

OCCUPATIONAL THERAPY INTERVENTION AND AIDS: DEVELOPING A
BEGINNING RESEARCH BASE AND FUNCTIONAL PERSPECTIVE

A THESIS

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BY

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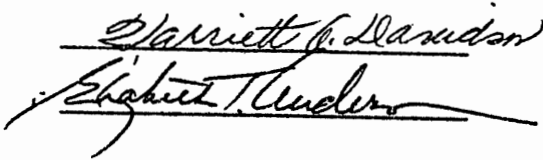
To the Dean of Graduate Studies and Research:

I am submitting herewith a thesis written by Dianna D. Puccetti entitled "Occupational Therapy Intervention and AIDS: Developing a Beginning Research Base and Functional Perspective." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Arts, with a major in Occupational Therapy.

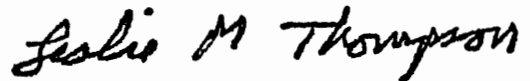


Dr. Jean Spencer,
Major Professor

We have read this thesis
and recommend its acceptance:



Accepted



Dean for Graduate Studies
and Research

DEDICATION

This study is dedicated to persons with AIDS and the challenges they face, for they are the true reason for this study.

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Activity levels of patients diagnosed as positive for human immunodeficiency virus (HIV+) or acquired immune deficiency syndrome (AIDS) were measured to develop a functional profile for occupational therapy treatment of patients with AIDS. A standardized measurement tool, the Human Activity Profile (HAP), was administered to 30 male subjects, ages 20-40. Data were analyzed using descriptive and inferential statistics. A one-tailed t-test was utilized to determine significant differences between mean scores of study subjects and of normative and impaired samples reported in the HAP Manual. Measures of association between time since diagnosis and activity level as measured by the HAP were determined through the application of the Pearson Product Moment Correlation Coefficient. Findings of the study indicated that the activity levels of patients diagnosed with HIV+/AIDS are significantly affected by the disease process. Correlation between time since diagnosis and activity level could not be supported given the small sample size.

TABLE OF CONTENTS

Dedication	iii
Acknowledgements	iv
Abstract	v
Table of Contents.	vi
List of Tables	viii
List of Figures.	ix
Chapter I. Introduction	1
Statement of the Problem.	2
Purpose of the Study.	3
Statement of the Hypotheses	3
Assumptions and Limitations	3
Operational Definition of Terms	4
Objectives of the Study	5
Chapter II. Review of the Literature	
Historical Perspective – Occupational Therapy Treatment Interventions with other epidemic populations in the past	6
Relationship of Activity Level, Energy, and Individual Functioning.	7
Conceptual Framework – Gaining a Functional Perspective for Occupational Therapy Treatment	9
Demographic Trends/Economic Impact.	10
Evolution and Demands of a Chronic Illness.	12
Chapter III. Methodology	
Research Design	16
Sample Description.	16
Instrument	17
Procedure	21
Analysis of Data	21

Chapter IV. Results

Sample Profile	23
HAP Primary Scores	
MAS/AAS	26
Activity Age	29
Fitness and Activity Classifications	30
Expected Energy Potential vs Lifestyle	
Energy Potential.	31
Dyspnea Scale.	31
Research Subscales	32
Relationship Between Time Since Diagnosis and the MAS	33

Chapter V. Discussion

Implication for Use of the HAP	35
Development of a Functional Profile	38
Challenges of a Chronic Illness	40

Chapter VI. Summary/Conclusions 43

References 46

Appendices 49

A. Research Instruments	50
. Human Activity Profile	51
. Demographic Information Profile	57
. Protocol for Completing the Human Activity Profile Demographic Information Sheet	58
. Consent Form	59
B. Human Subjects Review Forms	60
. Texas Woman's University	61
. University of Texas Medical Branch	63

LIST OF TABLES

TABLE	PAGE
1 Reported Occupations of HIV+/AIDS Sample with Category Heading for Type of Work	24
2 Reported Living Status of HIV+/AIDS Study Subjects	25
3 HIV+/AIDS Group Classification Composite	26
4 Differences in Mean MAS and AAS Scores of Normative and Impaired HAP Manual Sample and the HIV+/AIDS Study Sample	27
5 t-statistic and Level of Statistical Significance of HAP Manual Samples and the HIV+/AIDS Sample	28
6 Median MAS and AAS Scores for HAP Impaired Adult Populations and HIV+AIDS Adults	29
7 HAP Fitness Classification for HIV+/AIDS	30
8 HAP Activity Classification for HIV+/AIDS	30
9 Frequency of Response on the Dyspnea Scale by HIV+/AIDS Study Population	32
10 HAP Research Subscales-Mean Scores for Healthy Subjects Compared to HIV+/AIDS Group	33

LIST OF FIGURES

FIGURE		Page
1	Feedback Loop—Gaining a Functional Perspective for Occupational Therapy Treatment with AIDS	40
2	Intermeshing of Medical, Social, Ethical, and Economic Considerations with AIDS	41

CHAPTER I

INTRODUCTION

In an article entitled "Occupational Therapy: A Focus for Roles in Practice," Burke (1984) prophesied that occupational therapy services in the eighties would expand to "new populations of individuals who would be experiencing major and permanent changes in their health and behavior" (p. 27). Although Burke did not directly apply this statement to the treatment of patients with acquired immune deficiency syndrome (AIDS), it is certainly timely and applicable. AIDS has been referred to as the disease of the eighties and has been compared to the paralytic polio epidemic of the 1950's in terms of the rate at which it has spread. The first official reporting of the disease on June 5, 1981 in the Center for Disease Control (CDC) Morbidity and Mortality Weekly Report (MMWR) outlined initial data on five cases. Since 1983, when statistics began to mount rapidly, the topic of AIDS has been covered in virtually every type of mass media available. The general public has experienced waves of reaction in response to the AIDS information explosion including insouciance, fear, and hysteria. These waves of public reaction resulted in the Surgeon General's Report on Acquired Immune Deficiency Syndrome (1986) which was mailed to every household in the United States and represented the most significant mass educational effort ever staged in this country in relation to a single disease entity.

Statement of the Problem

The emergence of acquired immune deficiency syndrome as a major medical, social and economic problem necessitates that occupational therapists become and remain knowledgeable about the disease and its impact on the health care system. Since the realization of the epidemic in the early eighties, reporting of information in the occupational therapy literature has been primarily descriptive in nature. While this format has been important in facilitating the sharing of initial information, it is imperative that the profession move beyond this stage and into a research model. This shift will provide the data necessary for the development of a clear disease perspective and theory base for the occupational therapy treatment of patients with AIDS. If the profession is to assume a proactive stance regarding this population, it is critical that this shift begin to occur as rapidly as possible.

At no time during the recent practice of the profession of occupational therapy has there been an opportunity to gather data for validation of the importance of occupational therapy treatment and potential functional outcomes from the early stages of the identification and evolution of a disease entity. Predictions for the 1990's project a continued increased in the number of new AIDS cases. Although there is no cure for the disease, medical advances and treatment options are expanding in the care of these patients. As a result, patients with AIDS are experiencing increased longevity and a need for a variety of health care services. Occupational therapy intervention can promote maximum functional independence at each stage of the disease and can

assist in maintaining the patient's quality of life. In the past, occupational therapy has provided rehabilitation services for chronic health problems such as tuberculosis, polio, multiple sclerosis, and the aging, and similar opportunities exist for service to the AIDS population.

Purpose of the Study

The purposes of this study were 1) to apply the use of a standardized evaluation tool to gather information concerning the activity levels of patients diagnosed as positive for Human Immunodeficiency Virus (HIV+) or AIDS, and 2) to develop a functional profile as a beginning theory base for the occupational therapy treatment of AIDS patients.

Statement of the Hypotheses

1. There will be no significant difference in the activity levels of patients diagnosed HIV+ or AIDS as compared to the activity levels reported on the normative sample described in the Human Activity Profile Manual.
2. There will be no significant relationship between the length of time from diagnosis and the patient's activity level as measured on the Human Activity Profile (HAP).

Assumptions and Limitations

Assumptions

1. The number of patients with HIV+ and AIDS will continue to increase throughout the next decade.
2. With medical intervention, patients diagnosed HIV+ or AIDS will continue to live longer.

3. Activity level is a reflection of overall health and reflects quality of life.
4. The majority of patients contracting the disease will remain within the age frame of the "prime wage earning" years and there will be increased emphasis on addressing the issue of work and grading activity levels up and/or down in response to the disease.

Limitations

1. This study will look at the population within a given time span and does not purport to measure longitudinal effects.
2. This study will not include a representative sample of female subjects or pediatric age groups.
3. This study is specific to a university affiliated tertiary medical care center in the Southwestern portion of the United States which serves patients from urban, small town, and rural areas within a 300-400 mile radius.

Operational Definition of Terms

It is important to identify and define certain terms to provide a clear and consistent understanding of their meaning for the purpose of this study. Terms and operational definitions include:

HIV+--the state of having been diagnosed antibody positive for Human Immunodeficiency Virus as measured by diagnostic criteria for medical classification outlined by the Center for Disease Control. HIV+ includes patients in Groups I, II, and III of that system (CDC, 1986).

AIDS--the state of having acquired full blown symptoms of the disease as measured by the Center for Disease Control medical

classification system. Individuals within this group may have the following subgroup classifications: Constitutional Disease, Neurologic Disease, Secondary Infectious Diseases, Secondary Cancers, or other conditions as defined in Group IV of that classification system (CDC, 1986).

Activity level--the degree or amount of activity that an individual performs during his/her daily routine as measured by the Maximum Activity Score (MAS) and the Adjusted Activity Score (AAS) of the Human Activity Profile. The reported activities included in the test instrument were based on metabolic units of energy or the MET level system.

Objectives of the Study

A standardized measurement tool was used to address the following objectives: 1) to compare information obtained from the research sample with the normative population described in the HAP Test Manual; 2) to identify similarities among patients in relation to activity levels and activities of daily living with HIV+ and AIDS patients; 3) to provide a uniform way of reporting the activity levels of HIV+ and AIDS patients; and, 4) to develop a functional profile as a beginning theory base for occupational therapy treatment of patients who are diagnosed HIV+ or AIDS.

CHAPTER II

REVIEW OF THE LITERATURE

Historical Perspective

The occupational therapy literature is rich with descriptive information of patients treated during the past epidemics of this century including tuberculosis and polio. Review of this literature has direct application to the present when planning treatment for the patient diagnosed HIV+ or AIDS. In the second edition of Willard and Spackman's Occupational Therapy (1947), an entire chapter is devoted to the subject of "Occupational Therapy for the Tuberculous." This description, authored by Hudson (1947), outlines the role of occupational therapy and approach to the patient as well as describing the relationship of occupational therapy to other disciplines. Despite outdated terminology, the concept of graded activity and the importance of utilizing educational material during treatment are strongly stated.

Papers published from the Third Internal Poliomyelitis Conference (1955) stressed the need for enhancement of performance skills in relation to the functional skills of daily living. Evaluation and activity designed to maximize the patient's abilities given the limitations of his disease were emphasized.

In dealing with both tuberculosis and polio, therapists sought to grade activity in relation to energy expenditure according to the patient's status. In addressing the needs of persons with AIDS it is being shown that activities must be graded up and down as the energy

available for activities changes in relation to the patient's acute exacerbations and remissions.

During the 1950's, research in the area of cardiac rehabilitation produced knowledge of energy requirements for many activities of daily living. These requirements were stated in terms of cardiac output or metabolic equivalents of MET levels. In describing an occupational therapy cardiac rehabilitation program, Bird and Phelps (1986) described treatment regimes designed to be conducted in phases over an extended period of time. The prescribed program included both restoration and maintenance components (graded activity and education) and attempted to match each person's regime to his own habit structure and life style. Ogden (1979, 1981, 1985) has developed treatment programs to emphasize physical restoration and has placed major emphasis on patient education through development of her texts on cardiac rehabilitation programming and treatment of chronic obstructive pulmonary disease.

Relationship of Activity Level, Energy Level, and Individual Functioning

The relationship of activity level, and individual functioning is addressed from many perspectives in the literature, but preliminary data in dealing with the AIDS population show that patients who remain in the work force, or who remain active at home or in the community, experience a higher level of functioning, a more consistent energy level, and a positive attitude (Brandt, 1989). According to Parent (1986), occupational therapists historically have planned treatment programs requiring activity involving different and diverse amounts of energy use by patients. Balancing the concepts of activity, energy level and

individual needs is basic to designing occupational therapy interventions for AIDS patients. In achieving this balance, consideration must be given to the physical energy needed for activity, but attention must also focus on psychosocial factors such as anxiety and depression that can limit energy. Patients diagnosed with HIV or AIDS experience a difficult period of psychological adjustment in relation to their diagnosis and its implications. Schindler (1988) discusses the psychological impact of AIDS and discusses psychosocial intervention with this patient population.

Davis-Dosaka, Draml, Miyake, and Rochford (1986) stress purposeful activity to engage the low energy patient and discuss in their work the importance of four dimensions: imparting purpose, role of choice, meeting expectations, and interaction with peers. Patients with AIDS can show difficulty across all four of these dimensions and may be viewed as immobilized. Rosenbusch (1986) describes the use of psychic energy as an activator of the low energy patient, and presents several specific methods for mobilization of the patient's psyche. The activities that Rosenbusch suggests in her article are not new or novel to occupational therapy treatment, and she views them as useful tools for occupational therapists involved in the treatment of patients with difficult symptoms or a poor prognosis.

Occupational therapy interventions should allow patients to collaborate in establishing treatment priorities, address conditions that interfere with functioning, promote maximum functional independence and improve the quality of life. If these conditions are addressed in

treatment then a balance of activity, energy, and functioning will occur.

Conceptual Framework-Gaining a Functional Perspective for Occupational Therapy Treatment

Treatment of impaired individuals with varying degrees of disability across the entire age continuum is not new to occupational therapy. Treatment is performed in diverse and varied settings and covers the primary areas of pediatrics, adult physical health, psychiatry, and geriatrics. While the occupational therapist would rarely encounter some of the diseases associated with AIDS, the actual functional deficits such as decreased strength and endurance, loss of sensory and motor control due to neuropathy, etc., that result from the disorders are not unfamiliar (Bonck, 1978; Denton, 1987). The occupational therapist involved in the treatment of patients with AIDS needs to possess the following attributes: a broad knowledge base of occupational therapy theory and treatment, knowledge about AIDS which is kept current, a strong sense of personal identity and comfort with their own sexuality, and knowledge and a high comfort level in dealing with the issue of death and dying. The therapist should also be able to extrapolate from the past by building on proven treatment practices with other chronically ill populations, possess a "pioneering" spirit, and feel comfortable in implementation of treatment in new situations (Puccetti, 1989).

Standard assessments, evaluations and basic treatment principles apply and provide the information necessary for intervention and

remediation. Because the AIDS epidemic is in its early stages many descriptive articles and protocols have been produced to guide occupational therapy treatment (UTMB, 1987; Gordon, 1987), and to describe legal, professional and ethical responsibilities of the occupational therapist (Steich, 1987) in the treatment of this population.

Denton (1987) outlined suggested treatment phases and intervention strategies which divided occupational therapy treatment into three phases dealing with Pre-AIDS, Early to Mid-Stage Disease, and End-Stage Disease. His intervention model stresses education and health promotion during the initial phase; aggressive intervention to maintain function during the mid-phase; and finally, outlines offering choices and planning for maintenance of function and interests during the final phase. Denton's strategies are based on functional occupational therapy interventions and are useful and practical when planning and providing treatment.

Endorsement is made in the occupational therapy literature (Pizzi, 1988; Schindler, 1988) for support of Kielhoffner and Burke's Model of Human Occupation when evaluating and treatment persons with AIDS. While this framework has been cited most frequently, this author feels it is of importance to gain a more general functional perspective for occupational therapy treatment with HIV+/AIDS individuals before a model is adopted.

Demographic Trends/Economic Impact

As of July 1989, 100,000 cases of AIDS had been diagnosed in the United States. Predictions for the 1990's project a continued increase in the

number of cases. Conservative estimates expect the number of new AIDS cases in the United States to double every 12-15 months for the next five years. This will mean approximately 270,000 cases and 180,000 deaths by 1991 and by the year 2008, one million cases of AIDS are projected.

Rogers (1989) states that the economic impact of AIDS creates a challenge to health care institutions in the present climate of cost containment. She further stresses that how society responds to the AIDS epidemic will influence the future of health care for all Americans. A report published by the Institute of Medicine (cited in Pizzi, 1988) emphasized a continued increase in the numbers of persons with AIDS. Highlights from the report further emphasized a ten-fold increase in pediatric AIDS cases by the end of 1991, documented that experimental drugs have proven beneficial in prolonging life, and reported that 98% of the known cases of HIV+/AIDS are individuals between 20-60 in their worker years.

In view of this combination of factors, the issue of work and gainful employment must be addressed in order to assure that individuals are able to remain productive in the work force and in their individual lives for as long as possible. Parent (1986) speaks to the value system of work and independence that is prevalent in the United States. She states that this value system may make it difficult for those with chronic debilitating diseases to give up their independence in performing work or daily activities.

An article by Redwine (1990) spoke to the economic impact of AIDS in Texas. The data in the report were taken from the Legislative Task Force on AIDS, Report to the Seventy-First Legislature, "AIDS in Texas: Facing Crisis." The report offers the following statistics: inpatient and outpatient AIDS will cost Texans at least \$380 million in 1992. That figure is eight times the cost in 1987. When calculating the cost from the loss of future earnings, the cost of AIDS is even more staggering. The value of earnings lost in Texas due to AIDS was estimated to be at least \$930 million in 1988, and that figure is projected to reach \$3.1 billion by 1992. These statistics are sobering particularly when one considers that they represent the reported costs and projected losses for only one state. The figures certainly speak to the need for cost-effective intervention and rapid changes in the health care system.

Evolution and Demands of a Chronic Illness

AIDS is evolving into a chronic disease and it is imperative that this fact be addressed within the health care system. Strauss and Glaser in Chronic Illness and the Quality of Life (1975), developed a framework which outlines seven primary social and psychological problems faced by persons with chronic health problems. Their approach to these problems includes: 1) prevention of medical crises and their management once they occur, 2) control of symptoms, 3) carrying out of prescribed regimens, 4) prevention of, or living with, social isolation caused by lessened contact with others, 5) adjustment to changes in the course of the disease, whether it moves downward or has remissions, 6) attempts at

normalizing both interaction with others and lifestyle, and 7) search for necessary money or finding to pay for treatments or to survive despite partial or complete loss of employment.

According to Anderson (1981), the goal of the chronically ill person is not just to stay alive or keep symptoms under control, but to live as normally as possible despite symptoms and the disease. Attainment of this goal is dependent on comprehensive strategies which include the individual, the caregiver or family, and health care providers. Inherent in attainment of this goal is a service delivery mechanism that allows for this type of strategy to be realistic.

Health care delivery in the United States is primarily a sickness-crisis intervention model. Although the 1970's and 1980's brought awareness and emphasis on health promotion, the health care system continues to deliver service primarily within the sickness intervention model. With the epidemic nature of AIDS and the emerging chronicity of the disease, inadequacies and gaps become readily apparent. One model that points to the inadequacies of our present system was developed by The Nursing Practice Branch of the Division of Nursing and was presented in 1979. Anderson and Bauwens (1981) outline this model in their text Chronic Health Problems: Concepts and Applications. The model delineates the three levels of health care: primary, secondary, and tertiary. Anderson and Bauwens make the following distinctions when defining these levels of care. Primary care is oriented toward promotion and maintenance of health, prevention, early intervention, and chronic latent illness with service delivery in the home or outpatient

setting. Secondary care is oriented toward diagnosis and treatment and includes emergency care and acute care in any health care setting; and tertiary care is directed toward long-term care, rehabilitation, and care of the dying.

In applying this model to the AIDS epidemic it is possible to begin to gain an appreciation of the service delivery inadequacies that are a reality to individuals attempting to gain needed services and to health care providers as they attempt to meet the varied needs of this population within the present system. Those working in the health care system understand the chronic nature of AIDS (Brandt, 1989). Newsweek (1986) in a feature article entitled "Future Shock" provides yet another example from the public press in a discussion of the challenges facing the health care system in its present delivery model.

Although some shifts have taken place, the majority of health care providers fall within the familiar medical model of providing secondary care. While some health care curricula emphasize health promotion and prevention, the majority continue to emphasize treatment of symptoms and disease. Breslow (1989) encourages health status measurement in health promotion. This is of particular importance as we deal with increasing chronic illness within the general population and in particular the AIDS epidemic.

In the forward of AIDS: Facts and Issues (1986) Congressman Ted Weiss, 17th District, New York, U. S. House of Representatives makes the point that the burden of providing care has been left entirely to state and local governments and community organizations. The catastrophic

costs and problems with our health care delivery system are not limited to AIDS, but the AIDS epidemic has facilitated and identified major problems with effective service delivery. Weiss fails to mention the burden of providing daily care and of the frustration in seeking needed medical intervention that has fallen on families, lovers, and friends of those affected by the disease.

Works by Peabody (1986) and Monette (1988) reflect this struggle in a poignant way. Deficits and gaps in the health care system have brought about reactive responses of seeking alternatives and available options. Organizations such as the San Francisco AIDS Foundation, and the Shanti Project led the way in early service provision. O'Connor (1987), Delancy and Goldblum (1987), Eidson (1988) and many others have utilized their literary efforts to publish self-help books, manuals and leaflets that emphasize health promotion strategies for patients and caregivers.

It will be important as patients live longer and healthier lives with medical treatment that the issue of functional activity and graded work tasks be addressed so that an individual may remain active. Because occupational therapists are trained to grade and adapt activities this provides a unique opportunity for the profession to contribute to a model of promoting and maintaining health and quality of life.

CHAPTER III

METHODOLOGY

Research Design

The study utilized a survey research design. Patients diagnosed as HIV+ or AIDS were given a standardized self-report questionnaire concerning their daily activities to complete. The utilization of survey design offered an efficient way of gathering data, and the standardized questionnaire provided a basis for comparison and categorization of data. Representativeness is crucial in survey designs and sampling procedures were performed in a systematic manner to assure that a representative sample was obtained.

Sample Description

The research sample was drawn from patients scheduled for medical appointments in the Infectious Disease Clinic at the University of Texas Medical Branch at Galveston. Subjects were selected systematically from the population served and were identified by utilizing the clinic census sheet and including every other client as a potential subject. This method of systematic selection was performed to assure a mix of newly diagnosed patients as well as those who had been followed in clinic for varying lengths of time. Those patients who did not fit the sample description or who had participated on previous days were excluded. The research pool was limited to male subjects, ages 20-40, with a diagnosis of HIV+ or AIDS. The sample size for this study was limited to the first 30 subjects selected by this method who agreed to participate.

Instrument

The Human Activity Profile (Fix and Daughton, 1988) was reviewed and selected as the data collection instrument for this study. The Human Activity Profile is a standardized instrument that was originally developed to measure quality of life achieved by patients in rehabilitation programs for chronic obstructive pulmonary disease. Since the initial research, the instrument has been used as a measure of activity level with a variety of both healthy and impaired populations. the HAP was designed to focus on common human activity that covers a broad range of energy requirements. Fix and Daughton organized the HAP Manual into sections so that information regarding scoring and interpretation, development and validation, and research subscales could be easily retrieved and examined by the reviewer.

The HAP allows the researcher to quickly survey the range of activity in which an individual participates. Each item represents a common activity requiring a known amount of average energy expenditure based on metabolic equivalents or MET levels. Items with the lowest numerical order have the lowest MET requirements; as item numbers increase so do MET requirements. Test items cover a range of ten METS. Each item is scored as one of three possible responses: "Still Doing This Activity," "Have Stopped Doing This Activity," or "Never Did This Activity."

The normative sample for the HAP consisted of 477 individuals without significant medical problems. The sample ranged in age from 20-79 and consisted of 314 (65.8%) females and 163 (34.2%) males. The

sample was obtained primarily from an urban population in the Midwest. The majority of the sample was employed.

Additional research samples were also chosen to represent specific characteristics including age and physical health. These samples included extremes on each end of the continuum, for instance, to span the variable of age, both healthy elderly adults and adolescents were included. To comprise the sample for physical impairment chronic lung disease patients, renal dialysis patients, and patients suffering from chronic pain were included. The sample for persons suffering a critical health event that does not lead to permanent overall activity impairment included myocardial infarct patients in a rehabilitation program, and healthy adults collected from several groups. The healthy sample of adults included individuals attending a health fair, students at two local colleges, and individuals representing occupations with widely differing skills such as city sewer workers, nurses, physician assistant students, and teachers. The combined sample size of healthy individuals was 654 and combined impaired samples 162 with the normative sample at 477 as reported previously.

The HAP produces scores on several different levels. Primary scores include the Maximum Activity Score (MAS) which is the highest oxygen-demanding activity that the respondent still performs, the Adjusted Activity Score (AAS) which is a measure of usual daily activities, and the Activity Age which is the age at which 50% of healthy adults of a given age and sex surpass a given MAS. Other scores and classifications that can be determined from the instrument include

Fitness Classification, and Activity Classification, Energy Analysis including Expected Energy Potential (EEP) and Lifestyle Energy Consumption (LEC).

A separate scale that is included as an optional feature is a Dyspnea Scale (DS). In addition, several research subscales are also included. Under the title Activity Subscales are a Self-Care Subscale, a Personal/Household Work Subscale, an Entertainment/Social Subscale, and an Independent Exercise Subscale. Yet another grouping of subscales is included under the title of Muscle Group Subscales and is divided under the headings of Hand Use, Leg Effort, Back Effort, and Wheelchair Effectiveness.

Text-retest reliability was established in a study of 29 subjects who participated in a smoking cessation program. Reliability coefficients for MAS and AAS were reported as .84 and .79. These numbers represent acceptable levels when utilizing the test-retest method.

Substantiation of both content and face validity is also presented within the text and Tables 17-19 are utilized to present test validity with several different samples. Included are representations of healthy and impaired populations as well as data for gender and age.

A separate section was utilized to describe the development of the Dyspnea Scale. The development was based on the same physiologic functions and the HAP. Test-retest reliability with a group of 35 individuals was found to be high with the correlation for the one-year interval reported as .80. Validity was established in a study conducted at three separate worksites with a total sample size of 472. The

Dyspnea Scale was found to correlate significantly with the MAS ($r=.46$) and AAS ($r=-.48$). It also showed equal-order correlations with age.

The many different scores, classifications, and subscales which are possible with the HAP give it versatility and a great deal of application within the clinical setting. Both the general HAP and the Dyspnea Scale are valuable in addressing activity levels and quality of life with the AIDS population. Another feature of the instrument is the Activity Subscale which addresses information that is of primary interest to occupational therapists in their practice and relate to the profession's hallmarks of self-care, work and play/leisure. These include the Self-Care subscale which demonstrates the basic skills necessary to live independently, the Personal/Household Work subscale which represents work skills, and the Entertainment/Social subscale which addresses activities that are performed for pleasure. This set of subscales can provide standardized information to address the issues of independent living, to document the level of caregiver assistance needed by a particular individual, and to demonstrate tendencies toward social isolation and withdrawal from pleasurable activities.

While the normative sample for the HAP is relatively small, the instrument is a standardized tool that is valid and reliable with both healthy and impaired samples. This characteristic is valuable in assessing the entire spectrum of HIV+ and AIDS patients who may present as healthy individuals with no apparent symptomology or physical limitations or as impaired individuals with severe disabilities and limitations. The Dyspnea Scale also presents an attractive feature with this

population. This can be attributed to the fact that Pneumocystis carinii pneumonia is one of the primary complicating factors in this disease. When applying this instrument to the AIDS population, it is projected that there would be significantly more males than females included in the research sample. For the purpose of this study the sample included only male subjects.

Procedure

Subjects were selected systematically from the clinic census sheet as described previously. Once identified as a potential subject, the client was asked to participate in the study. The research was described and an informed consent form was signed. The client was asked to complete the Demographic Information Profile according to the protocol established for this study. The self-report questionnaire was then administered according to the instructions printed in the test manual and booklet. All questionnaires were administered by this therapist or one additional research assistant who was trained and closely supervised by this therapist. All completed Demographic Information Profile sheets and HAP questionnaires were numbered and filed separately as stated in the research protocol to assure confidentiality.

Analysis of Data

The SPSS/PC+ computer package was utilized for analysis of data. The SPSS/PC+ Information Analysis System is a comprehensive tool for managing, analyzing, and displaying information. It offers a great deal of

versatility in reporting and correlating information. Analysis of data compared the respective results from the MAS and the AAS to the normative sample. Comparisons were also performed for mean scores on all reported subscales as compared to healthy samples. A one-tailed t-test was utilized to determine significant differences between subjects and the normative sample. The level of significance was determined at the .05 level. Measures of association between time since diagnosis and activity level as measured by the HAP were determined through the application of the Pearson Product Moment Correlation Coefficient. It is intended that this study will provide a beginning data base for future studies that can serve to expand our knowledge of activity levels of patients with AIDS.

CHAPTER IV

RESULTS

Results of this study were compiled from data collected on a sample of 30 male subjects contacted in the identified Infectious Disease clinics scheduled between February 1, 1990 and February 22, 1990. All procedures and protocols were followed as previously described.

Sample Profile

Responses on the Demographic Information Profile (DIP) provided data for development of the sample profile. Age range for inclusion in the study was 20-40 years with the mean age of the subjects being 31.8 years.

Twenty-one subjects, or 70% were Caucasian, 6 or 20% were Black, and 3 or 10% were Mexican American. Date of diagnosis covered a wide time period with dates being recorded from January 31, 1983 to February 12, 1990.

Reported occupations varied with 7 individuals describing physical labor intensive jobs and 13 individuals reporting service-delivery oriented positions. A complete breakdown of occupational responses is shown in Table 1.

TABLE 1

Reported Occupations of HIV+/AIDS Sample with Category Headings for Type of Work

<u>Physical Labor</u>		<u>Service Delivery</u>		<u>Professional</u>		<u>Disabled/unemployed</u>
Boiler maker	(1)	Bartender	(1)	Draftsman	(1)	(6)
Cable splicer	(1)	Cook	(3)	Glass Artist	(1)	
Iron worker	(1)	Dancer/	(1)	Computer	(1)	
		entertainer		programmer		
Machinist	(1)	Hairdresser	(1)	Student	(1)	
Maintenance	(1)	Kennel Mgr	(1)			
Seaman	(1)	Plant	(1)			
		service				
Stocker	(1)	Restaurant	(1)			
		Valet	(1)			
<u>TOTALS</u>		7	13	4	6	(n=30)

Educational level of the subjects showed the following: 3.3% had less than an eighth grade education, 46.7% had completed high school, 36.7% had some formal education beyond high school, and 13.3% had advanced skills training, certification or advanced degree.

In response to date last worked, eleven subjects reported that they remain in the work force either full or part-time. The remaining 19 subjects reported date of last employment ranging from January 31, 1983 to November 20, 1989. Seventeen subjects, or 56%, reported they were receiving disability compensation.

Thirty-six percent of the subjects reported they were still living independently; 43.3% reported that they had an identified caregiver, with 30.8% of this number describing their caregiver as full-time and 69.2% reporting them as part-time. Ten subjects reported a "double no" response to checklist combinations of not living independently with no identified caregiver. This suggests that one third of the subjects were

involved in living situations from which they felt little actual support or assistance. This type of living arrangement is not satisfactory for a person requiring physical assistance and may result in the person with AIDS being abandoned once they become physically dependent. Table 2 shows the reported living status of the study subjects.

Table 2

Reported Living Status of HIV+/AIDS Study Subjects (n=30)

Living Independently		Caregiver		Caregiver	
yes	no	yes	no	Full-time	Part-time
11	19	13	17	4	9

All 30 subjects reported receiving medication as part of their treatment regime. Twenty-one of the subjects or 70%, reported being on Azidothymidine (AZT). Other reported medications included inhalant pentamidine, beta interferon, and cytovene (DHPG) as well as numerous other antidepressants, antibiotics, sleeping medications, muscle relaxants, and aspirin or acetaminophen.

Assignment of the subjects into classification groups was determined from the medical record and was based on the Center for Disease Control's medical classification system. Table 3 shows the group classification composite for the subjects in the study. It is important to emphasize that even though approximately three-fourths of the sample are diagnosed as full blown AIDS with one or more complicating factors of the illness, the majority of the sample remain functional in basic

self-care activities with only four subjects requiring a full-time caregiver.

TABLE 3

HIV+/AIDS Group Classification Composite (n=30)

<u>CDC Classification</u>	<u>Frequency</u>	<u>Percent of Sample</u>
Group II (Asymptomatic infection)	1	3.3
Group III (Generalized lymphadenopathy)	7	23.3
Group IV (AIDS/ARC)	22	73.3

HAP Primary Scores

MAS/AAS

The Human Activity Profile produces scores that yield a variety of information. Primary scores include the MAS, the AAS, and the Activity Age. The information from the MAS and the AAS reflect calculated estimates on the respondent's highest level of energy expenditure and average of energy expenditure in comparison with peers of the same age and gender. The Activity Age provides an age equivalent for the respondent's activity level. Scores on the MAS for 30 test subjects ranged from 26 to 94 with a mean score of 71.4 and a standard deviation of 16.9. Scores on the AAS ranged from 3 to 94 with a mean score of 59.4 and a standard deviation of 25.5. A one-tailed t-test was utilized to determine whether there was a significant difference between both the normative sample and the impaired sample reported in the HAP Manual and the HIV+/AIDS study sample.

Since raw data were not available on the normative and impaired samples reported in the HAP Manual, a standard formula for calculating the t statistic using the mean, standard deviation, and sample size was applied. The t statistic was then calculated for the HAP sample and was then compared to the t statistic of the raw data from the study sample. Table 4 displays information showing differences in the three samples.

TABLE 4

Differences in Mean MAS and AAS Scores of Normative and Impaired HAP Manual Sample and the HIV+/AIDS Study Sample

Sample	MAS			AAS		
	m	sd	n	m	sd	n
HAP Normative	85.3	7.0	477	83.2	7.8	477
HAP Impaired	61.8	14.8	162	50.7	17.6	162
HIV+/AIDS Study Sample	71.4	16.9	30	59.5	25.5	30

Table 5 is included to display the t statistic and the level of significance calculated for the identified samples in the HAP Manual and the study sample. Raw data were not reported on the normative and impaired samples in the HAP Manual, thus, it was not possible to calculate the F values or level of significance utilizing an ANOVA. This procedure requires calculations utilizing the sum of squares (SS) and the mean of squares (MS) along with degrees of freedom (df) (Huck, Cormier, and Bounds, 1974). Since this information was not available, data were analyzed utilizing the t -test to compare each sample reported in the manual to the study sample.

TABLE 5

t-statistic and Level of Statistical Significance of HAP Manual Samples and HIV+/AIDS Sample

Group Comparison	MAS		AAS	
	t	p	t	p
HAP Normative vs study sample	4.412	p<.01*	6.84	p<.01*
HAP Impaired vs study sample	2.866	p<.01*	1.76	p<.10

*p= <.01

Based on the values reported in Table 5 it is possible to reject the null hypothesis for Hypothesis 1. A significant difference was found when comparing the MAS and AAS reported in the HAP Manual for the normative population to the HIV+/AIDS study sample. It was originally reported in the analysis of data section that the level of significance was to be determined at the .05 level on the normative HAP sample, however, on all calculations the level of significance was found to be at the .01 level. Level of significance between the HAP Impaired sample the the HIV+/AIDS study was also determined. A statistically significant difference was found on the comparison of the MAS, however, comparison of the AAS of the impaired sample to the AAS of the study sample (p .10) was not significant. This indicates that the samples were similar in terms of reduced activity. Table 6 presents additional information when comparing a breakdown of the HAP Impaired sample and the study sample. In comparing this data, some interesting comparisons can be made. Sample size corresponds most closely with the COPD and Renal populations that are reported. Age ranges on all the reported impaired

samples far exceed the age range for the study group. The median MAS and AAS scores of the HIV+/AIDS sample most closely compare with the chronic pain group. This is significant in that many persons with AIDS experience pain from a variety of sources including muscle and joint pain, pain from medications and treatment regimes, other physical pain related to neurological disorders, and psychological or emotional pain in relation to their illness.

TABLE 6

Median MAS and AAS Scores for HAP Impaired Adult Populations and HIV+/AIDS Adults

<u>HAP Subjects</u>	<u>n</u>	<u>age range</u>	<u>MAS</u>	<u>AAS</u>
Pain	83	16-65	63.3	51.6
COPD	30	37-77	58.8	48.7
CARD	10	45-71	83.7	75.7
Renal	39	22-83	55.2	43.6
HIV+/AIDS	30	20-40	71.4	59.4

Activity Age

The third primary score on the HAP is the Activity Age which provides an age equivalent for the respondent's activity level. The mean activity age for the HIV+/AIDS population was 56.28 years which represents a large difference from the actual mean age of the sample which was 31.8 years. In calculating the mean scores which were beyond the values reported on the Activity Age Chart, the last value given was used and was reported 70 years.

FITNESS AND ACTIVITY CLASSIFICATIONS

The Adjusted Activity Score translates into both a Fitness Classification and an Activity Classification which provides a general comparison of fitness and activity levels with peers of the same age and gender. Tables 7 and 8 describe the HIV+/AIDS population rankings on these classification scales.

TABLE 7

HAP Fitness Classification for HIV+/AIDS (n=30)

<u>Classification</u>	<u>Frequency</u>	<u>Percentage</u>
Low	13	43.3
Fair	9	30.0
Average or above	8	26.7

TABLE 8

HAP Activity Classification for HIV+/AIDS (n=30)

<u>Classification</u>	<u>Frequency</u>	<u>Percentage</u>
Impaired	10	33.3
Moderately active	12	40.0
Active	8	26.7

It is interesting to note that although 43.3% of the study sample are classified as low on the fitness classification scale, 40.0% remain moderately active in terms of activity classification. This may in part be due to the need to continue to function within their daily routine without the assistance and may be indicative of items on the HAP that are generally performed as part of living independently.

Expected Energy Potential vs Lifestyle Energy Potential

HAP scoring produces energy analysis measures on two different levels, the Expected Energy Potential (EEP) and the Lifestyle Energy Potential (LEP). When comparing the values for the EEP and the LEP to scores of the study group 27 of 30 subjects, or 90% had Lifestyle Energy Potentials lower than the expected potential. This is a significant percentage when considering energy available for functional daily activities of the respondents and speaks clearly to the fatigue and lethargy experienced by persons with AIDS.

Dyspnea Scale

An additional scale reported on the HAP is the Dyspnea Scale (DS) which provides a measure of problems with shortness of breath. Eight activities were listed for ranking by the respondent. Items were given a 0-3 ranking with 0=No, 1=Yes, a little, 2=Yes, clearly noticeable, 3=Yes, severe shortness of breath. The frequency of responses to each item on the DS was calculated. Percentages are reported in Table 9 and show the frequency of response to each item by the study population. No means for other populations were reported in the HAP Manual, so no comparison can be made between the normative and the study samples. A Dyspnea Score Percentile Chart is provided and gives percentile scores by age and gender. Many of the scores generated by the study were below the reported percentile levels recorded in the manual.

TABLE 9

Frequency of Response on the Dyspnea Scale by HIV+/AIDS Study Population

	Item Value	1	2	3	4	5	6	7	8
0	23.2	50.0	36.7	20.0	26.7	20.0	16.7	23.3	
1	50.0	33.3	36.7	43.3	43.3	33.3	26.7	43.3	
2	10.0	6.7	10.0	20.0	16.7	23.3	20.0	13.3	
3	13.3	10.0	13.3	13.3	13.3	20.0	33.3	16.7	
missing case		1	0	1	1	0	1	1	1
(n=30)	some items are reported on 29 responses as one subject did not answer all questions								

Research Subscales

The Human Activity Profile was developed to provide a general classification of energy expenditure rather than to document numerous specific activities. The HAP has generated eight research subscales which fall under either an activity subscale classification or muscle group classification subscale. These subscales report the types of activities the respondent practices and a description of the muscle groups used to perform the activities. Table 10 compares the reported mean for the HAP health sample as compared to the mean for the HIV+/AIDS sample.

TABLE 10

HAP Research Subscales-Mean Scores for Health Subjects Compared to HIV+/AIDS Group (n=30)

Subscale	HAP Mean	HIV+/AIDS Study Mean
Activity subscale		
Self-care	7.8	7.03
Personal/household work	24.1	17.6
Entertainment/social	13.6	9.5
Independent exercise	22.2	9.8
Muscle group subscales		
Hand use	27.0	20.56
Leg effort	41.9	25.33
Back effort	11.7	7.6
Wheelchair effectiveness	26.2	18.8

The study sample produced scores which were lower than the reported healthy sample on all eight activities. This is an important fact when addressing the treatment needs of the study population. Scales showing the greatest amount of difference in descending order were leg effort, independent exercise, wheelchair effectiveness and personal/household work. These were followed by hand use, entertainment/social, and back effort with self-care showing the least amount of difference between means.

Relationship Between Time Since Diagnosis and the MAS

The relationship between length of time from diagnosis and the patient's activity level as measured by the MAS of the HAP was investigated using the Pearson Product Moment Correlation to determine acceptance or rejection of Hypothesis 2. When calculated, the relationship showed a correlation of $r=-.0083$ which does not satisfy the level of significance necessary to accept or reject the null hypothesis. Scores on both axes

were spread over a wide range with MAS values ranging from 3 to 94, and the number of months since diagnosis ranging from 1 to 96. In a small sample of 30 subjects, these data present a scattered display. A larger sample size needs to be generated in the future to determine if a significant relationship exists between time since diagnosis and the subject's score on the MAS.

CHAPTER V

DISCUSSION

The results of this study indicate that the activity levels of individuals diagnosed with HIV+/AIDS are significantly affected by the disease process. This statement is supported from analysis of data obtained from the HAP self-report questionnaires that were completed by each of the 30 subjects in the study.

Implications for Use of the HAP

The HAP generates a great deal of information once it has been scored and analyzed. Interpretation can be useful in documenting an activity level that is based on functional activity and in identifying specific deficits in relation to daily activity. The HAP is easy to administer and took an average of 15 minutes for each subject to complete. Scoring follows specific guidelines, problems with inter- and intra-rater reliability are not an issue. These factors coupled with the fact that the HAP is an available, standardized tool makes its use attractive as part of the assessment process.

In future studies it will be important to utilize an additional instrument that is sensitive to functional changes over time. To meet this criteria, the instrument selected should address areas included in occupational therapy evaluation and treatment sessions. This will allow the impact of occupational therapy services to be measured.

Another attractive feature is the fact that the HAP is based on MET levels to categorize activity , and this leveling is familiar and

acceptable to occupational therapists. Information from the HAP can be utilized in conjunction with other occupational therapy evaluations that are more sensitive to change over time to present a consistently reported activity level, and to prioritize treatment interventions. The Research Subscales with their breakdown into activity subscales and muscle group subscales are particularly relevant to occupational therapy treatment.

The activity subscales indicate how individuals focus their efforts. The Self-care subscale indicates those activities which an individual needs to be able to perform to care for his basic needs. In this study, the normative mean and the study sample mean showed only a slight difference. This supports what was found in the data analysis, that only four of the thirty subjects required assistance with their basic self-care tasks, and the majority were independent in this area. The HAP Manual describes the Self-care subscale as those activities which are required to level independently. However, in terms of independence, it is important to also look at the Personal/Household Work subscale which is more indicative of higher level skills needed for independent living. This subscale showed a greater deviation in the group means.

Leg Effort and Independent Exercise Subscales are high energy scales and correlate most closely with the full limit of the HAP and the MAS. These scales represented the greatest deviation in comparison of means when looking at the normative sample and the study sample. This is significant when addressing mobility necessary for performance of

daily activities and the endurance necessary to perform these activities. This fact speaks clearly to the need to address these areas when evaluating and planning treatment interventions. This information is confounded even further by the fact the Wheelchair Effectiveness which deals with an alternative method of mobility but which also requires endurance was also significantly below the HAP mean. Mobilization of patients for continued independence and application of energy conservation and work simplification techniques cannot be over stressed when addressing the needs of HIV+/AIDS patients.

While Hand Use and Back Effort showed lesser degrees of difference between the means, they remain important in general overall functional ability and add to the patient profile. The remaining subscale, the Entertainment/Social Subscale, is an indicator of activities which individuals perform with other people or strictly for pleasure. From the data collected, it can be stated that the study group performs fewer activities purely for pleasure and that they may be more isolated than the normative sample. This data may be an indicator of fear of rejection or lack of social acceptance, depression or a lack of attention and balance in the area of leisure skills. As an individual with HIV+/AIDS expends increasing amounts of energy on activities that are required for daily functioning, he may conversely decrease the energy expended for leisure activity.

The Research Subscales indicate how an individual focuses his activity and expends the energy that is available. The subscales can be very useful in the clinical setting in terms of planning treatment and

in the research setting in terms of gaining a profile of a patient's functioning. In general, the data indicated that patients included in the study were apt to give up high-energy activities in order to continue daily functional activities.

It is not known how representative the data gained from the Demographic Information Profile actually is in relation to the total AIDS population, but it does present baseline data that can be expanded in the future for greater comparison. For example, responses on Date of Diagnosis covered a wide time span with one individual reporting diagnosis in January of 1983. The data represent a seven-year life span following diagnosis which is higher than that generally reported in the literature. Data collected on the research sample does support increased longevity with 50% of the subjects reporting date of diagnosis greater than two years ago.

Since the information recorded on the DIP is largely by self-report, it is difficult to determine if individual responses are accurate and based on fact. In future use of the form, it may prove useful to use the DIP as part of an interview that is completed by the therapist with information obtained from the medical record, or to further delineate or code information on the form to assure more consistent and accurate reporting of data by subjects.

Development of a Functional Profile

Data collection concerning occupational therapy treatment and functional outcomes is in its infancy in relation to AIDS. Thus, the opportunity to standardize reporting and documentation presents itself as a

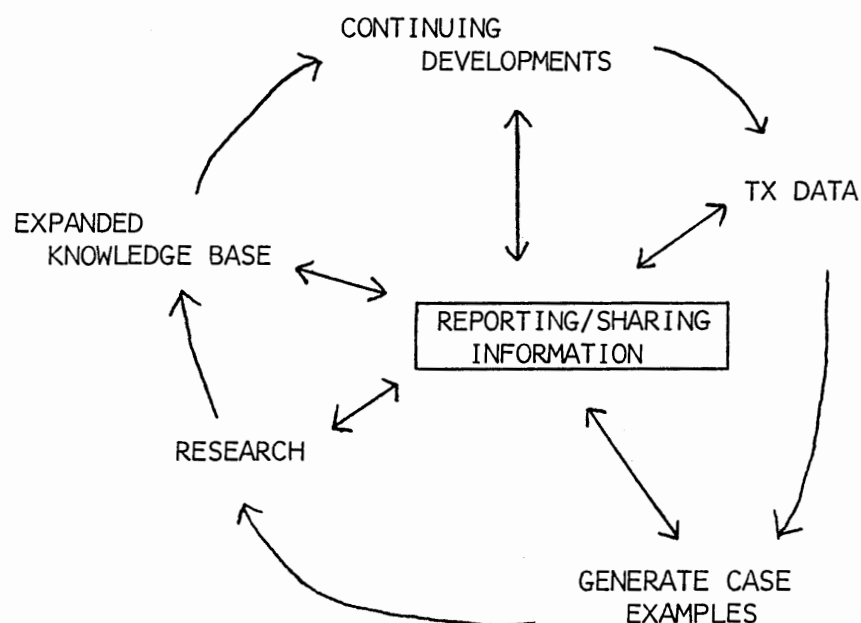
challenge. In Willard and Spackman's Occupational Therapy 6th Edition, the benefits of using uniform reporting systems are described and categorized under five general areas: standards, reimbursement, management, research and promotion. A uniform reporting system, instituted in 1977 at the Maryland State Department of Health and Mental Hygiene, is described in the text and offers a framework and actual example of how a system could be designed (Malone, 1983).

An example of a computerized data base applied for use with the AIDS population is reported by Lafferty, et al (1988). The authors effectively utilized their data to make recommendations for application of a computerized hospital system discharge data base. Conclusions from the study indicate that this is a cost-effective way to compile and track data. With the technology in reporting that is available for use, the type of data base described by Lafferty has application. To date, the majority of persons with AIDS have been treated in major medical centers and metropolitan areas. This fact will change in the early part of the 1990's as more patients seek treatment in their local communities. At that time, occupational therapists who have not been involved in treatment of this population will need rapid access to information so that they can respond to the changes and provide cost-effective treatment and quality care.

It is imperative that a conceptual framework emphasize early research to validate and support cost-effective interventions and the effectiveness of occupational therapy treatment. Figure 1 outlines a

simple model which stresses research and sharing of information to generate a broad knowledge base (Puccetti, 1989).

Figure 1 Feedback Loop-Gaining a Functional Perspective for Occupational Therapy Treatment with AIDS

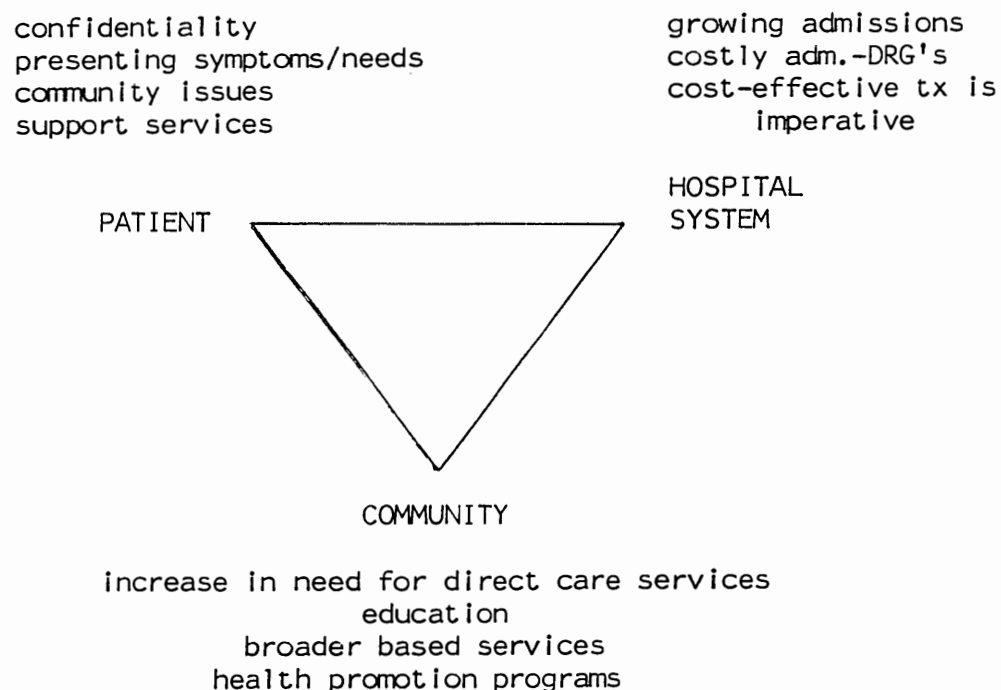


Impact studies that focus on functional outcomes will be of particular importance. It will be through research and validation of the ability to provide cost-effective treatment that occupational therapy's valuable contribution to this population is recognized.

Challenges of a Chronic Illness

It is impossible to view the AIDS epidemic as a separate entity within our society. In determining the total impact one must consider the intermeshing of medical, social, ethical, and economic considerations (Puccetti, 1989). Figure 2 shows the relationship between these considerations and the triad of the patient, the hospital, and the community.

Figure 2 Intermeshing of Medical, Social, Ethical, and Economic Considerations with AIDS



To balance the needs of these systems rapid changes in service delivery must occur. Change will be forced to occur through separate actions of the three entities as well as state and federal mechanisms. Although these changes will not be made through the actions of occupational therapy, effective occupational therapy treatment can have an impact within each area. The occupational therapist can provide direct care to the patient with AIDS through intervention designed to promote functional activity and independence. Treatment intervention should be designed to treat both the physical and psychological aspects of the disease and should promote return to work or work evaluation and work hardening when possible.

Within the hospital system the occupational therapist can be of value in treating acute admissions to assist with earlier discharge and discharge planning including home programs and assessment. It is also important to address the needs of the family and caregiver prior to discharge to assure as smooth a transition as possible to the outpatient setting. This type of intervention during inpatient admissions should lead to overall cost savings.

Occupational therapy services are also valuable in outpatient clinic areas. Patient education in energy conservation, work simplification, activity configuration, stress management, relaxation techniques, and provision of occupational therapy intervention to meet other presenting needs can easily be performed in a cost-effective manner.

However, it is in the community and the patient's home and work environment that the occupational therapist may have the most dramatic impact. Service provision in the home to promote increased independence and enhanced ability to function within the environment may assist in reducing costly admissions or outpatient visits to the hospital. Evaluation and modification of the work setting along with the application of patient education techniques such as activity configuration, energy conservation or work simplification may allow a person with AIDS to remain in the work force for longer periods of time. Thorough work evaluations can assist in recommending alternative work settings or options which would allow increased work productivity.

CHAPTER VI
SUMMARY/CONCLUSIONS

Summary

This study utilized a standardized instrument which measured activity to address four primary objectives. The first objective was to gain a comparison of information obtained from the research sample with the normative population described in the HAP Test Manual. This objective was met through the study and a statistically significant difference was found between the samples.

The second objective focused on identification of similarities in relation to activity levels and activities of daily living with HIV+ and AIDS patients. The HAP generated a great deal of data that can be analyzed in many different ways. The data showed that activity levels of persons with AIDS were affected by the disease. Because occupational therapists are concerned with activity levels, energy, and individual functioning this information was valuable.

Third was to provide a uniform way of reporting the activity levels of patients diagnosed HIV+ or AIDS. The standardized scoring and easy reporting of information met this objective and generates the recommendation to continue administration of the profile to gain additional data.

The fourth, and final objective was to develop a functional profile as a beginning theory base for occupational therapy treatment. A profile has been proposed as part of this study; it remains open to

expansion and revision but it should serve as an initial step addressing the study population.

Conclusions

AIDS is a relatively new disease within our society and is the number one health problem in the United States today. The impact of this disease has mobilized action on countless fronts and presents a challenge to the entire health care system. Predictions are for a continued increase in the numbers of cases with increased longevity due to medical advances. Occupational therapy can respond in a proactive manner to this disease by addressing the needs of the person with AIDS at each stage of his illness. Occupational therapists need to focus on providing interventions that have proven effective with other chronically ill populations in the past.

Standardized evaluations such as the Human Activity Profile used in this study can be useful in individual patient care, but information and data gained from the evaluation can also expand our knowledge base of the disease and its impact on activity. Because of this fact, studies utilizing the HAP and evaluations that are more sensitive to change over time are needed to increase the sample size and validity of the data. Research needs to be expanded rapidly to validate potential contributions of the profession in the treatment of AIDS. Funding should be solicited to support these research endeavors, and outcomes should be used to validate the effectiveness of occupational therapy services.

Activity and functional independence in activities of daily living are hallmarks of occupational therapy. Occupational therapy treatment

with other chronically ill populations in the past has been effective in promoting function and quality of life through the use of purposeful activity. Treatment of persons with AIDS provides a similar challenge within a changing health care arena.

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APPENDICES

APPENDIX A
RESEARCH INSTRUMENTS

HUMAN ACTIVITY PROFILE

HUMAN ACTIVITY PROFILE



TEST BOOKLET

David M. Daughton, M.S. and A. James Fix, Ph.D.

Name _____ Age _____ Sex _____ Date _____

Occupation _____ Education _____

List any medical problems or injuries which currently limit your activities: _____

HAP Summary Score Grid

Primary Score	Score	Percentile
MAS	_____	_____
AAS	_____	_____
Activity Age	_____	
Fitness Classification		
Low _____	Fair _____	Average and above _____
Activity Classification		
Impaired _____	Moderately active _____	Active _____
Energy Analysis	Score	Percentile
EEP	_____	
LEC	_____	
Dyspnea Scale	_____	_____

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This form is printed in maroon ink on ivory paper. Any other version is unauthorized.

Printed in the U.S.A.

Reorder #1457-18

Instructions

This booklet contains items which describe common activities that people do in their daily lives. Read each item carefully and place an "X" in the column which indicates whether you are still doing the activity, have stopped doing the activity, or never did the activity. Use the following instructions in making your responses:

Place an "X" in the column marked *Still Doing This Activity* if:

you completed the activity unassisted the last time you had the need or opportunity to do so.

Place an "X" in the column marked *Have Stopped Doing This Activity* if:

you have engaged in the activity in the past, but you probably would not perform the activity today even if you had the opportunity.

Place an "X" in the column marked *Never Did This Activity* if:

you have never engaged in the specific activity.



	<i>Still Doing This Activity</i>	<i>Have Stopped Doing This Activity</i>	<i>Never Did This Activity</i>
1. Getting in and out of chairs or bed (without assistance)			
2. Listening to the radio			
3. Reading books, magazines, or newspapers			
4. Writing (letters, notes)			
5. Working at a desk or table			
6. Standing (for more than 1 minute)			
7. Standing (more than 5 minutes)			
8. Dressing or undressing (without assistance)			
9. Getting clothes from drawers or closets			
10. Getting in or out of a car (without assistance)			
11. Dining at a restaurant			
12. Playing cards/table games			
13. Taking a bath (no assistance needed)			
14. Putting on shoes, stockings, or socks (no rest or break needed)			
15. Attending a movie, play, church event, or sports activity			
16. Walking 30 yards (27 meters)			
17. Walking 30 yards (nonstop)			
18. Dressing/undressing (no rest or break needed)			
19. Using public transportation or driving a car (99 miles or less)			
20. Using public transportation or driving a car (100 miles or more)			
21. Cooking your own meals			
22. Washing or drying dishes			
23. Putting groceries on shelves			
24. Ironing or folding clothes			
25. Dusting/polishing furniture or polishing a car			
26. Showering			
27. Climbing 6 steps			
28. Climbing 6 steps (nonstop)			
29. Climbing 9 steps			
30. Climbing 12 steps			
31. Walking ½ block on level ground			
32. Walking ½ block on level ground (nonstop)			
33. Making a bed (not changing sheets)			
34. Cleaning windows			
35. Kneeling, squatting to do light work			

	<i>Still Doing This Activity</i>	<i>Have Stopped Doing This Activity</i>	<i>Never Did This Activity</i>
36. Carrying a light load of groceries			
37. Climbing 9 steps (nonstop)			
38. Climbing 12 steps (nonstop)			
39. Walking ½ block uphill			
40. Walking ½ block uphill (nonstop)			
41. Shopping (by yourself)			
42. Washing clothes (by yourself)			
43. Walking 1 block on level ground			
44. Walking 2 blocks on level ground			
45. Walking 1 block on level ground (nonstop)			
46. Walking 2 blocks on level ground (nonstop)			
47. Scrubbing (floors, walls, or cars)			
48. Making a bed (changing sheets)			
49. Sweeping			
50. Sweeping (5 minutes nonstop)			
51. Carrying a large suitcase or bowling (one game)			
52. Vacuuming carpets			
53. Vacuuming carpets (5 minutes nonstop)			
54. Painting (interior/exterior)			
55. Walking 6 blocks on level ground			
56. Walking 6 blocks on level ground (nonstop)			
57. Carrying out the garbage			
58. Carrying a heavy load of groceries			
59. Climbing 24 steps			
60. Climbing 36 steps			
61. Climbing 24 steps (nonstop)			
62. Climbing 36 steps (nonstop)			
63. Walking 1 mile			
64. Walking 1 mile (nonstop)			
65. Running 110 yards (100 meters) or playing softball/baseball			
66. Dancing (social)			
67. Doing calisthenics or aerobic dancing (5 minutes nonstop)			
68. Mowing the lawn (power mower, but not a riding mower)			
69. Walking 2 miles			
70. Walking 2 miles (nonstop)			
71. Climbing 50 steps (2½ floors)			
72. Shoveling, digging, or spading			

	<i>Still Doing This Activity</i>	<i>Have Stopped Doing This Activity</i>	<i>Never Did This Activity</i>
73. Shoveling, digging, or spading (5 minutes nonstop)			
74. Climbing 50 steps (nonstop)			
75. Walking 3 miles or golfing 18 holes without a riding cart			
76. Walking 3 miles (nonstop)			
77. Swimming 25 yards			
78. Swimming 25 yards (nonstop)			
79. Bicycling 1 mile			
80. Bicycling 2 miles			
81. Bicycling 1 mile (nonstop)			
82. Bicycling 2 miles (nonstop)			
83. Running or jogging ¼ mile			
84. Running or jogging ½ mile			
85. Playing tennis or racquetball			
86. Playing basketball/soccer (game play)			
87. Running or jogging ¼ mile (nonstop)			
88. Running or jogging ½ mile (nonstop)			
89. Running or jogging 1 mile			
90. Running or jogging 2 miles			
91. Running or jogging 3 miles			
92. Running or jogging 1 mile in 12 minutes or less			
93. Running or jogging 2 miles in 20 minutes or less			
94. Running or jogging 3 miles in 30 minutes or less			

Complete next page only if instructed to do so

Dyspnea Scale

Answer the following questions only if you have been instructed to do so. Read each question carefully and place an "X" in the space next to the number which best describes your answer.

Would you become short of breath if you . . .

1. Walked $\frac{1}{2}$ block uphill?
 - ☐ (0) No, not at all.
 - ☐ (1) Yes, a little.
 - ☐ (2) Yes, clearly noticeable; I probably would have to slow down during this activity.
 - ☐ (3) Yes, severe shortness of breath; I would be forced to stop and catch my breath.
2. Walked 1 block on level ground (nonstop)?
 - ☐ (0) No, not at all.
 - ☐ (1) Yes, a little.
 - ☐ (2) Yes, clearly noticeable (need to slow down during activity)
 - ☐ (3) Yes, severe shortness of breath (need to stop and catch breath)
3. Walked 2 blocks on level ground (nonstop)?
 - ☐ (0) No, not at all.
 - ☐ (1) Yes, a little.
 - ☐ (2) Yes, clearly noticeable (need to slow down during activity)
 - ☐ (3) Yes, severe shortness of breath (need to stop and catch breath)
4. Walked 6 blocks on level ground (nonstop)?
 - ☐ (0) No, not at all.
 - ☐ (1) Yes, a little.
 - ☐ (2) Yes, clearly noticeable (need to slow down during activity)
 - ☐ (3) Yes, severe shortness of breath (need to stop and catch breath)
5. Climbed 12 steps (nonstop)?
 - ☐ (0) No, not at all.
 - ☐ (1) Yes, a little.
 - ☐ (2) Yes, clearly noticeable (need to slow down during activity)
 - ☐ (3) Yes, severe shortness of breath (need to stop and catch breath)
6. Climbed 24 steps (nonstop)?
 - ☐ (0) No, not at all.
 - ☐ (1) Yes, a little.
 - ☐ (2) Yes, clearly noticeable (need to slow down during activity)
 - ☐ (3) Yes, severe shortness of breath (need to stop and catch breath)
7. Climbed 36 steps (nonstop)?
 - ☐ (0) No, not at all.
 - ☐ (1) Yes, a little.
 - ☐ (2) Yes, clearly noticeable (need to slow down during activity)
 - ☐ (3) Yes, severe shortness of breath (need to stop and catch breath)
8. Carried a heavy load of groceries 30 feet on level ground?
 - ☐ (0) No, not at all.
 - ☐ (1) Yes, a little.
 - ☐ (2) Yes, clearly noticeable (need to slow down during activity)
 - ☐ (3) Yes, severe shortness of breath (need to stop and catch breath)

DEMOGRAPHIC INFORMATION FILE

Test Booklet No. _____

DEMOGRAPHIC INFORMATION PROFILE

AGE _____ SEX _____ RACE _____ DATE OF DIAGNOSIS _____

OCCUPATION _____ EDUCATIONAL LEVEL _____
years

DATE LAST WORKED _____ ARE YOU RECEIVING DISABILITY
COMPENSATION?

yes no

ARE YOU CURRENTLY LIVING INDEPENDENTLY? _____
yes no

DO YOU HAVE A CAREGIVER? _____
yes no full part
time time

MEDICATIONS YOU ARE CURRENTLY
TAKING? _____

GROUP/CLASSIFICATION _____

PROTOCOL FOR COMPLETING THE HUMAN ACTIVITY PROFILE DEMOGRAPHIC
INFORMATION SHEET

PROTOCOL FOR COMPLETING THE HUMAN ACTIVITY PROFILE
DEMOGRAPHIC INFORMATION SHEET

1. Test booklet number is recorded by therapist in the designated space the upper right corner to assure test booklet and Demographic Information Sheet match.
2. Subject completes the following information: AGE , SEX , RACE , OCCUPATION , and EDUCATIONAL LEVEL. Educational level should be reported as the number of years of education completed.
3. Subject records date last worked; if subject is currently employed and still working record current and the date in the appropriate space.
4. Subject checks YES or NO in the specified space as to their status of disability compensation.
5. Date of original diagnosis of HIV+ or AIDS is recorded including month and year.
6. Subject checks YES or NO to designate if they are currently living independently without need of assistance from another individual.
7. Subject checks YES or NO if they have a designated person to assist them with ANY part of their daily functioning. The Full-time box is checked if the subject can not manage basic self-care needs. The Part-time box is checked if the subject needs assistance with selected independent living activities, but can manage most basic needs without assistance on a consistent basis.

CONSENT FORM

IRB: 1/19/90

THE UNIVERSITY OF TEXAS MEDICAL BRANCH AT GALVESTON

Subject Consent

I have been asked to participate as a subject in the research project entitled, Occupational Therapy Intervention and AIDS: Developing a Beginning Research Base and Functional Perspective, under the direction of Dianna D. Puccetti, OTR a graduate student at Texas Woman's University in Houston and Jean Spencer, Ph.D., OTR, faculty advisor for the project.

I understand that the purpose of this study is to gather information on the daily activity levels of individuals diagnosed HIV+ or AIDS.

I understand that this study may be of benefit to me in providing information that may be useful in recommending potential occupational therapy interventions as a part of my overall treatment plan at the Infectious Disease Clinic. In general, the information gained from the study may provide knowledge that can assist with treatment of other persons whose needs may be similar to mine. I understand that there is no known physical risk involved in this study. I understand that it is possible that I will experience psychological stress in relation to the questions regarding activity level including past and present activities. I further understand that the research protocol protects my confidentiality by the use of a code number rather than my name.

1. I understand that the informed consent is required of all persons in this study.
2. The principle procedures have been identified to me. I understand that I am responsible only for completing a Demographic Information Sheet and Human Activity Profile checklist which documents my participation in daily activities. I understand that these procedures will take 30-40 minutes.
3. The risks and discomforts from the procedures have been explained to me.
4. The expected benefits from the procedures have been explained to me.
5. An offer has been made to answer any questions that I may have about these procedures. If I have any questions before, during or after the study, I may contact Dianna Puccetti, OTR at (409) 761-1975 or Jean Spencer, Ph.D., OTR, Research Advisor at (713) 794-2131.
6. I have been told that I may stop my participation in this project at any time without prejudice.
7. I have been told that The University of Texas Medical Branch at Galveston, like virtually all other Universities in the United States, does not have a mechanism for compensation of the injured research subject. Therefore, I understand that I cannot look to any such mechanism to receive financial remuneration for any such injury resulting from my participation in this project. If physical injury occurs as a direct result of this research, emergency treatment which is available to the general public will be available to me. Neither UTMB, TWU, nor Dianna Puccetti can assume financial responsibilities or liability for the expenses of such treatment.
8. I have a right to privacy, and all information that is obtained in connection with this study that can be identified with me will remain confidential as far as possible within state and federal law. However, information gained from this study that can be identified with me may be released to no one other than the investigator, my physician, and to the other participating medical centers in this study. The results of this study may be published in scientific journals without identifying me by name.

I voluntarily agree to participate as a subject in the above named project.

Date

Signature of Subject

Signature of Witness

Signature of Authorized Third Party
and Relationship to the Subject

Using language that is understandable and appropriate, I have discussed this project and the eight items listed above with the subject and /or his authorized representatives.

Date

Signature of Project Director or Assistant

APPENDIX B
HUMAN SUBJECTS REVIEW FORMS

TEXAS WOMAN'S UNIVERSITY

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER



HSRC APPROVAL FORM

Name of Investigator(s): Dianna D. Puccetti
Social Security Number(s): 466-88-4457
Address: 4322 Ave I
Galveston, Texas 77550

Dear: _____

Your study entitled: _____

(The applicant must complete the top portion of this form)

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.

Any special provisions pertaining to your study are noted below:

_____ Add to informed consent form: "I understand that the return of my questionnaire constitutes my informed consent to act as a subject in this research".

_____ The filing of signatures of subjects with the Human Subjects Review Committee is not required.

_____ Other: see attached sheet.

_____ No special provisions apply.

Sincerely,

William R. Gould, Ph.D.
Chairman, HSRC - Houston Center

12-12-89
Date

HSRC Fall, 1989

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER



HUMAN SUBJECTS REVIEW COMMITTEE REPORT FORM

APPLICANT'S NAME: Dianna D. Puccetti

PROPOSAL TITLE: Occupational Therapy Intervention and AIDS:

Developing a Beginning Research Base and Functional Perspective

(applicant must complete top portion of this form)

COMMENTS: _____

DATE: 12/5/89

[Signature] Disapprove Approve

[Signature] Disapprove Approve

[Signature] Disapprove Approve

[Signature] Disapprove Approve

[Signature] Disapprove Approve

UNIVERSITY OF TEXAS MEDICAL BRANCH

The University of Texas Medical Branch at Galveston

School of Medicine
Graduate School of Biomedical Sciences
School of Allied Health Sciences
School of Nursing

Marine Biomedical Institute
Institute for the Medical Humanities
UTMB Hospitals



Office of
Sponsored Programs—Academic

January 19, 1990

M E M O R A N D U M

TO: Dianna D. Puccetti, OTR/Dr. Richard Pollard
Supervisor-OTR/Professor & Chief, Diagnostic Virology Laboratory
Occupational Therapy D-87/Internal Medicine H82

FROM: E. Ray Stinson, Ph.D. *N. Hammock*
for Director of Sponsored Programs-Academic

SUBJECT: Expedited Review, Human Subjects

Project Director: Dianna D. Puccetti, OTR/Dr. Richard Pollard OSP #90-24
Project Title: "Occupational Therapy Intervention and AIDS: Developing a
Beginning Research Base and Functional Perspective"

Under the Institutional Review Board's mechanism for reviewing minimal risk protocols, your project referenced above has been approved on January 19, 1990. I am, therefore, pleased to inform you that you may proceed with this project effective immediately.

Project Directors of approved projects are responsible for reporting to the Institutional Review Board any unanticipated adverse reactions observed during the conduct of the project as well as any severe or serious side effects whether anticipated or unanticipated.

Should your project require modification which alters the risk to the subject or the method of obtaining informed consent, the project must be reevaluated by the Institutional Review Board before the modification is initiated.

Completed subject consents should be maintained in the designated place for at least three years after the termination of the project. In order to be in compliance with the requirements of the FDA regulations, 21 CFR 56.27a, a copy of the completed consent document must be provided to the subject.

COMMENTS: Attached is the revised subject consent form with the date of IRB approval. Please use these copies of the revised consent form with the IRB approval date and make additional copies as they are needed.

ERS/nh