outlines the findings of this study in a cohesive manner. It shows how and what HIV content should be considered in the curriculum. From the thesis, misconceptions and a lack of application of the bio-pyschosocial principles were evident among clinicians and academics. It is proposed that the results from this thesis be the basis for determining entry points in all physiotherapy input. Each area of teaching can locate itself within the bio-psychosocial philosophy and identify topics for inclusion of content into appropriate aspects of teaching including common impairments.In practice, key assessment principles will assist in determining the functional participation and environmental picture. At all times this process should be informed by the principle that HIV is inclusive and is pervasive in nature. The episodic nature of HIV should also guide the clinicians to determine their role at any given point. Against this background, the physiotherapist's role should be easier to understand, place and categorise. As part of the way forward it is necessary for capacity building and advocacy activities to be initiated for both academics and clinicians in need. For effective mainstreaming in the curricula and in practice, it is important to identify and forge strategic partnerships with, for example other health and social departments. The pervasive nature of HIV necessitates collaboration with other departments in that they can contribute to HIV management and partnering with them in teaching and practice will ensure that the role of physiotherapy is fully exploited.

HIV is prevalent condition (at pandemic level) which is affecting 29.1% of the South African population. The presence of HIV affects the physiotherapy management of clinical conditions. From the results of this thesis there are gaps in knowledge and skills among physiotherapists. To deal with these gaps the framework proposed in figure 9.1 allows for mainstreaming of HIV into curriculum and practice. By applying mainstreaming principles, the three levels of curriculum taxonomy are accounted for at the micro level, through the body systems, and the meso level through the role of physiotherapy, dealing with internal and external domains and teaching approaches. The macro level is accounted for by facilitatory activities such as advocacy among clinicians and academics and forming strategic partnerships at all levels. In this way, mainstreaming principles will guide the development of a curriculum and practice aims that will contribute and respond to the rehabilitation needs of PLWH. Future research should endeavour to monitor how HIV has been mainstreamed in the curriculum and specific impacts on education and practice.

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APPENDIX 1

- **Appendix 1: Ethical clearance certificate**

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Myezwa

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M050206**
PROJECT	Mainstreaming HIV Into Physiotherapy Education and Practice
INVESTIGATORS	H Myezwa
DEPARTMENT	Dept of Physiotherapy
DATE CONSIDERED	05.02.25
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 05.05.10 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof A Stewart

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 2

- **Appendix 2.1: ICF Checklist**
- **Appendix 2.1.2: Guidelines for questioning in the use of the ICF**
- **Appendix 2.2: Excerpt of ICF isiZulu**
- **Appendix 2.3: Excerpt of ICF Isisotho version**

APPENDIX 2.1

ICF Checklist © World Health Organization, September 2001. Page 1
ICF CHECKLIST

Version 2.1a, Clinician Form
for International Classification of Functioning, Disability and Health

This is a checklist of major categories of the International Classification of Functioning, Disability and Health (ICF)
of the World Health Organization . The ICF Checklist is a practical tool to elicit and record information on the functioning and disability of an individual. This information can be summarised for case records (for example, in
clinical practice or social work). The checklist should be used along with the ICF or ICF Pocket version.

H 1. When completing this checklist, use all information available. Please check those used:

[1] written records [2] primary respondent [3] other informants [4] direct observation
If medical and diagnostic information is not available it is suggested to complete
appendix 1.1: Brief Health Information (p 9-10) which can be completed by the respondent.
H 2. Date __ __ /__ __/__ __ ***H 3. Case ID*** _ _ , __ __ __ , __ ***H 4. Participant No.*** __ __ , __ __ ,

Day Month Year CE or CS Case No. 1st or 2nd Evalu FTC Site Participant

A. DEMOGRAPHIC INFORMATION

A.1 NAME *(optional)* First _____ FAMILY_____

A.2 SEX (1) [ ] Female (2) [ ] Male

A.3 DATE OF BIRTH _ _/_ _/_ _ *(date/month/year)*

A.4 ADDRESS *(optional)*

A.5 YEARS OF FORMAL EDUCATION _ _

A.6 CURRENT MARITAL STATUS: *(Check only one that is most applicable)*
(1) Never married [ ] (4) Divorced [ ]
(2) Currently Married [ ] (5) Widowed [ ]
(3) Separated [ ] (6) Cohabiting [ ]

A.7 CURRENT OCCUPATION *(Select the single best option)*
(1) Paid employment [ ] (6) Retired [ ]
(2) Self-employed [ ] (7) Unemployed (health reason) [ ]
(3) Non-paid work, such as volunteer/charity [ ] (8) Unemployed (other reason) [ ]
(4) Student [ ] (9) Other [ ]
(5) Keeping house/House-maker [ ] *(please specify)* _____

A.8 MEDICAL DIAGNOSIS of existing Main Health Conditions, *if possible give ICD Codes.*

1. No Medical Condition exists
2. …….. ICD code: __. __. __.__. __
3. …….. ICD code: __. __. __.__. __
4. …….. ICD code: __. __. __.__. __
5. A Health Condition (disease, disorder, injury) exists, however, its nature or diagnosis is not known

PART 1a: IMPAIRMENTS of BODY FUNCTIONS

- . Body functions are the physiological functions of body systems (including psychological functions).
- . Impairments are problems in body function as a significant deviation or loss.

Qualifier: **0** No impairment, **1** Mild impairment, **2** Moderate impairment
Extent of impairments **3** Severe impairment, **4** Complete impairment, **8** Not specified
9 Not applicable

Short List of Body Functions	Qualifier
b1. MENTAL FUNCTIONS	
b110 Consciousness	
b114 Orientation *(time, place, person)*	
b117 Intellectual *(incl. Retardation, dementia)*	
b130 Energy and drive functions	
b134 Sleep	
b140 Attention	
b144 Memory	
b152 Emotional functions	
b156 Perceptual functions	
b164 Higher level cognitive functions	
b167 Language	
b2. SENSORY FUNCTIONS AND PAIN	
b210 Seeing	
b230 Hearing	
b235 Vestibular *(incl. Balance functions)*	
b280 Pain	
b3. VOICE AND SPEECH FUNCTIONS	
b310 Voice	
b4. FUNCTIONS OF THE CARDIOVASCULAR, HAEMATOLOGICAL,	
IMMUNOLOGICAL AND RESPIRATORY SYSTEMS	
b410 Heart	
b420 Blood pressure	
b430 Haematological *(blood)*	
b435 Immunological *(allergies, hypersensitivity)*	
b440 Respiration *(breathing)*	
b5. FUNCTIONS OF THE DIGESTIVE, METABOLIC AND ENDOCRINE SYSTEMS	

b515 Digestive	
b525 Defecation	
b530 Weight maintenance	
b555 Endocrine glands *(hormonal changes)*	
b6. GENITO-URINARY AND REPRODUCTIVE FUNCTIONS	
b620 Urination functions	
b640 Sexual functions	
b7. NEUROMUSCULOSKELETAL AND MOVEMENT RELATED FUNCTIONS	
b710 Mobility of joint	
b730 Muscle power	
b735 Muscle tone	
b765 Involuntary movements	
b8. FUNCTIONS OF THE SKIN AND RELATED STRUCTURES	
ANY OTHER BODY FUNCTIONS	
ICF Checklist © World Health Organization, September 2001. Page 3	

Part 1 b: IMPAIRMENTS of BODY STRUCTURES

- Body structures are anatomical parts of the body such as organs, limbs and their components.
- Impairments are problems in structure as a significant deviation or loss.

First Qualifier: ***Extent of impairment***	**Second Qualifier:** ***Nature of the change***	**Third Qualifier** ***(suggested):*** ***Location***
0 No impairment **1** Mild impairment **2** Moderate impairment **3** Severe impairment **4** Complete impairment **8** Not specified **9** Not applicable	**0** No change in structure **1** Total absence **2** Partial absence **3** Additional part **4** Aberrant dimensions **5** Discontinuity **6** Deviating position **7** Qualitative changes in structure, including accumulation of fluid **8** Not specified **9** Not applicable	**0** More than one region **1** right **2** left **3** both sides **4** front **5** back **6** proximal **7** distal

Short List of Body Structures	**First Qualifier*:*** ***Extent of impairment***	**Second Qualifier:** ***Nature of the change***	**Third Qualifier:** ***Location***
s1. STRUCTURE OF THE NERVOUS SYSTEM			
s110 Brain			
s120 Spinal cord and peripheral nerves			
s2. THE EYE, EAR AND RELATED STRUCTURES			
s3. STRUCTURES INVOLVED IN VOICE AND SPEECH			
s4. STRUCTURE OF THE CARDIOVASCULAR,			
IMMUNOLOGICAL AND RESPIRATORY SYSTEMS			
s410 Cardiovascular system			
s430 Respiratory system			
s5. STRUCTURES RELATED TO THE DIGESTIVE,			
METABOLISM AND ENDOCRINE SYSTEMS			
s6. STRUCTURE RELATED TO GENITO-URINARY AND			
REPRODUCTIVE SYSTEM			
s610 Urinary system			
s630 Reproductive system			
s7. STRUCTURE RELATED TO MOVEMENT			
s710 Head and neck region			
s720 Shoulder region			
s730 Upper extremity *(arm, hand)*			
s740 Pelvis			
s750 Lower extremity *(leg, foot)*			
s760 Trunk			
s8. SKIN AND RELATED STRUCTURES			

ANY OTHER BODY STRUCTURES
ICF Checklist © World Health Organization, September 2001. Page 4
PART 2: ACTIVITY LIMITATIONS & PARTICIPATION RESTRICTION

- *Activity is the execution of a task or action by an individual.. Participation is involvement in a life situation.*
- *Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are problems an individual may have in involvement in life situations.*

The Performance qualifier describes what an individual does in his or her current environment. Because the current environment brings in the societal context, performance can also be understood as "involvement in a life situation" or "the lived experience" of people in the actual context in which they live. This context includes the environmental factors - all aspects of the physical, social and attitudinal world that can be coded using the Environmental Factors.
The Capacity qualifier describes an individual's ability to execute a task or an action. This construct indicates the highest probable level of functioning that a person may reach in a given domain at a given moment. To assess the full ability of the individual, one would need to have a "standardized" environment to neutralize the varying impact of different environments on the ability of the individual. As standardized environment may be: (a) an actual environment commonly used for capacity assessment in test settings; or (b)where this is not possible, a hypothetical environment a uniform impact.

Note: Use Appendix 1.2 if needed to elicit information on the Activities and Participation of the individual

First Qualifier: ***Performance* extent of participation restriction**	**Second Qualifier:** ***Capacity (without assistance)*** ***Extent of Activity limitation***
0 No difficulty **1** Mild difficulty **2** Moderate difficulty **3** Severe difficulty **4** Complete difficulty **8** Not specified **9** Not applicable	**0** No difficulty **1** Mild difficulty **2** Moderate difficulty **3** Severe difficulty **4** Complete difficulty **8** Not specified **9** Not applicable

Short List of A&P domains

	Performance Qualifier	***Capacity Qualifier***
d1. LEARNING AND APPLYING KNOWLEDGE		
d110 Watching		
d115 Listening		
d140 Learning to read		
d145 Learning to write		
d150 Learning to calculate *(arithmetic)*		
d175 Solving problems		
d2. GENERAL TASKS AND DEMANDS		
d210 Undertaking a single task		
d220 Undertaking multiple tasks		
d3. COMMUNICATION		
d310 Communicating with -- receiving -- spoken messages		
d315 Communicating with -- receiving -- non-verbal messages		
d330 Speaking		
d335 Producing non-verbal messages		
d350 Conversation		

Short List of A&P domains

d4. MOBILITY	**Performance Qualifier**	**Capacity Qualifier**
d430 Lifting and carrying objects		
d440 Fine hand use *(picking up, grasping)*		
d450 Walking		
d465 Moving around using equipment *(wheelchair, skates, etc.)*		
d470 Using transportation *(car, bus, train, plane, etc.)*		
d475 Driving (riding bicycle and *motorbike, driving car, etc.)*		
d5. SELF-CARE		
d510 Washing oneself *(bathing, drying, washing hands, etc)*		
d520 Caring for body parts *(brushing teeth, shaving, grooming, etc.)*		
d530 Toileting		
d540 Dressing		
d550 Eating		
d560 Drinking		
d570 Looking after one`s health		
d6. DOMESTIC LIFE		
d620 Acquisition of goods and services *(shopping, etc.)*		
d630 Preparation of meals *(cooking etc.)*		
d640 Doing housework *(cleaning house, washing dishes laundry, ironing, etc.)*		
d660 Assisting others		
d7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS		
d710 Basic interpersonal interactions		
d720 Complex interpersonal interactions		
d730 Relating with strangers		
d740 Formal relationships		
d750 Informal social relationships		
d760 Family relationships		
d770 Intimate relationships		
d8. MAJOR LIFE AREAS		
d810 Informal education		
d820 School education		

d830 Higher education		
d850 Remunerative employment		
d860 Basic economic transactions		
d870 Economic self-sufficiency		
d9. COMMUNITY, SOCIAL AND CIVIC LIFE		
d910 Community Life		
d920 Recreation and leisure		
d930 Religion and spirituality		
d940 Human rights		
d950 Political life and citizenship		

ANY OTHER ACTIVITY AND PARTICIPATION

PART 3: ENVIRONMENTAL FACTORS

- *Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.*

Qualifier in environment: **0** No barriers **0** No facilitator
Barriers or facilitator **1** Mild barriers +**1** Mild facilitator
2 Moderate barriers +**2** Moderate facilitator
3 Severe barriers +**3** Substantial facilitator
4 Complete barriers +**4** Complete facilitator

Short List of Environment
Qualifier
barrier or facilitator

e1. PRODUCTS AND TECHNOLOGY	
e110 For personal consumption *(food, medicines)*	
e115 For personal use in daily living	
e120 For personal indoor and outdoor mobility and transportation	
e125 Products for communication	
e150 Design, construction and building products and technology of buildings for public use	
e155 Design, construction and building products and technology of buildings for private use	
e2. NATURAL ENVIRONMENT AND HUMAN MADE CHANGES TO	
ENVIRONMENT	
e225 Climate	
e240 Light	
e250 Sound	
e3. SUPPORT AND RELATIONSHIPS	

e310 Immediate family	
e320 Friends	
e325 Acquaintances, peers, colleagues, neighbours and community members	
e330 People in position of authority	
e340 Personal care providers and personal assistants	
e355 Health professionals	
e360 Health-related professionals	
e4. ATTITUDES	
e410 Individual attitudes of immediate family members	
e420 Individual attitudes of friends	
e440 Individual attitudes of personal care providers and personal assistants	
e450 Individual attitudes of health professionals	
e455 Individual attitudes of health-related professionals	
e460 Societal attitudes	
e465 Social norms, practices and ideologies	
E5. SERVICES, SYSTEMS AND POLICIES	
e525 Housing services, systems and policies	
e535 Communication services, systems and policies	
e540 Transportation services, systems and policies	
e550 Legal services, systems and policies	
e570 Social security, services, systems and policies	
e575 General social support services, systems and policies	
e580 Health services, systems and policies	
e585 Education and training services, systems and policies	
e590 Labour and employment services, systems and policies	
ANY OTHER ENVIRONMENTAL FACTORS	

PART 4: OTHER CONTEXTUAL INFORMATION

4.1 *Give a thumbnail sketch of the individual and any other relevant information.*
4.2 *Include any **Personal Factors** as they impact on functioning (e.g. lifestyle, habits, social background, education, life events, race/ethnicity, sexual orientation and assets of the individual).*

.1 1:

BRIEF HEALTH INFORMATION
[ ] Self Report [ ] Clinician Administered
X.1 Height : __/__/__ cm *(or inches)*

X.2 Weight: __/__/__ kg *(or pounds)*

X.3 Dominant Hand *(prior to health condition)*: Left [ ] Right [ ] Both hands equally [ ]

X.4 How do you rate your physical health in the past month?
Very good [ ] Good [ ] Moderate [ ] Bad [ ] Very bad [ ]

X.5 How do you rate your mental and emotional health in the past month?
Very good [ ] Good [ ] Moderate [ ] Bad [ ] Very bad [ ]

X.6 Do you currently have any disease(s) or disorder(s) ?
[ ] NO [ ] YES
*If YES, please specify:*_____

X.7 Did you ever have any significant injuries that had an impact on your level of functioning?
[ ] NO [ ] YES
If YES, please specify _____

X.8 Have you been hospitalized in the last year?
[ ] NO [ ] YES
If YES, please specify reason(s) and for how long?
1. _____; ___. ___. ___ days
2. _____; ___. ___. ___ days
3. _____; ___. ___. ___ days

X.9 Are you taking any medication (either prescribed or over the counter)?
[ ] NO [ ] YES
If YES, please specify major medications
1. _____
2. _____
3. _____

X.10 Do you smoke?
[ ] NO [ ] YES

X.11 Do you consume alcohol or drugs?
[ ] NO [ ] YES
If YES, please specify average daily quantity
Tobacco: _____
Alcohol: _____
Drugs: _____

X.12 Do you use any assistive device such as glasses, hearing aid, wheelchair, etc.?
[ ] NO [ ] YES
If YES, please specify _____

X.13 Do you have any person assisting you with your self-care, shopping or other daily activities?
[ ] NO [ ] YES
If YES, please specify person and assistance they provide

_____

X.14 Are you receiving any kind of treatment for your health?
[ ] NO [ ] YES
If YES, please specify _____

X.15 Additional significant information on your past and present health:
_____
_____

X.16 IN THE PAST MONTH, have you cut back (i.e. reduced) your usual activities or work because of your*health condition*? (a disease, injury, emotional reasons or alcohol or drug use)
[ ] NO [ ] YES If yes, how many days? _____

X.17 IN THE PAST MONTH, have you been totally unable to carry out your usual activities or work because of your *health condition*? (a disease, injury, emotional reasons or alcohol or drug use)
[ ] NO [ ] YES If yes, how many days? _____

Appendix 1.1.2: Guidelines for questioning in the use of the ICF

GENERAL QUESTIONS FOR PARTICIPATION & ACTIVITIES
The following probes are proposed as a guide to help the examiner when interviewing the respondent about problems in functioning and life activities, in terms of the distinction between capacity and performance Take into account all personal information known about the respondent and ask any additional probes as necessary. Probes should be rephrased as openended questions if necessary to elicit greater information.

Under each domain there are two kinds of probes:

*The first probe tries to get the respondent to focus on his or her **capacity** to do a task or action, and in particular to focus on limitations in capacity that are **inherent or intrinsic features of the person** themselves. These limitations should be direct manifestations of the respondent's health state, without the assistance. By **assistance** we mean the help of another person, or assistance provided by an adapted or specially designed tool or vehicle, or any form of environmental modification to a room, home, workplace and so o. The level of capacity should be judged relative to that normally expected of the person, or the person's capacity before they acquired their health condition.*

*The second probe focuses on the respondent's **actual performance** of a task or action in the person's actual situation or surroundings, and elicits information about the effects of environmental barriers or facilitators. It is important to emphasize that you are only intereste in the extent of difficulty the respondent has in doing things, **assuming that they want to do them**. Not doing something is irrelevant if the person chooses not to do it.*

I. Mobility
(Capacity)

(1) In your present state of health, how much difficulty do you have walking long distances (such as a kilometer or more) without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?
(Or: "…than you had before you developed your health problem or had the accident?)
(Performance)

(1) In your present surroundings, how much of a problem do you actually have in walking long distances (such as a kilometer or more)?

(2) Is this problem walking made worse, or better, by your actual surroundings?

(3) Is your capacity to walk long distances without assistance more or less than what you actually do in your present surroundings?

II. Self-care
(Capacity)

(1) In your present state of health, how much difficulty do you have washing yourself, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?
(Or: "…than you had before you developed your health problem or had the accident?)
(Performance)

(1) In your own home, how much of a problem do you actually have washing yourself?

(2) Is this problem made worse, or better, by the way your home is set up or the specially adapted tools you use?

(3) Is your capacity to wash yourself without assistance more or less than what you actually do in your present surroundings?

III. Domestic Life
(Capacity)

(1) In your present state of health, how much difficulty do you have cleaning the floor of your where you live, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?
(Or: "…than you had before you developed your health problem or had the accident?)
(Performance)

(1) In your own home, how much of a problem do you actually have cleaning the floor?

(2) Is this problem made worse, or better, by the way your home is set up or the specially adapted tools you use?

(3) Is your capacity to clean your floor without assistance more or less than what you actually do in your present surroundings?

IV. Interpersonal Interactions
(Capacity)

(1) In your present state of health, how much difficulty do you have making new friends, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?
(Or: "…than you had before you developed your health problem or had the accident?)
(Performance)

(1) In your present situation, how much of a problem do you actually have making friends?

(2) Is this problem making friends made worse, or better, by anything (or anyone) in your surroundings?

(3) Is your capacity to make friends, without assistance, more or less than what you actually do in your present surroundings?

V. Major Life Areas
(Capacity)

(1) In your present state of health, how much difficulty do you have getting done all the work you need to do for your job, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?
(Or: "…than you had before you developed your health problem or had the accident?)
(Performance)

(1) In your present surroundings, how much of a problem do you actually have getting done all the work you need to do for your job?

(2) Is this problem fulfilling your job requirements made worse, or better, by the way the work environment is set up or the specially adapted tools you use?

(3) Is your capacity to do your job, without assistance, more or less than what you actually do in your present surroundings?

VI. Community, Social and Civic Life
(Capacity)

(1) In your present state of health, how much difficulty do you have participating in community gatherings, festivals or other local events, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?
(Or: "…than you had before you developed your health problem or had the accident?)
(Performance)

(1) In your community, how much of a problem do you actually have participating in community gatherings, festivals or other local events?

(2) Is this problem made worse, or better, by the way your community is arranged or the specially adapted tools, vehicles or whatever you use?

(3) Is your capacity to participate in community events, without assistance, more or less than what you actually do in your present surroundings?

Guidelines For The Use Of ICF Checklist Version 2.1a

1. *This is a checklist of major categories of International Classification of Functioning, Disability and Health (ICF) of the World Health Organization . The ICF Checklist is a practical tool to elicit and record information on the functioning and disability of an individual. This information can be summarised for case records (for example, in clinical practice or social work).*

2. *This version (2.1a) is for use by a clinician, health or social care professional.*

3. *The checklist should be used along with the ICF full or short version which is scheduled for publication in September 2001. Until then the ICIDH-2 Final Draft, full version, WHO, 2001will serve as reference document for the ICF checklist. The raters should familiarize themselves with the ICIDH-2 Final Draft by attending a brief educational programme or self-taught curriculum.*

4. *All information from written records, primary respondent, other informants and direct observation can be used to fill in the checklist. Please record all sources of information used on the first page.*

5. *Parts 1 to 3 should be filled in by writing the qualifier code against each of the function, structure, activity and participation term that shows some problem for the case being evaluated. Appropriate codes for the qualifiers are given on the relevant pages.*

6. *Comments can be made regarding any information that can serve as the additional qualifier or that is thought to be significant for the case being evaluated.*

7. *Part 4 (Environment) has both negative (barrier)and positive (facilitator) qualifier codes. For all positive qualifier codes, please use a plus (+) sign before the code.*

8. *The categories given in the checklist have been selected from the ICF and are not exhaustive. If you need to use a category that you do not find listed here, use the space at the end of each dimension to record these.*

APPENDIX 2.2: EXCERPT OF ICF ISIZULU

Uhlu lokuhlunga (ICF Checklist)
Ihumusho 2.1a oluyifomu yocwaningo
esetshenziswa emhlabeni wonke ukuhlunga ukusebenza, ukukhubazeka nesimo sempilo yomuntu.

Lokhu kuwuhlu lokuhlunga izigaba ezinkulu zomhlala wonke, ekuhlungeni ukusebenza, ukukhubazeka nesimo sempilo yomuntu (ICF), enhlanganweni yomhlaba ebhekelele isimo sempilo ebizwa ngokuthi yi-World Health Organisation (WHO). Lolu luhlu luyisikhali esisiza kakhulu ekucubunguleni nasekuqopheni ulwazi, olumayelana nokusebenza nokukhubazeka kwalowo nalowo muntu ngamunye. Lolu lwazi lungaqoqwa lusetshenziswe kubantu ngokwehlukana (njengasekuphileni kwabantu nakwenhlalakahle) Lolu luhlu lungasetshenziswa luhambisane nohlu lokuhlunga (ICF) noma i-ICF Pocket Version.

Uma ugcwalisa lolu lezi zinhla, sebenzisa lonke ulwazi noma imininingwane ekhona: Qaphelisisa lolu lwazi olusetshenzisiwe:
[1] okuqoshwe phansi [2] umphenduli wokuqala [3]omunye onolwazi ngubuzwayo [4] ulwazi ozitholele lona

Uma umhlahlo wezokwelapha ungekho uyelulekwa ukuthi uqedele ukugcwalisa ngokuthi usebenzise isixhumelo/ isijobelele 1: Ulwazi olufingqiwe ngempilo (ikhasi 9 -10) okungagcwaliswa ngumphenduli.

H2. Usuku __ __/__ __ /__ __ H3 Inombolo yokwenziwe __ __,__ __ __,__
Usuku inyanga unyaka CE or CS case no. Ukuhlola kokuqala noma kwesibili

H4. Inombolo obambe iqhaza __ __ __/ __ __/ __ __
FTC Site Obambe iqhaza

A. ULWAZI NGEMININGWANE

A.1.**Igama** *(alibalulekile)*_____ **Isibongo**: _____
A.2.**Ubulili** *(1)*[ ] Owesifazane*(2)* [ ] Owesilisa
A.3.**Usuku lokuzalwa** __ __/__ __/__ __ (usuku/ inyanga/ unyaka)
A.4 **Ikheli** (*alibalulekile*)
A.5. **Iminyaka yemfundo esikoleni** ___ ___ ___
A.6.Isimo somshado ngaleyo nkathi: *(khetha okukodwa okuhambisana nawe)*

(1) angikaze ngishade	[ ]	(4) ngadivosa	[ ]
(2) ngishadile	[ ]	(5) ngingumfelwa	[ ]
(3) ngehlukanisile	[ ]	(6) ngingumfelokazi	[ ]
(7) nginomasihlalisane	[ ]		

A.7 OKUMAYELANA NOMSEBENZI: *Khetha okukodwa okuhambelana nawe)*

(1) Umsebenzi okhokhelayo	[ ]	(6) Uthathe impesheni	[ ]
(2) Uyazisebenza	[ ]	(7) Akasebenzi (*ngenxa yempilo*)	[ ]
(3) Umsebenzi ongakhokhelwa wokuvolontiya	[ ]	(8) Akasebenzi (*ngenxa yezinye izizathu*)	[ ]
(4) Umfundi	[ ]	(9) Okunye	[ ]
(5) Unakekela ikhaya	[ ]	(10) *(sicela ucacise*)	[ ]

A.8 IMININGWANE NGESIFO ESIDALA UKUXHWALA (*Uma kungenzeka, bhala amakhodi e-ICD)*

1. Akukho kugula okukhona
2. ..... ICD code: _ _ _ _ _
3. ..... ICD code: _ _ _ _ _
4. ..... ICD code: _ _ _ _ _
5. Isimo sempilo (isifo, okonakele, ukulimala) kukhona, yize noma isizathu salokho singaziwa

INGXENYE 1a: UKUKHUBAZEKA KOKUSEBENZA KOMZIMBA

- Ukusebenza komzimba kusho lokho okwenziwa yizitho zomzimba *(kanye nokusebenza kwengqondo).*
- Ukukhubazeka, yizinkinga ezikhona ekusebenzeni komzimba ngokuphelele noma kungqindeke, ngenxa yokulahlekelwa yizitho zomzimba noma ukwehluka kwezinto ezithile emzimbeni.

Ukuchaza: 0 akukho, **1** kuncane, **2** kuphakathi nendawo, **3** kukhulu,
Ubungako bokukhubazeka: **4** kubi kakhulu (isitho asisebenzi) **4.** ukukhubazeka okuphelele
5 akuchazeki **9** akudingeki

Uhla olufishane lokusebenza komzimba	
b1. UKUSEBENZA KWENGQONDO	
b110 Ukuphaphama (kungakanani?)	
b114 Uyazi ngokwenzekayo (isikhathi, indawo, abantu)	
b117 Ukuhlakanipha (kubandakanya ukukhubazeka komqondo, nokulahleka kwawo)	
b130 Amandla nogqozi lokusebenza	
b134 Ukulala	
b140 Ukuqaphela	
b144 Ukukhumbula	
b152 Ukusebenza kwemizwa	
b156 Ukuqondisisa	
b164 Ukusebenza kwamazinga aphakeme okwazi	
b167 Ulimi	
b2. UKUSEBENZA KWEMIZWA NOBUHLUNGU	
b210 Ukubona	
b230 Ukuzwa	
b235 Izindlebe (kubandakanya ukuma nokuhamba ungawi)	
b280 Ubuhlungu	
b3.UKUSEBENZA KWEZWI NOKUKHULUMA	
b310 Izwi	
b4. UKUSEBENZA KWEMITHAMBO YENHLIZIYO, UKUGOBHOZA KWEGAZI, UKUVIKELEKA KOMZIMBA KANYE NEZOKUPHEFUMULA	
b.410 inhliziyo	
b.420 umfutho wegazi	
b.430 isimo segazi nokugobhoza kwalo (igazi)	
b.435 ukuvikeleka (okungahambisani nomzimba)	

APPENDIX 2.3: EXCERPT OF ICF ISISOTHO VERSION

Lenaneo la ho Lekola la ICF © Mokgatlo wa Lefatshe wa Bophelo (**ICF Checklist** © World Health Organization), Loetse 2001. Leqephe 1

LENANEO LA HO LEKOLA LA ICF

Phatlalatso 2.1a, Foromo ya Setsebi sa Tleleniki

bakeng sa Tlhophiso ya Matjhaba ya ho Sebetsa, ho Hloka Boitekanelo le Bophelo

Lena ke lenaneo la ho lekola la dikarolo tsa sehlooho tsa Tlhophiso ya Matjhaba ya ho Sebetsa, ho Hloka Boitekanelo le Bophelo (ICF) la Mokgatlo wa Lefatshe wa Bophelo. Lenaneo la ho Lekola la ICF ke sesebediswa se sebetsang sa ho qolla le ho ngola rekoto ya tlhahisoleseding mabapi le ho sebetsa le ho hloka boitekanelo ha motho. Tlhahisoleseding ena e ka kgutsufatswa bakeng sa direkoto tsa diketsahalo (ho etsa mohlala, tshebetsong ya tleleniki kapa mosebetsi wa bodulo). Lenaneo la ho lekola le lokela ho sebediswa mmoho le ICF kapa phatlalatso ya Pokotho ya ICF.

H 1. Ha o tlatsa lenaneo lena la ho lekola, sebedisa tlhahisoleseding yohle e fumanehang. Thusa o lekole tseo tse sebedisitsweng:

[1] direkoto tse ngotsweng [2] moarabi ya ka sehloohong [3] ba bang batsebisi [4] tlhokomelo e tobileng

Ha tlhahisoleseding ya bongaka le e bontshang bokulo e sa fumanehe ho eletswa hore ho tlatswe sehlomathiso 1: Tlhahisoleseding e Kgutshwane ya Bophelo (maqephe 9-10) e ka tlatswang ke moarabi.

H 2. Letsatsi **__ __ /__ __/__ __**

H3. ID ya Ketsahalo **_ _ , __ __ __ , __**

H4. Nomoro ya Monka-karolo. **__ __ , __ __ , __ __**

Letsatsi Kgwedi Selemo CE kapa CS Nomoro ya Ketsahalo. 1 kapa 2 ya Monka-karolo Setsheng sa Evalu FTC

A. TLHAHISOLESEDING YA DINTLHA TSA MAEMO

A.1 LEBITSO *(ka boikgethelo)* La pele _____ LA LELAPA_____

A.2 BONG (1) [ ] E motshehadi (2) [ ] E motona

A.3 LETSATSI LA TSWALO _ _/_ _/_ _ *(letsatsi/kgwedi/selemo)*

A.4 ATERESE *(ka boikgethelo)*

A.5 DILEMO TSA THUTO E TLWAELEHILENG _ _

A.6 MAEMO A JWALE A LENYALO: *(Lekola feela a tshwanelehileng ka ho fetisisa)*
(1) Ha ke so ka ba ke kena lenyalong [ ] (4) Ke kgaotse lenyalo [ ]
(2) Ke sa tswa kena lenyalong [ ] (5)Molekane o hlokahetse [ ]
(3) Re arohane [ ] (6) Re dula mmoho [ ]

A.7 MOSEBETSI NAKONG YA JWALE *(Tshwaya kgetho e le nngwe e ntle ho feta tsohle)*
(1) Mosebetsi o nang le moputso [ ] (6) Motho ya pensheneng [ ]
(2) Ho itshebetsa [ ] (7) Ha o sebetse (lebaka la bophelo) [ ]
(3) Mosebetsi o se nang moputso, jwalo ka ho ithaopa/ho thusa [ ] (8) Ho hloka mosebetsi (le leng lebaka) [ ]
(4) Moithuti [ ] (9) O mong [ ]
(5) Ho lebela ntlo/Molebedi wa ntlo [ ] *(thusa o hlalose)* _____

A.8 TLHAHLOBO YA BONGAKA E BONTSHA BOKULO ba Maemo a Sehloohong a Bophelo ba jwale, *ha ho kgoneha nehelana ka dikhoutu tsa ICD.*

1. Ha ho Maemo a Bongaka a teng
2. …….. Khoutu ya ICD: __. __. __.__. __
3. …….. Khoutu ya ICD: __. __. __.__. __
4. …….. Khoutu ya ICD: __. __. __.__. __

5. Maemo a Bophelo a teng (bokulo, ho sebetsa ho fosahetseng, ho tswa kotsi), leha maemo kapa ho bonahala ho sa tsejwe.

KAROLO 1a: DITSHITISO TSA HO SEBETSA HA MMELE

- Mesebetsi ya mmele ke ho sebetsa ha ditshebetso tsa ditho tsa mmele (ho kenyeletsa le mesebetsi ya kelello).
- Ditshitiso ke mathata a mabapi le ho sebetsa ha mmele jwalo ka ho fapana kapa tahleho e bonahalang.

Lehlalosi: **0** Ha ho tshitiso, **1** Tshitiso e nyane, **2** Tshitiso e mahareng
Boholo ba ditshitiso **3** Tshitiso e matla, **4** Tshitiso e feletseng, **8** Ha ho tlhaloso
9 Ha e sebetse

Lenaneo le Lekgutshwane la Mesebetsi ya Mmele	***Lehlalosi***
b1. MESEBETSI YA KELELLO	
b110 Maemo a Kelello	
b114 Ho itlwaetsa *(nako,sebaka,motho)*	
b117 Ya kelello *(ho kenyeletsa, Bohole kelellong,bohlanya)*	
b130 Mesebetsi ya matla le sefutho	
b134 Boroko	
b140 Tlhokomelo	
b144 Kgopolo	
b152 Mesebetsi ya kameho ya maikutlo	
b156 Mesebetsi ya ho bonisisa	
b164 Mesebetsi ya bohato bo hodimo ba kutlwisiso	
b167 Puo	
b2. MESEBETSI YA KUTLO LE BOHLOKO	
b210 Ho bona	
b230 Ho utlwa	
b235 Karolo e ka hare ya tsebe *(ho kenyeletsa le mesebetsi ya Tekatekano)*	
b280 Bohloko	
b3. LENTSWE LE MESEBETSI YA PUO	
b310 Lentswe	
b4. MESEBETSI YA DITSHEBETSO TSA METHAPO YA PELO, HO SEBETSA HA MADI,	
HO SEBETSA HA BOITSHIRELETSO BA MMELE LE TSELA YA HO PHEFUMOLOHA	

APPENDIX 3

Appendix 3.1: **Permission letters to access records**

Appendix 3.2: **Data collection sheets**

APPENDIX 3.1: LETTERS REQUESTING PERMISSION TO ACCESS RECORDS

7 York Road
Parktown
Johannesburg 2193

Baragwanath Hospital
Dear Mrs G Bogoshi

Ref: Request to access records for part of my PhD study:
Title: Mainstreaming HIV into physiotherapy education and practice.

I would like to make a request to access the records of patients that have been admitted to Chris Hani Baragwanath hospital during 2003 and 2004. This is in partial fulfillment of my PhD study. This requirement is to fulfill the objective 2 outlined in my proposal

- To obtain a relevant contextual picture of the function and participation of people living with AIDS in South Africa.

To fulfill this objective I will need to study the records to extract information on the diagnosis of patients admitted to Baragwanath hospital, the type of impairments functional problems and disabilities identified and whether these clients were referred for further rehabilitation or not.

The types of records required are:

- Records filed between January 2003 and December 2004.
- Type of patient- patients found to be HIV positive
- All personal data will not be captured in any way- Names will be systematically covered
-

Mode of capturing data - A spreadsheet will be used to capture data. The records will not be removed from the records room or the vicinity. To facilitate this I am requesting working space within the records office for one day a week starting mid August until December 2005

Please find attached a copy of my ethical clearance and permission to conduct research and a copy of the research proposal.

Thanking you in anticipation.

Mrs Hellen Myezwa

Gauteng Department of Health
CHRIS HANI BARAGWANATH HOSITAL
P.O. Bertsham, 2013
Tel: +27 11 933 8000; Fax: +27 933 3135
www.chrishanibaragwanathhospital.co.za

Dr. A. Manning
Clinical Director
Tel: +27 11 933 8146
Fax: +27 11 938 8161
E-mail: arthurm@gpg.gov.za

24 August 2005

Mrs H. Myezwa
Wits University
Dept of Physiotherapy
27 St Andrews Rd
Parktown
2193

Dear Mrs Myezwa

Re: Request to access records for PhD study

Permission is hereby granted for you to have access to patient files for your PhD study.

Yours truly,

DR. A. MANNING
CLINICAL DIRECTOR

APPENDIX 3.2: DATA COLLECTION SHEETS

Sheet a used to screen the records:

Front Sheet no……..

Month with files under review……

Date reviewed……..

Total no of files reviewed……

Categories	No of files reviewed
Files with HIV and reviewed for physio referrals	
Files with HIV but diagnosis unsuitable for physio	
Files for HIV but died	
Files with other diagnosis	
Files with no information	

Sheet b conditions commonly diagnosed and referral status

Used to assess each record for information

no	Condition/ diagnosis	age	gender	Condition on discharge Ambulant Non ambulant	Referral to rehabilitation Y/N		Tests conducted
					Yes	no	
1							
2							
4							
5							
6							
7							
8							

APPENDIX 4

- **Appendix 4.1: Coding of the ICF**
- **Appendix 4.2: Results - data used to rate ICF checklist in different categories**
- **Appendix 4.3: Consent letters**
- **Appendix 4.3 Informed consent form: study participants**
- **Appendix 4.5 Explanation of approach to statistical analysis for the ICF**

APPENDIX 4.1: CODING OF THE ICF

Each component across the body functions, structure, activity and participation is represented by an alphanumeric coding structure. The letter b,s,d, and e are used to denote each component (Body function - b, body structure - s, activities, participation -d , and environmental factors - e). Each component contains domains that are denoted by a numerals known as codes. The numeric code begins with the chapter number (one digit) followed by the second level (two digits) and the third and fourth level (one digit each):

B	:	Body function	:	domains (has 8 domains b1 to b8) for example b1 mental functions b2 sensory functions
S	:	Body structure	:	domains (has 8 domains s1-s8) for example s1 nervous system structure, s2 Ear, Eye structures
D	:	Activities	:	domains (has nine domains d1-d9) for example d1 learning and applying knowledge, d2 general tasks and demands.
E	:	Participation	:	(has five domains e1-e5) for example e1 products and technology, e2 natural environment and man-made changes to environment, (see appendix 1 for full ICF) If the full health experience of the individual or group is to be described, the WHO recommends that all components are useful (WHO 2001).

Where the domain is depicted by one alpha and a numeric symbol, it is referred to as the first level domain. In the full ICF each of these domains is followed by more detailed classifications i.e. categories that convey more detailed classifications. For example: b730 muscle power functions , b7300- power of isolated muscles and muscle groups, b7301 - power of muscles of one limb. These as mentioned before are referred to as codes. In its current version, the ICF has 1424 codes (WHO 2001).

APPENDIX 4.2: RESULTS: DATA USED TO RATE ICF CHECKLIST IN DIFFERENT CATEGORIES

This section presents the results obtained to rate the ICF checklist

1. The results of study 2 which established the inter and intra-rater reliability for muscle testing using dynamometry are presented together with the oxford grading.
2. The laboratory results that were obtained are also presented for the in patient and the out-patient group

4.2.1 Inter-Rater Reliability - Muscle Testing Using Dynamometry

Aim - establishing inter-rater reliability - muscle testing using dynamometry

Three raters participated in this study to establish reliability. Nine volunteers participated in the study four males and five females. In the second and third session two male volunteers did not arrive for the data collection session. Data were collected three times.

4.2.1.1 Intra-rater reliability and inter-rater reliability

Intra-rater reliability

Table 4.2.1: Results for Intra Observer Correlation for Dynamometry n=23

	Rater 1		Rater 2		Rater 3	
	Biceps	**Quadriceps**	**Biceps**	**Quadriceps**	**Biceps**	**Quadriceps**
ICC (intraclass orrelation)	0.23	0.67	0.23	0.46	0.12	0.68
CI	0-0.75	0-1.34	0-0.76	0-1.05	0-0.51	0.2-1.16
SE	0.26	0.34	0.27	0.29	0.21	0.24

The intra rater reliability for biceps was considered low ranging from 0.12-0.23 while the quadriceps intra rater reliability was considered moderate ranging from 0.46-0.68. This variation was attributed to possible variability in stabilizing the biceps whereas the quadriceps is easier to stabilize.

Inter-rater reliability

Table 4.2.2 Spearmans Moment Correlation Coefficient Results for Dynamometry (n=7)

		session 1		Session 2		Session 3	
		Biceps	**Quadriceps**	**Biceps**	**Quadriceps**	**Biceps**	**Quadriceps**
Rater 1 vs. Rater 2	Rho (p-value)	0.66 p=0.0002	0.72 p=0.00	0.72 p=0.002	0.57 p=0.007	0.76 p=0.000	0.60 p=0.004
Rater 2 vs. Rater 3	Rho (p-value)	0.41 p=0.03	0.57 p=0.001	0.21 p=0.36	0.66 p=0.001	0.57 p=0.02	0.54 p=0.001
Rater 1 vs. Rater 3	Rho (p-value)	0.55 p=0.003	0.64 p=0.00	0.31 p=0.17	0.53 p=0.01	0.65 p=0.002	0.70 p=0.003

The inter-rater reliability for raters 1 and 2 was very good for the biceps muscle and moderate for the quadriceps. Rater 1 was unable to participate in the data collection. Reliability between rater 2 and 3 was moderate for the quadriceps muscle ranging between 0.54-0.66 and low for the biceps between rho 0.21 and 0.57 (Shrout & Fleiss, 1979). Based on these results one rater was chosen to carry out all the dynamometry measurements. In addition the Oxford grading system used in the clinical setting was performed and was used to as an initial indicator of the presence of problems and confirmed by the comparison of the dynamometry measurement.

4.2.1.2 **Manual muscle testing using Oxford grading in patients at Baragwanath Hospital and Out-patients at Rustenburg mine hospital**

Manual muscle testing using oxford grading for the in patient group Baragranath hospital.

Manual muscle testing using Oxford grading

Table 4.2.3: Oxford grading in the in-patient group (Baragranath hospital) (n=80)

Muscle groups	**Frequencies of left upper and lower limb oxford grading**	**Frequencies of right upper and lower limb oxford grading**
Oxford grading	**0 1 2 3 4 5**	**0 1 2 3 4 5**
Elbow flexors	2 0 0 20 22 36	1 0 0 15 21 43
Wrist extensors	1 0 2 15 25 36	0 0 1 15 26 38
Knee extensors	1 0 1 18 20 37	1 0 2 19 20 37
Ankle dorsi flexors	2 0 1 16 6 43	1 0 2 18 14 44

Manual muscle testing using oxford grading for the out-patient group (Rustenburg Mine Hospital).

Table 4.2.4: Oxford Grading Mining Out-Patient Group Rustenburg (n=51)

Muscle groups	Frequencies of left upper and lower limb oxford grading						Frequencies of right upper and lower limb oxford grading					
Oxford grading	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**	**4**	**5**
Elbow flexors	0	0	0	0	0	36	0	0	0	0	0	43
Wrist extensors	0	0	0	0	0	36	0	0	0	0	0	38
Knee extensors	0	0	0	0	0	37	0	0	0	0	0	37
Ankle dorsi flexors	0	0	0	0	6	43	0	0	0	0	10	44

To rate the muscle strength on the ICF checklist, dynamometry measurements were taken from a group of normal subjects matched only for gender, geographical location and age. This was used to assess the muscle strength status and to rate it on the ICF check list. (The means were tested for true difference using the student t test.) Results are shown in Table 4.2.5.

Table 4.2.5: Dynamometry In-Patient (n=80) and Mining Cohort (n=51)

Muscle	Patient position	Placement of dynamometer	Mean(SD) In-patient cohort	range	Mean Mining cohort	range
Elbow flexors	Supine	5cm proximal to the wrist crease	4.30 (±1.91)	0-9.00	10.33 (±1.85)	7-15
Hip flexors	Supine	5cm proximal to knee joint	4.93 (±2.32)	0-9.4	10.59 (±1.67)	7.20-15.40
Knee extensors	Supine - in patient cohort Sitting - mining cohort	5cm proximal to the ankle joint	5.15 (±2.61)	0-10.00	9.76 (±1.45)	6.40 - 13.20
Wrist extensors	Supine	1cm below carpo metacarpal joints	3.00 (±1.35)	0-6.00	6.64 (±1.61)	2.2-10.00
Dorsi flexors	Supine	2cm below the tarso metatarsus joints	3.42 (±1.62)	0-8.00	7.80 (±2.14)	4-13.00

These results were used to link to the rating of the persons muscle strength on the ICF.

Statistical analysis

4.2.1.3 **Results of laboratory tests obtained**

Table 4.2.6: Laboratory Test Results Baragwanath In-Patient Group

Test	n	Mean (SD)	Range	Reference values South African Institute for Medical Research (SAIMR)
CD4	45	117.5 (±145.9)	2-570	
MCVMean corpuscular volume (MCV)	69	98.1 (±96.1)	60.3 - 880	79.1-98.9fl
Potassium	68	4.0 (±0.82)	2.5 - 6.6	3.3-5.3mmol/l
Sodium	68	133.1 (±5.4)	116-147	135-147mmol/l
Chlorine	67	93.3 (±24.4)	10.4-115	99 - 113mmol/l
CO2	66	19.9 (±5.62)	6-37	18-29mmol/l
Urea	67	10.6 (±16.6)	1.4 - 88	2.6 - 7mmol/l
Creatinine	66	110.8 (±132.8)	5-853	60-100µmol/l
Glucose	28	7.9 (±11.9)	1.5 - 68.2	3.0-6.0mmol/l
WCC	69	8.8 (±8.3)	0-54	4 - 10 x 10^9/l
HB	69	10.2 (±2.7)	4.7 - 15.8	14.3-18.3 g/dl
Platelets	69	291.9 (±159.9)	12 - 720	137 -373x 10^9/l
Viral load			Not tested	

Table 4.2.7 Laboratory Test results Rustenburg Mining Out-patient group

Test	n	Mean (SD)	Range	Reference values South African Institute for Medical Research (SAIMR)
CD4	46	355.1 (±177.1)	1-760	
MCV				79.1-98.9fl
Potassium	12	4.3 (±0.61)	3.3 - 5.4	3.3-5.3mmol/l
Sodium	12	138 (±6.1)	131 - 153	135-147mmol/l
Chlorine	8	91.1 (±32.4)	11.4 - 109	99 - 113mmol/l
CO2	6	23.5 (±6.4)	12 - 29	18-29mmol/l
Urea	13	9.8 (±21.8)	2.3 - 82	2.6 - 7mmol/l
Creatinine	11	69.3 (±13.9)	44 - 89	60-100µmol/l
Glucose	-	-	-	3.0-6.0mmol/l
WCC	22	5.44 (±2.5)	2.1 - 14.7	4 - 10 x 10^9/l
HB	42	13.7 (±1.8)	8.6 - 16.5	14.3-18.3 g/dl
Platelets	29	249.3 (±71.9)	129 - 554	137 -373x 10^9/l
Viral load				

APPENDIX 4.3: INFORMATION SHEETS AND CONSENT LETTERS

Letter 1

Information sheet to seek initial permission to access patients and records
To the clinical management team:

Dear……..
I am currently registered for a PhD with the University of the Witwatersrand. The title of my study is "Mainstreaming HIV/AIDS into the education and practice of physiotherapy."
The aim of this study is to ensure that the training offered to physiotherapists in South Africa includes the needs of people living with HIV. This multistage study has five main objectives with one objective informing the next. The objectives of the study are to:

1. Describe HIV/AIDS disease in terms of the International Classification of Function for the S.A context.
2. Obtain a relevant picture of the functional and participation picture of people living with Aids.
3. Assess the curriculum in terms of the content of HIV disease profile and referral patterns.
4. Assess the curriculum according to the United Nations defined mainstreaming criteria.
5. Develop a conceptual framework and practice aims that will inform physiotherapy education.

In order to fulfill objective number 2 it is necessary for me to assess people who are HIV positive with regard to their physical and functional status. I will be doing this by using the International Classification of Function checklist and an assessment of their joint and muscle status. However, as I am not a direct member of the clinical team (but an honorary staff member) I would require your assistance in obtaining the permission of the client so that his medical records and condition status are availed to me. Please could you approach the patient and seek his permission for me to speak to him and to have access to his medical records. Once permission is granted I will give a full explanation to the patient and information sheets availed. He /she may then decide after the information is given in full if they would like to participate in the study or not.

If the patient is in agreement that the researcher has access to him/her and his/her medical records, he/she may tick the appropriate box below:

……
I give my consent to speak to the researcher and receive more information about the study before I make my decision to participate.

☐ Yes Signature……..……..
☐ No

APPENDIX 4.4: INFORMED CONSENT FORM: STUDY PARTICIPANTS

I …… (Name of participant) I.D. number……

Hereby accept the invitation to join the research project and give my permission on …… (date) at...……...

(Place) to take part in the study entitled

'***Mainstreaming HIV/AIDS in physiotherapy education and practice.'***

I understand the study is being carried out by Mrs Hellen Myezwa, a student and lecturer at the University of Witwatersrand for the requirements of the doctor of philosophy.

I am aware that I am taking part of my own free will and may stop my participation at any time. I understand that my stopping participation would not prevent me from obtaining any services at the hospital and I would not be treated unfairly in any way. I am fully informed that all information will not be given to anyone else but that I will have access to any information that relates to my health status. I agree that information obtained from this study be published (written up in a journal for learning purposes) so that the findings may be of benefit to others.

The whole study has been explained to me and I am aware that it is the researchers wish that the results inform the education process for physiotherapists so as to make sure the correct input on HIV/AIDS is given in their training for the benefit of the clients whom they will serve. I know that I will not receive any direct payment from the study except where necessary my transport and telephone costs will be payed to me.

With the above information I think I understand my involvement and agree to participate in the study:

Participant name and signature:…….

Investigators name and signature…….……

Research assistants name and signature……

Data capture sheet goniometry and dynamometry

Patient no……...

Please attach sheet to ICF checklist Karnofskys scale rating…….

ROM - Goniometry **Muscle strength dynamometry**

Physical assessment

Joint Range	Position	ROM	ROM	Oxford grading R	0xford grading L
Shoulder					
flexion	Supine ly				
extension	supine				
Abduction (up to 90◦)					
Elbow					
Flexion	Supine ly				
extension	Supine ly				
Wrist					
Flexion	Supine ly				
extension	Supine ly				
Hand					
Lumbrical flexion	Supine ly				
Interossie flexion	Supine ly				
Hip					
Flexors up to 90◦	supine ly				
Extensors	Side lying				
Knee					
Flexors	supine ly				
Extensors	supine				
Ankle					
Dorsi flexors	supine				
Plantar flexors	supine				
Dynamometry		***Dominant side only note if non dominant side cannot be used***			
Elbow				x	x
Flexors	supine ly			x	x
Wrist				x	x
extensors	supine ly			x	x
Hip				x	x
flexors	supine ly			x	x
Knee				x	x
Flexors	supine			x	x
Extensors	supine			x	x
Ankle				x	x
Dorsi flexors	supine ly			x	x
Plantar flexors	supine ly			x	x

APPENDIX 4.5: Explanation of approach to statistical analysis for the ICF

- The ICF had a total of X variables and created a large data set
- The analysis was guided by the objective of the study which sough to develop a profile using the ICF. Therefore the specific objective of the analysis was to obtain the descriptive statistics and to determine the interrelationships between the domains and their subcatecogories. Inorder to do this, categories on the domains of impairments activities and social restrictions were tested for association using the Pearsons chi square in bivariate analysis.
- The following procedures were performed on all the outcome variables which were defined only at first level domain
- Those variables that were significant (having a p-value <0.05) .
- To quantify the level of association, those variables that were significant were then included in a univariate logistic regression model. Odds ratios confidence intervals and p values were obtained.

Multiple regression

In order to get a holistic picture of which of the significant variables in the univariate analysis would remain significant after adjusting for the demographic variables namely age, gender, marital ststus, cd4 count (where applicable), level of education

Step wise regression was performed (backward elimination). The model below illustrates one of the outputs

THE LOGISTIC PROCEDURE

Model Information

Data Set	WORK.DATA1	
Response Variable	B435Immunological	B435Immunological
Number of Response Levels	4	
Model	cumulative logit	
Optimization Technique	Fisher's scoring	

Number of Observations Read - 51
Number of Observations Used - 40

Response Profile

Ordered Value	B435Immunological	Total Frequency
1	8	1
2	2	2
3	1	4
4	0	33

Probabilities modeled are cumulated over the lower Ordered Values.

NOTE: 11 observations were deleted due to missing values for the response or explanatory variables.

FORWARD SELECTION PROCEDURE

Step 0: Intercepts Entered

Model Convergence Status
Convergence criterion (GCONV=1E-8) satisfied.
-2 Log L = 50.478

Residual Chi-Square Test		
Chi-Square	**DF**	**Pr > ChiSq**
12.1193	6	0.0594

Step 1: Effect E2BNaturalEnviro entered

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The LOGISTIC Procedure

Model Convergence Status

Convergence criterion (GCONV=1E-8) satisfied.

Score Test for the Proportional Odds Assumption		
Chi-Square	**DF**	**Pr > ChiSq**
0.1464	2	0.9294

Model Fit Statistics

Criterion	Intercept Only	Intercept and Covariates
AIC	56.478	50.516
SC	61.545	57.272
-2 Log L	50.478	42.516

Testing Global Null Hypothesis: BETA=0			
Test	**Chi-Square**	**DF**	**Pr > ChiSq**
Likelihood Ratio	7.9615	1	0.0048
Score	8.9629	1	0.0028
Wald	6.3213	1	0.0119

Residual Chi-Square Test		
Chi-Square	**DF**	**Pr > ChiSq**
6.7393	5	0.2408

Step 2: Effect AgeYrs Entered

Model Convergence Status

Convergence criterion (GCONV=1E-8) satisfied.

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The LOGISTIC Procedure

Score Test for the Proportional Odds Assumption		
Chi-Square	**DF**	**Pr > ChiSq**
21.6237	4	0.0002

Model Fit Statistics

Criterion	Intercept Only	Intercept and Covariates
AIC	56.478	47.415
SC	61.545	55.860
-2 Log L	50.478	37.415

Testing Global Null Hypothesis: BETA=0			
Test	**Chi-Square**	**DF**	**Pr > ChiSq**
Likelihood Ratio	13.0625	2	0.0015
Score	10.8947	2	0.0043
Wald	7.7198	2	0.0211

Residual Chi-Square Test		
Chi-Square	**DF**	**Pr > ChiSq**
2.7173	4	0.6062

NOTE: No (additional) effects met the 0.05 significance level for entry into the model.

Summary of Forward Selection						
Step	**Effect Entered**	**DF**	**Number In**	**Score Chi-Square**	**Pr > ChiSq**	**Variable Label**
1	E2BNaturalEnviro	1	1	8.9629	0.0028	
E2BNaturalEnviro						
2	AgeYrs	1	2	4.5920	0.0321	AgeYrs

APPENDIX 5

- **Appendix 5.1: Letter to seek permission from academic staff**
- **Appendix 5.2: Results of Initial Audit of University Curricula**

APPENDIX 5.1: LETTER TO SEEK PERMISSION AND INFORMATION SHEET - ACADEMIC STAFF

Letter - Requsting information from individual lecturers

Dear colleague

Hallo my name is Hellen Myezwa. I am a lecturer at the University of the Witwatersrand. I am currently registered to carry out studies for a PhD with the University of the Witwatersrand. My study area is "mainstreaming HIV/AIDS into the education and practice of physiotherapy." I am inviting you to participate in this study by completing the attached questionnaire. Your input will influence the future direction of training in response to the HIV/AIDS pandemic. It will help to produce a more rounded physiotherapist who can contribute effectively to the national programme on HIV and make the input of physiotherapy of appropriate importance in the management of HIV

This multistage study, which has five main objectives with one objective informing the next. The aim of this study is to make sure that the training offered to physiotherapists in South Africa has looked at the needs of people living with HIV. In order to do this I will:

1. To describe HIV/AIDS disease in terms of the International Classification of Function for the S.A context.
2. To obtain a relevant picture of the functional and participation picture of people living with Aids.
3. To assess the curriculum in terms of the content of HIV disease profile and referral patterns.
4. To assess the curriculum according to the United Nations defined mainstreaming criteria.
5. To develop a conceptual framework and practice aims that will inform physiotherapy education.

As part of this study, I need to establish the current level of integration of HIV into your existing curriculum in all areas of specialization i.e. sports, orthopaedics, neurology, public health and respiratory. Paediatrics has not been focused on as it requires a different focus of study. This will be done by the analysis of your current university physiotherapy curriculum, the completion of a questionnaire based on mainstreaming principles and where there are gaps focus group discussions. I would appreciate your input through the completion of the attached questionnaire. Upon completion of the analysis of these results a further focus group discussion will be held with a representative from your department to fill in any gaps that may be evident.

Thank you for your time

Letter requesting physiotherapy curriculum

Hellen Myezwa

Dear …….

Re: Request for Physiotherapy Curriculum

My name is Hellen Myezwa, I am currently registered as a PhD student at the University of Witwatersrand and also lecturer in the physiotherapy department. The topic for my study is "Mainstreaming HIV into physiotherapy education."

The overall research question is:

"What is the appropriate physiotherapy curriculum model to mitigate the functional disability and participation manifestations presented by people living with HIV/AIDS in South Africa?" The anticipated output is thus to develop a model for mainstreaming HIV into the curriculum and practice of physiotherapy.

The findings from this research will be useful for:

- Preparing the student for working in an environment where HIV is pervasive
- Responding more appropriately to the needs of clients and patients with HIV within a multi-disciplinary team
- Contributing to national regional and local responses to HIV/AIDS within the continuum of prevention treatment care and support.
- Stimulating research in HIV around the areas where there are clear gaps

The objectives of the study therefore are to:

1. describe HIV/AIDS disease in terms of the International Classification of Function for the S.A context.
2. obtain a relevant picture of the functional and participation picture of people living with Aids.
3. assess the curriculum in terms of the content of HIV disease profile and referral patterns.
4. assess the curriculum according to the United Nations defined mainstreaming criteria.
5. develop a conceptual framework and practice aims that will inform physiotherapy education.

In order for me to fulfill objectives 3 and 4 of my study, I need to review the physiotherapy curricula of all eight university departments. To that effect, I am requesting a detailed copy of your physiotherapy curriculum in order to assess the HIV content within your university's physiotherapy course. In addition the university's HIV policy would add value to building a better overall picture.

The assessment of the curriculum will be in answer to objective 3 (partly) and 4. The curriculum will be used for the sole purpose of this study and will neither be copied nor distributed to any other persons. The contents of your curriculum will be kept confident and I will return the copy on

completion of its review. A brief summary of the outcome of the review of your curriculum will be sent to you should you be interested. No reference of the name of your department will be made in the report of this study.

Your assistance will be highly appreciated.

Yours Sincerely

Hellen Myezwa
PhD Student and Lecturer
University of Witwatersrand

APPENDIX 5.2: RESULTS OF INITIAL AUDIT OF UNIVERSITY CURRICULA

Table 5.2: Results of the First and Second Round Curriculum Audit

Results of initial audit of university curricula

This audit sought to extract the following information:
1. Purpose of the course - the intended or desired aim or goal
2. Outcomes of the course - the end result
3. Assessment of the course - the act of assessing or appraisal

Institution / year	Type of Document	Year of Study	Subject /Areas where HIV/AIDS is Reflected	Purpose of the Course	Outcomes	Topics	Content	Assessment
University of Cape Town (2005)	Full curriculum	1st year	Becoming a professional	None apparent	None apparent	HIV awareness for their own protection	Basic relevancy of HIV in their professional lives	None apparent
		3rd year	Basic and applied neurosciences Neurological manifestations of HIV	None apparent	Assess an adult with HIV functionally Plan and execute a daily plan	Neurological manifestations of HIV	Neurological manifestations of HIV	None apparent
University of the Witwatersrand (2006)	Full curriculum	None apparent	Paediatric-HIV and its impact on child development	None apparent	None apparent	Epidemiology, transmission, testing, TB Encephalopathy, developmental delay, PCP and LIP	None apparent	None apparent
	Clinical Physiotherapy work book - 4th year	3rd year	Infection control	None apparent	None apparent	None apparent	None apparent	None apparent
	Curriculum				-Confidence in physiotherapy treatment -Effective rehabilitation of patient -Discernment regarding involvement of physiotherapy i.e. indications and contra-indications	-Transmission, testing, -role of physiotherapy in exercise rehabilitation for HIV/AIDS patients. -Pathophysiology of PCP and the role of physiotherapy in the management of the PCP patient. -Pathophysiology of -TB and the role of physiotherapy in the management		Clinical placements/ exams Theory test and exam

Institution / year	Type of Document	Year of Study	Subject /Areas where HIV/AIDS is Reflected	Purpose of the Course	Outcomes	Topics	Content	Assessment
University of the Witwatersrand (cont)		4th year	Cardiopulmonary physiotherapy	None apparent	Confidence in handling patients	Testing how to handle a needle stick injury	None apparent	Clinical placements and exams
University of the Free State (200…)	Extract of module	2nd year	Separate course on HIV	None apparent	None apparent	Background pathology and epidemiology	Pathology of the condition Complication and opportunistic infections	Positive effects of Nevirapine mother to child
			None apparent	None apparent	None apparent	Specific impacts of HIV	Social impact Effect on the population Policy of government matters Psychological impact on the patient and family	
			None apparent	None apparent	None apparent	Implications for physiotherapy	The terminal sick patient Physiotherapy handling of complications Effects of exercise Handling and contact with body fluids and needle stick injury Handling of hospital and intensive care precautions for physiotherapists Basic consultation skills	
		3rd year	None apparent	None apparent	None apparent	To undertake training for home carers	None apparent	

Institution / year	Type of Document	Year of Study	Subject /Areas where HIV/AIDS is Reflected	Purpose of the Course	Outcomes	Topics	Content	Assessment
University of the Free State (200…)		3rd and 4th Year	None apparent	None apparent	None apparent	Nutrition	Basic nutrition for patients HIV	
			None apparent	None apparent	None apparent	Psychological impacts and intervention	Psychological impact on the patient and family	None apparent
			Neurological changes			Neurological changes	Changes in the neurological system	
Medical University of South Africa (Medunsa)	Full curriculum	*3rd Year*	Conditions medical surgical	*Empower students with knowledge*	*1.Socially make informed decisions 2.clinically awareness to ensure they are sensitised to the condition Precautions Knowledge empowerment so that expected outcomes are realistic*	Immunological disease	AIDS	Clinical block evaluations test

Institution / year	Type of Document	Year of Study	Subject /Areas where HIV/AIDS is Reflected	Purpose of the Course	Outcomes	Topics	Content	Assessment
University of Pretoria (2003)	Full curriculum	1st Year	Courses not taught as specific diagnosis	Awareness				
		2nd and 3rd Year	Spinal cord injuries	None Noted	Understand HIV as one of the causes of SCI Apply the necessary precautions during treatment of an SCI patient with HIV	Spinal cord manifestations		As part of clinical medicine Practical and clinical
			Clinical physiotherapy 220	None Noted	Safety measures patient handling			
	Course notes	3rd Year	POL 300	None Noted		What is HIV HIV History and epidemiology, S&S, Gender implications, HIV/AIDS and law counselling, peer education and adherence		

Institution / year	Type of Document	Year of Study	Subject /Areas where HIV/AIDS is Reflected	Purpose of the Course	Outcomes	Topics	Content	Assessment
University of Pretoria (cont.)			Under pulmonology, orthopaedics and PNF "WE teach according to problem based learning do not teach the disease on its own but teach basic principles and treatment modalities"			Emphasise safety precautions regarding HIV, TB hepatitis and other contagious diseases		
			Manual therapy					
			Women's health	Leadership and professional conduct	Knowledge skill and attitude related to the course	Contra-indications and precautionary measures Breastfeeding		
	Study Guides	2nd, 3rd and 4th Year				Ethics professional development , leadership management		Self assessment, peer assessment, practical tests applying skills, reflection exercises, small research exercises, assignments video tapes web based self tests

Institution / year	Type of Document	Year of Study	Subject /Areas where HIV/AIDS is Reflected	Purpose of the Course	Outcomes	Topics	Content	Assessment
University of Kwazulu Natal	Full curriculum	2nd round None received	None noted	None noted	None noted	None noted	None noted	None noted
University of the Western Cape	Information sheet	2nd round None received	1st year philosophy of care 2nd year theory of HIV/AIDS	None noted	None noted	HIV/AIDS in philosophy of care Underlying theory of HIV/AIDS Transmission, infection, pathology, prevention, stages and treatment	None noted	None noted
Stellenbosch	None received	2nd round None received						

APPENDIX 6

- **Appendix 6.1: Focus Group Interview Schedule**
- **Appendix 6.2: Categories and Concepts Derived from the Transcribed Data**
- **Appendix 6.3: Example of Transcripts**
- **Appendix 6.4: List of topics emerging out of Focus groups and preceding studies**

APPENDIX 6.1: FOCUS GROUP INTERVIEW SCHEDULE

Focus group questions

1. Would you consider HIV as a subject that should be taught on its own within the physiotherapy curriculum?
2. Should HIV stand alone?
3. From your experience what do you see as a role for physiotherapists in the management of HIV
4. Do you personally refer any patients to physiotherapy
5. What considerations determine the depth breath and content of input on HIV?
6. What determines the detail of pathophysiological input?
7. Should HIV be integrated into other areas such as paediatrics, neurology, orthopaedics, public health or community?
8. Are there specific areas that should be taught that therapists are likely to encounter and treat in HIV positive patients?
9. What principles have you identified as important for delivering prevention treatment and care in HIV specifically for therapists?
10. What practical beliefs values and practices do you see as important for the delivery of prevention treatment and care
11. Should there be discussion of the large scale implications of the disease within physiotherapy education and practice?
12. What preventative measures are taught?
13. *How many socio-economic issues are included?*
14. *What methods of teaching are utilized by others?*
15. What do you think the physiotherapists' role is in enlightening other health workers in the physiotherapists' role in HIV?
16. *What informs the curriculum development of courses for this programme*
17. *Is that how it has happened as HIV curriculum has developed in your department?*
18. *What areas concern you with regard to HIV prevention treatment and care that you feel from your experience should be of matter to physiotherapists?*

APPENDIX 6.2: CATEGORIES AND CONCEPTS DERIVED FROM THE TRANSCRIBED DATA

No	Concepts	Categories	Themes
1a	- HIV Pervasive in all areas - lack of & difference in understanding - more depth required - increased content - HIV curriculum not response to clinical picture - response to ↑ prevalence - lecturers to have relaxed attitudes to HIV	**Need for HIV in Curriculum**	- need for Curriculum -
1b	- **.** an important subject - HIV has a high prevalence - situation needs to inform any curriculum - changing prognosis of the curriculum - personal relevance	**Need for curriculum**	- need for Curriculum -
1c	- Exposure to - clinical presentation - clinical picture - no practical application (e.g. Paediatrics) - staging - fragmented approach to HIV input (especially in adults) - the need for numbers to quantify problem - contact with people who are HIV positive in teaching - reality of how patients present - increased prevalence in women's health	**Current Gaps felt by clinicians and therapists**	- need for Curriculum -

2.	- HIV implications for Physiotherapy and disease aetiology
	- episodic nature/ recurrence of illness
	- rehabilitation role
	- palliative role
	  - physiotherapy treatment approach
	  - physiotherapy practical role (What is it?)
	  - approach to the HIV patient
	  - managing the very ill
	- CD4 vs. mobility/function
	- effective physiotherapy interventions
	- ethics
	- exercise When to exercise
	- dealing with general weakness
	- disclosure issues (challenge laws and charters)
	- approach - good nutrition good drugs and mobility
	- input into specific areas such as orthopaedics
	- HIV and breast feeding
		Physiotherapy Content	- curriculum - specific to physiotherapy

2a	- Scraping the surface, give principles assessment and interpretation
	- chest conditions
	- neurological conditions (Stroke Peripheral Neuropathy)
	- coincidental co morbidities
	- pathology
	- ARVs
	  - implication application
	  - effectiveness/Non effective
	  - role
	  - mechanisms
	  - complications
	  - programmes
	  - PMTCT/ children
	- case variation
	- patient staging - relation to physiotherapy
	- depth of common conditions
	- common medical problems
	- physiotherapy specific input
	- psychiatric conditions
		Content of Curriculum	- curriculum - specific to physiotherapy

2b	- treatment including medical treatment - inform the therapist of the true prognosis - prognostic changes - refer to ARV for secondary complications - understanding overall management and treatment	**Prognosis**	- curriculum - specific to physiotherapy
2c	- clear roles in HIV - techniques - management principles - optimise patients health - role of physiotherapy in the community lacking - use of generic module on role of teaching different disciplines - self learning	**Role of physiotherapy in HIV**	- curriculum - specific to physiotherapy
2d	- should be left to Department of Education (DoE) - refer to DoE input only - challenge laws & charters - academic therefore the large scale implications should not be included. - political issue - grandparents - orphans - general population response to HIV - caregiver support and Education - gender victimization - family - family structure and HIV	**Large Scale Implications**	- curriculum - specific to physiotherapy -
2e	- universal precautions - cannot help with prevention when its too later in the hospital - primary prevention role of HW - role & Influence of public	**Prevention**	- curriculum - specific to physiotherapy

2f	- risk
	  - to patient
	  - to self
	- universal precautions
	- information on appropriate & correct use of precautions
	- inappropriate precautions
		Physiotherapy Self protection	- curriculum - specific to physiotherapy

2f-1	- loss of hope
	- loss of Morale
	- staff overload
	  - other health workers
	  - physiotherapists
	- effect of HIV on personal level
		Coping and Therapist burn-out
		Part of self protection;
			- underlying Concerns

2g	- counselling skills - creates openness about HIV - encourages better response to patient - Important for physiotherapist/patient relationship - patient communication - skills, approach, need	**Counselling**	- curriculum - specific to physiotherapy
	- death sentence - treat patient/Person not condition - judgmental - avoidance pretend patient has no AIDS - see person not disease - stigma/destigmatisation - beliefs - need relaxed attitude to HIV	**Personal Attitudes to H/A**	- underlying Concerns
4	- stand alone initial phase /microbiology, clinical sciences - integrated approach - increased HIV content - increased Depth and breath - comprehensive input - coordinated input - avoid repetition - teaching methods - ward rounds, interactive, lively - focus on principles - evidence based -	**Mechanics/structure of curriculum**	- curriculum design
5	- patients HIV status unknown (disclosure) - liberty to approach the subject with patients - need for non interference in undergraduate programme - no presence of physiotherapists in out-patient HIV clinics - misconceptions about prognosis - perception of death sentence - lack of understanding of HIV - differences in understanding of HIV - doctors determining content & depth - source of information from the media - restriction of the physiotherapists role - fear of patient aggression - lack of disclosure affects total care package	**Threats to content**	- curriculum - specific to physiotherapy

6	- keep at undergraduate level
	- student
	  - Negative attitudes
	  - Perceptions
	  - Attitudes
	- physiotherapists avoid HIV
	- abdication of care by health workers (Aag he has HIV so you see less effort)
	- unsure what physiotherapy specific input should be
	- inappropriate approach to patients
	- reality of death
	- effect of encountering HIV on students
	- staff overload - offer HW
	- student anticipating bad experience
	- policy and regulations prohibitive
	- no contact with HIV in the community
	- profession to take lead in HIV
		Concerns of clinicians and academics	underlying Concerns

7	- Training needed for qualified staff - Qualified staff unaware of HIV/AIDS approaches	**Further training needs**	Continuous professional development

APPENDIX 6.3: EXAMPLE OF TRANSCRIPT

Interview	Concept
Focus Group discussion	
Topic HIV in the curriculum	
Helen Joseph - clinical staff Physiotherapy department	
6 members of staff	
Introduction given and observers introduced…	
From your experience as clinicians, would you consider that HIV should be taught as a subject on its own in the physiotherapy curriculum?	
Ja.Definitely.	Inclusion of HIV
Any reasons why?	
I hadn't thought of it as a possibility but HIV is so all-encompassing, it takes bits and pieces from so many different areas of physiotherapist: from neuro, the respiratory, when you get patients who end up with TB signs, all sorts of things. To draw everything together would be useful, I think.	HIV pervasive in all areas of physiotherapists
It seems to be creeping into all our patients; it doesn't matter whether they are in patients neuro or OPD patients. I think we often- that's often been the main problem, if you can say that, in a patient, it's overlooked and we focus on an actual area whereas we should be focusing as well on the main problem.	HIV pervasive in areas of physiotherapy practice
I think in each- like may be you do orthopaedics or you do this and this… there should be a section where you have HIV is in cooperated. We don't know the specifics in neuro that this patient will have polyneuropathy the implication of a CD4 count of this and they aren't on ARVs or they are - how much physiotherapy can you do? So we don't know the outcome, we don't know if we should be standing back and they should be on ARVs for 6 months and then they come to physiotherapy … …	Integration of HIV into curriculum Detailed specific info on HIV Staging of HIV and physiotherapy
So, and having said that, what would you think would determine the breadth and the depth of the content that should be given in the curriculum?	
Well, perhaps… but may be the amount of patients you see with HIV/AIDS would obviously then- I would say would be part of a large, would be quite a large…teaching or whatever, in that area. May be perhaps like some kind of- doing like a survey if it's possible to find out how many patients we treat with HIV/AIDS as well. So that plays a very big role and I think it's absolutely necessary from my experience.	Prevalence of HIV influence curricula
I think you can also look at the other subjects that are in the curriculum, so if it's a big section of med and surg. then are all the areas so that could focus more the medical factors are covered in med and surg and other areas focus primarily on physiotherapy and prognosis regarding physiotherapy.	Integrated approach Role of physiotherapy in HIV
I can't help asking this question, it's not in my study but do you feel you were adequately prepared for what you are meeting now?	
Uh-uh, no. In certain areas yes, in certain areas not. In neuro in particular, no.	HIV input in neuro
No. Definitely not.	
We've kind of been making it up as we go along. We weren't taught things like peripheral neuropathy and we've had to learn how to deal with that.	Missing conditions(peripheral neuropathy) Unsure of physiotherapy input
A lot of the conditions that we come across are very similar to patients that don't have HIV like certain types of conditions pneumonia for e.g. So that, may be, respiratory yes, but definitely on neuro, no.	Similar to HIV negative patients
I think that's stumped us the most this year. I think in particular, as Joan said, the prognosis and the rehab process of that because with HIV being a deteriorating process, how much work are we going to put to gain function if they are deteriorating anyway? So I think for neurology and the polyneuropathy we've had plenty from HIV, especially. And I mean I've been stuck on how far should I go, what should my approach be?	Physiotherapy approach to HIV Approach to specific conditions (polyneuropathy)

That's an interesting point because you are in a hospital setting, that's where we are, and so what do you think would determine the detail of patho-physiological input?	
Are you saying what should determine it? ***Or even what do you think it should be?***	
I think it should be deep def with neuro I would be interested to know about it and how approaches work, exactly what is causing the problem equip yourself to better understand it, explain it, figure it out yourself, research about it yourself treatment techniques If you're going to go shallow you're never really going to understand the problem.	More depth in neurology
I think as much as there is to know because I personally feel, and I've spoken to many doctors who feel the same, that even though there's been so much research in this area, there are so many different presentations that often they come up with the strangest, newest, weirdest presentation are unbelievable. So ja, I think as much as there is to know, and I think we'll continue to learn as we move on as well.	Continuing education
I think one determining factor is the statistics that are happening, and I mean, I suppose that's why you're here - with the statistics of HIV/AIDS, we don't even have to take a poll, we all know that it's huge. So I think that's why we all say it should be quite big because the stats say, and there are many of them. I mean, if it was one patient in a year, we wouldn't want to know so much about it. But because really the majority of the patients out there now are neuro patients and are positive, so I think because there is such a high statistic of figure, our input has to be high	High prevalence of HIV
And do you always know your patients' status?	
We shouldn't but we do. no	
It's pretty standard to test nowadays. It is standard. They really test- I it's more like having a sputum sample and take an HIV test. I don't know if you agree with me. From the clinical presentation you can tell.	Knowledge of Patients HIV status
And they get a certain look on their face	HIV Clinical presentation
Ja, I thin, I don't think- we're not meant to know. Am I right?	
A lot of them do HIV tests because they pick it up on other things So you always know	
Does it make a difference to you if you know?	
No, not at all. Not treatment-wise. I think it helps you to understand a patients' condition better, which is why we need to know. Like personally, I treat all patients the same. And I must be honest with you, a lot of the time, if someone is negative, I'm very surprised. Because I don't know if I've had many patients who had a negative result	Approach to patient with known HIV status
I must be honest, it's not a good thing that I'm admitting, that sometimes I really do lose hope in my treatment, I'll give you an example - one of the patients got referred to my ward , got pneumonia and I worked so hard on his chest …. 5 days, 2 hours of the day, everything, and I thought this guys is going to get of his bed he's going to get better. And then I found out that he was HIV positive and then I was like, ag, well I've done this, but how much difference have I really made because he's got a death sentence on his head anyway. So to me I'm almost not going to get anywhere. I'm not really saying	Loss of hope Treatment Efforts vs. prognosis Perception of death sentence
I agree I also feel like that sometimes Sometimes I just feel useless, like should I be putting this much effort in this patient and killing myself if they've got a death sentence on their head?	
For me, it's the other way as well. Should I be pushing this patient who's really not well as much as I would be pushing, say, someone else??? When I think they will get better if they get up So, how much do you push them if you know their CD4 count is very low and they're really showing illness and you can exacerbate things….	Approach to patients physiotherapy treatment given HIV status

And you can actually take that further and say that I- I've realized, I've walked past and I feel we're in physiotherapy, and when you speak to the doctors and they say well, that patient is going to go anyway, I don't think you can help him. Which is sad, in a way, because the patient might need physiotherapy, but they do tell you that there's nothing you can do?	Death sentence Treatment effort vs. prognosis
I've been asked to mobilise a patient with a CD4 count of 10 which is quite low to all of us, for one. You go and you do your thing and you get them out of bed and you take them the next day that patient is not there. It's a complicated thing to try and judge.	Palliative care Point of discussion with prof, while physiology of ex may be the same. The message to say research shows effect to be the same in HIV an important one Perception of need for treatment (multi-disciplinary team)

APPENDIX 6.4: LIST OF HIV TOPICS EMERGING FROM THE STUDIES

As a prerequisite participants said there is need for a coordinated and integrated approach to including HIV in the physiotherapy curriculum.

Basic information on HIV

- Current prevalence global to local
- Determinants of HIV/AIDS infection and spread including
  - Types of HIV
  - Social determinants
  - Sex and sexuality
- Impacts of HIV
- Clinically
- Socio-economically
- Family and caregiver

Pathophysiology of HIV
- HIV structure and influence on HIV proliferation
- HIV entry
- Key receptors of HIV
- Role of chemokines and cytokines in HIV infection *(in view of their subsequent role in ex)*
- Stages of HIV
- Episodic nature
- HIV Prognosis understanding overall management in relation to prognosis
- Relation of stages to clinical, functional and general and physiotherapy treatment decisions

ARVs
- Implication application
- Effectiveness/non effective
- Role of ARVs
- Mechanisms through which they work
- Complications as a result of ARVs
- Programmes
- MCTC/ children

HIV effects on body systems
Direct and indirect effects on all systems
- Haematology
- Aetiology of anaemia

Cardio/Pulmonary

- Impact on oxidative system
- Impact on diffusion capacity
- Impact on metabolic pathway
- impact on cardiac system
- Common conditions epidemiology aetiology and S & S(should I list conditions)
- Pneumonias including interstitial lymphoid pneumonitis
- Tuberculosis
- Aerobic incapacity
- Fatigue

Metabolic disorders
- Lipodystrophy
- Lactic acidosis
- Insulin resistance and insulin resistance
- Weight loss

Neurology
- Direct and indirect effect of HIV on neurological system
- Impact of ARVs on neurological system

Common conditions epidemiology aetiology and S & S
- HIV and stroke
- Global encephalopathy
- peripheral nerve dysfunction& peripheral neuropathy
- Progressive multifocal leucoencephalopathy
- AIDS dementia complex
- Guillian Barré Syndrome
- Spinal cord disorders
- Meningitis

Musculoskeletal system
- Impact of HIV on fracture healing
- Direct and indirect impact on muscles

Common conditions epidemiology aetiology and S & S
- Myopathies
- Inflammatory arthropathies
- Infectious musculoskeletal conditions

Role of the physiotherapist
- HIV management approaches
- Rehabilitation approaches and role
- (role of the physiotherapist in a community setting)
- Palliative role
- Rehabilitation and physiotherapy theory and relation to HIV
- ICF and HIV
- Relationship of episodic HIV to physiotherapy role
- Multi-disciplinary team
- Treatment modalities evidence and current use, precautions and contra-indications

HIV and disability
- Concepts of disability and relation to HIV
- HIV disability and function
- CD4 and function
- Disability and HRQOL
- Exercise HIV and disability

Application facilitators

- Counselling
- Self assessment of attitudes
- Policies guiding HIV management
- Appropriate approach to HIV patients
- Disclosure and patients charter public health act
- Role definition and marketing physiotherapy role
- Application of Universal precautions
- Clinical decision-making in HIV
- Dealing with known threats (overcrowding, staff shortages, death, beliefs stigma)??

Methods of teaching

- Lecture
- Case presentation
- Interactive learning
- Information integrated in specific aspects??
- Creating a multi-disciplinary paradigm

APPENDIX 7

- **Appendix 7.1: Letter of invitation to the Delphi survey and return Sheet**
- **Appendix 7.2: Integrating HIV in the Curriculum - A Delphi Tool**

APPENDIX 7.1: LETTER OF INVITATION TO THE DELPHI SURVEY AND RETURN SHEET

19 May 2008

Dear Colleague

MAINSTREAMING HIV INTO PHYSIOTHERAPY CURRICULUM: PROPOSED CORE CURRICULUM NEEDS

I am a Ph.D. student at the University of the Witwatersrand, and currently engaged in a study entitled "**Mainstreaming HIV into physiotherapy curriculum"** under the supervision of Professors A Stewart (University of the Witwatersrand Department of Physiotherapy) and P Solomon (McMaster University Canada School of Rehabilitation Science). To date three studies have been conducted to inform the process of developing the core HIV/AIDS content for physiotherapy. The purpose of this part of the study is to obtain consensus from all the universities on the proposed content.

Findings from the three studies conducted as part of this study, indicate the need for comprehensive, holistic and mainstreamed (where the inclusion of the subject matter is carefully integrated into each topic by identifying the entry points) input on HIV. The results so far show that people living with HIV (PLWH) experience a high level of impairments activity limitations and participation restrictions yet physiotherapists are not realizing the full potential of their role. All eight universities include HIV in the curriculum; however, the curricular documents do not reflect comprehensive input reflecting physiotherapy philosophy and approach. While academics and clinicians agree on the need for a comprehensive well coordinated input of HIV into the curriculum, there is inconsistency in understanding and where in the curriculum input on HIV should be. From the above results core curriculum content for physiotherapists was derived.

Therefore the next step is to use the results that have been gained from these studies to test how much academic staff in South Africa are in agreement with what has been identified and if there are additional suggestions.

With this background, you are kindly requested to be part of a panel of physiotherapy education experts to evaluate the draft format of the developed **core curriculum needs** .Your participation in this Delphi is sought for your expertise in physiotherapy education in your specific area of teaching. The proposed approach to the inclusion of HIV is "mainstreaming" and therefore it is imperative that each area of specialization have a say on how they would see the inclusion of HIV/AIDS in their respective areas of interest. Your suggestions and comments, as the experts in your fields, regarding the **proposed core curriculum needs** will serve as guidelines in the finalisation of the core curriculum guidelines for South African universities.

The first step in the Delphi process involves completion of the enclosed structured questionnaire. The questionnaire should take approximately 20-25 minutes to complete. There is space provided at the end of each section for any additional comments/suggestions. It is expected that the

documents will reach you by the beginning of June. Should changes to the programme be required after the first round of assessment, you may be requested to evaluate the programme for a second and/or third round for consensus to be achieved (Delphi technique). You are kindly requested to complete the questionnaire within five working days as this evaluation is taking place in the final stages of the research study. Depending on the results of each round's questionnaire, an adapted questionnaire will be compiled for each round of evaluation. It is envisaged that the whole process of evaluation will be completed by end of July 2008. Your participation will help to provide clearer guidelines on what can be considered core content for the inclusion of HIV into the curriculum for South African physiotherapy graduates

I would like to assure you that your participation in this study is confidential. Only I as the researcher will receive the questionnaires and will give codes to them thus removing any form of identification. The final results from the Delphi evaluation process will also accompany that communication.

It will be appreciated if you could complete the attached form and fax or e-mail it to confirm your participation in the study.

Thank you in advance for you valuable input and participation.

Yours sincerely

Hellen Myezwa

APPENDIX 7.2: INTEGRATING HIV IN THE CURRICULUM - A DELPHI TOOL

RETURN SHEET

Are you willing to participate and be involved in this study? *(Please indicate with an 'x')*

Yes : ☐ No : ☐

If "YES", do you prefer your mail (questionnaires) via: *(Please indicate with an 'x')*

Electronic (e-mail) : ☐ Fax : ☐

Could your identity be revealed in the presentation of the study (only as a member of the Delphi panel and not in connection with any input on the evaluation of the programme, as that information is confidential)? *(Please indicate with an 'x')*

Yes : ☐ No : ☐

Personal Details (Please complete for correspondence purposes only)

Name and surname : _____

Title : _____

Position : _____

Institution : _____

Qualifications : _____

Postal address : _____

Contact Details

Tel Number : _____

Fax Number : _____

Cell Number : _____

E-mail Address : _____

Thank you

Hellen Myezwa

Postal address:

Department of Physiotherapy
School of Therapeutic Sciences
Faculty health Sciences
7 York Road Parktown 2193
Tel: 0117173721
Fax: 0117173719
Cell: 0834696249

Thank you for agreeing to participate in a Delphi study as described in the information sheet attached. The Delphi study is part of a wider study addressing the following question of input to mainstream HIV into physiotherapy curriculum

Please tick or give the appropriate answer/s:

PART 1 - DEMOGRAPHIC DETAILS

- **DOB (day-month-year)** ☐
- **Years of Experience in Academia (yrs)** ☐

Highest Qualification Obtained

- ☐ Diploma
- ☐ BSc (Physiotherapy)
- ☐ MSc
- ☐ PhD

Area of Teaching

- ☐ Orthopaedics
- ☐ Neurology
- ☐ Public Health
- ☐ Community Physiotherapy
- ☐ Paediatrics
- ☐ Neuromusculoskeletal
- ☐ Cardiopulmonary
- ☐ Other

PART 2 - QUESTIONNAIRE

Should this topic be covered in the curriculum					Indicate the level of detail to which the following topics are taught in your department :				
don't know	Strongly disagree	Disagree	Agree	Strongly Agree	taught but not in detail	taught adequate detail	taught too much detail	not sure	not taught

1 THE ABILITY TO CONTRIBUTE TO PREVENTION OF DISEASE AND PROMOTION OF HEALTH WITH DUE CONSIDERATION FOR THE IMPACTS OF HIV/AIDS

1.1 Basic Information on HIV

The current prevalence global to local Determinants of HIV/Aids infections+A16 and spread including: ■ Types of HIV ■ Social determinants ■ Sex and sexuality ■ Comments and Suggestions									

Impact of HIV

- Clinical presentations of the patient
- Socio-economic implications of HIV/AIDS
- impact of HIV on the family and caregiver
- Comments and Suggestions

2 A WELL FOUNDED KNOWLEDGE OF HIV DISEASE, PATHOLOGY PROCESSES MEDICAL MANAGEMENT AS A BASIS FOR PHYSIOTHERAPY INPUT TO HIV/AIDS MANAGEMENT

2.1 Pathophysiology of HIV

- HIV structure and factors influencing HIV proliferation
- Mechanism of HIV entry at cellular level
- Key receptors of HIV in the cellular structure within the different body systems
- Role of chemokines and cytokines in HIV (in view of their subsequent role in exercise)
- Stages of HIV
- Episodic nature of HIV/AIDS and the relation to the pathophysiology
- HIV prognosis

- HIV prognosis in relation to understanding overall management of HIV/AIDS
- Relation of stages to clinical presentation, functional ability, general health and physiotherapy treatment decision
- Comments and Suggestions

2.2 Anti-Retroviral Therapy (ARVs)

- Implications of ARVs' to physiotherapy management
- Effectiveness/non effectiveness of ARVs
- Role of ARVs in the overall management of HIV
- Mechanisms of how ARVs work
- Complications Of ARVs
- Structure and organisation for ARV programmes
- Mother to Child transmission programmes
- Comments and Suggestions

2.3. HIV Effects on Body Systems

Direct and indirect effects on all systems

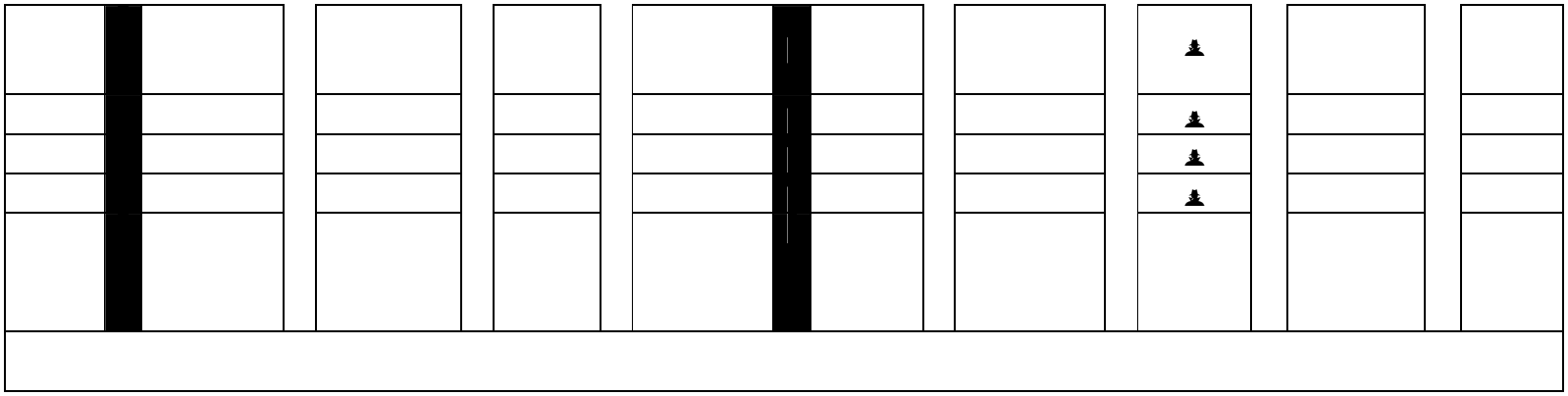
- Direct and indirect effects on the haematological system
- Aetiology of anaemia in relation to HIV
- Comments and Suggestions

2.4 Cardio/Pulmonary - HIV

- Effects on Oxidative system
- Effects on diffusion capacity
- Effects on metabolic pathway
- Effects on cardiac system
- Comments and Suggestions

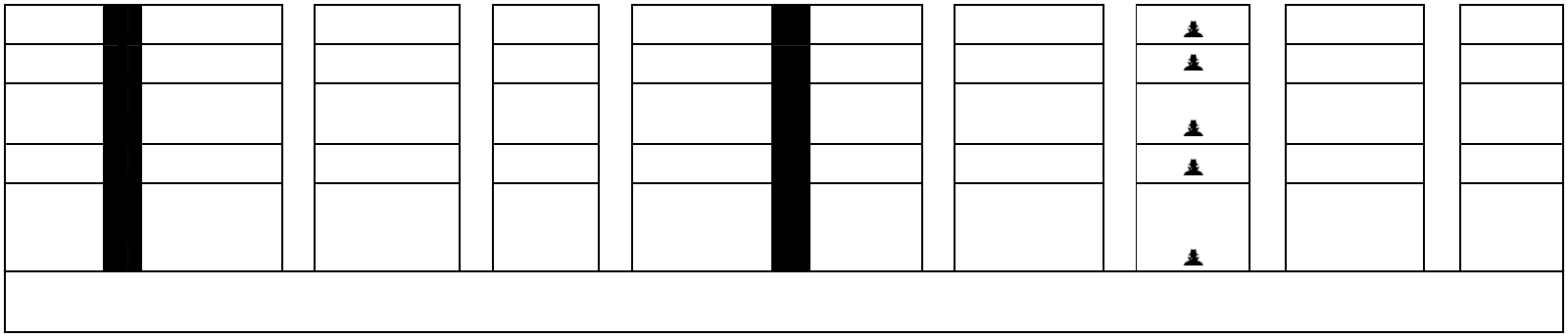
2.4.1 Common conditions related to HIV - epidemiology aetiology and signs and symptoms

- Pneumonias including interstitial lymphoid pneumonitis
- Tuberculosis
- Aerobic incapacity
- Fatigue
- Relation of the above conditions to physiotherapy management
- Comments and Suggestions



2.5 Metabolic Disorders in relation to HIV

- Lipodystrophy
- Lactic acidosis
- Insulin resistance and intolerance
- Weight loss
- Relation to physiotherapy management
- Comments and Suggestions



2.6 Neurology

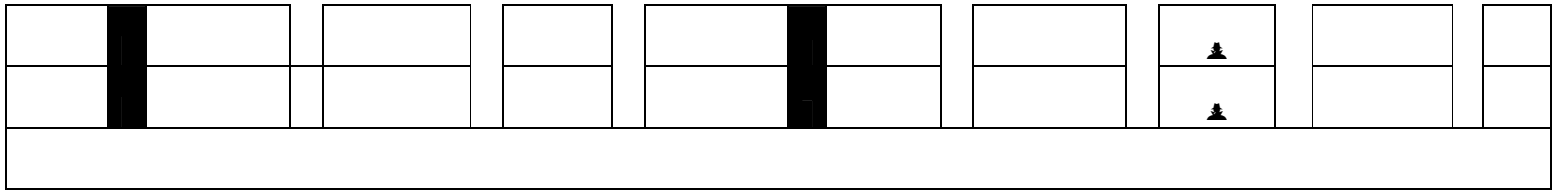
- Direct and indirect effect of HIV on neurological system
- Impact of ARVs on neurological systems
- Comments and Suggestions

2.6.1 Common conditions related to HIV epidemiology aetiology and signs and symptoms

- HIV and stroke
- Global encephalopathy
- Peripheral nerve dysfunction and peripheral neuropathy
- Progressive multifocal leucoencephalopahty
- AIDS dementia complex
- Guillian Barré Syndrome
- Spinal cord disorders
- Meningitis
- Relation to physiotherapy management
- Comments and Suggestions

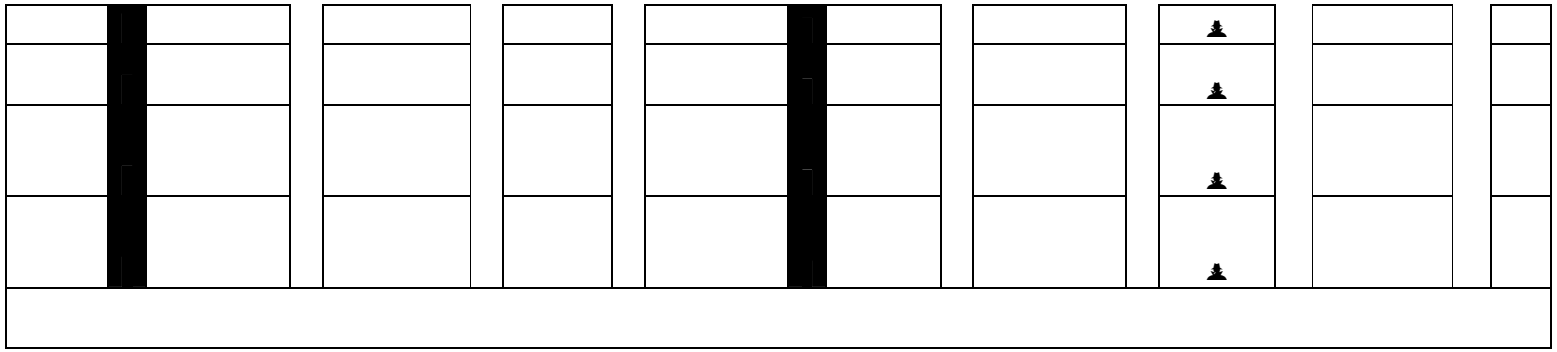
2.7 Musculoskeletal System

- Impact of HIV on fracture healing
- Direct and indirect impact on muscles
- Comments and Suggestions



2.7.1 Common conditions epidemiology aetiology and signs and symptoms

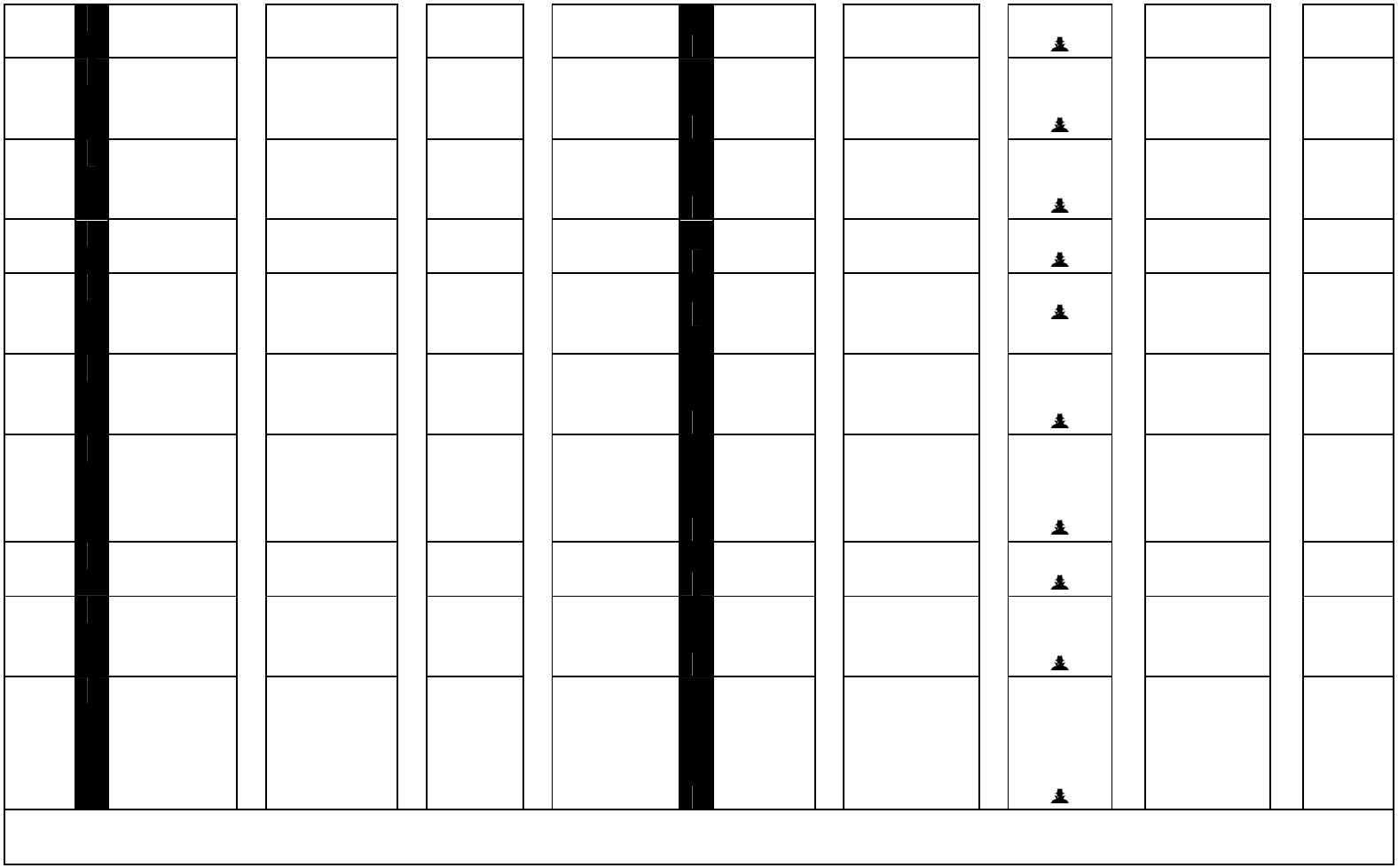
- Myopathies
- Inflammatory arthropathies
- Infectious musculoskeletal conditions
- Relation to physiotherapy management
- Comments and Suggestions



3 AN UNDERSTANDING OF THE PHYSIOTHERAPEUTIC PRINCIPLES, PHILOSOPHIES AND PROBLEM-SOLVING WITH DUE CONSIDERATION FOR THE IMPACT OF HIV/AIDS INPUTS

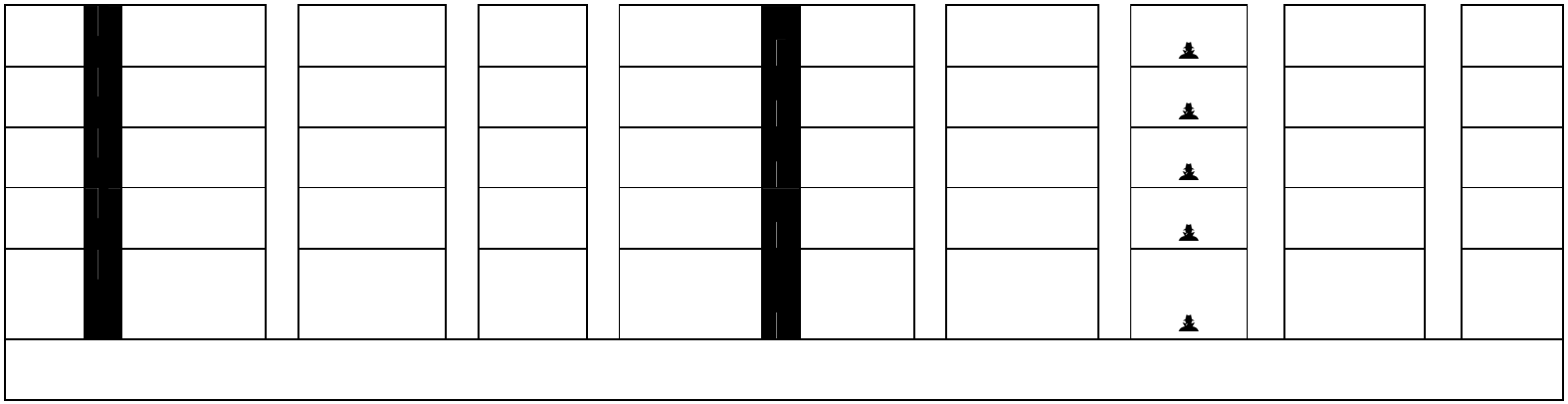
3.1 Role of the Physiotherapist

- Understanding HIV management approaches
- Rehabilitation approaches and role in HIV management
- Role of the Physiotherapist in a community setting
- Palliative role for the physiotherapist
- Rehabilitation and physiotherapy theory and relation to HIV
- ICF and HIV uses and implications for the physiotherapist
- The role of the physiotherapist in managing common impairments
- Relationship of episodic HIV to physiotherapy role
- The role of the multi-disciplinary team in HIV management
- Physiotherapy Treatment modalities evidence and current use, precautions and contra-indications in the treatment of HIV
- Comments and Suggestions



3.2 HIV and Disability

- Concepts of disability and their relation to HIV
- HIV disability and function
- CD4 levels and the relation to function
- The relationship between disability and HRQOL
- Effects impacts and evidence of exercise in HIV and disability
- Comments and Suggestions



4 THE ABILITY TO APPLY APPROPRIATE ATTITUDES AND BEHAVIOUR PATTERNS TO ENSURE QUALITY PROVISION OF PHYSIOTHERAPY MANAGEMENT AND CARE IN HIV/AIDS NEEDS AND THE ABILITY TO APPLY SOCIAL AND BEHAVIOURAL SCIENCES IN THE PHYSIOTHERAPY PROFESSION

4.1 Application Facilitators

- Counselling basic approaches to counselling
- Self assessment of attitudes
- Policies guiding HIV management
- Appropriate approach to HIV patients
- Disclosure and patients charter public health act
- Role definition and marketing physiotherapy role
- Application of Universal precautions
- Clinical decision-making in HIV
- Dealing with known threats (overcrowding, staff shortages, death, beliefs stigma)
- Comments and Suggestions

