Interfacing Ryan White Program with outpatient occupational therapy services at the University of Toledo Medical Center

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Interfacing Ryan White Program with Outpatient Occupational Therapy Services at The University of Toledo Medical Center

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Occupational Therapy Doctorate Program

Department of Occupational Therapy

The University of Toledo Health Science Campus

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Note: This document describes a capstone dissemination project reflecting an individually planned experience conducted under faculty and site mentorship. The goal of the capstone experience is to provide the occupational therapy doctoral student with a unique experience whereby he/she can demonstrate leadership and autonomous decision-making in preparation for enhanced future practice as an occupational therapist.
# Interfacing Ryan White Program

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Executive Summary

Unfortunately the number of people living with HIV/AIDS is increasing around the world, but fortunately medicine is helping to increase the life span of this population (UNAIDS, n.d.). After conducting a literature review and obtaining information from a needs assessment, it was determined that HIV/AIDS patients are experiencing symptoms and deficits that medication cannot treat. The symptoms and deficits of this population are impacting the performance, quality, and safety of daily occupations, yet occupational therapy services are not included in most HIV/AIDS specific clinics. Due to the increasing number of HIV and AIDS cases, a community-based program addressing these issues is needed.

The goal of interfacing the Ryan White program with outpatient occupational therapy services at UTMC is to increase performance, quality, and safety of daily occupations in the HIV/AIDS patients served by the Ryan White Program at The University of Toledo Medical Center (UTMC). The program objectives will address the areas of performance (amount of occupation one does throughout the day), quality (how well are occupations being performed), and safety (reducing risk of injury during occupational performance). During the first year of this program, a possible 32 to 63 participants, in the mid to late stages of HIV/AIDS illness, could possibly receive occupational therapy services through outpatient rehabilitation services at UTMC. The participants will receive client-centered occupational therapy treatment based on their individualized needs and wants. The effectiveness of this interface will be determined by a pretest-posttest evaluation of Occupational Self Assessment scores; percentages of participants who met program objectives; and a process oriented summary of participants treated, sessions completed, a list of common interventions, and a list of OSA items commonly chosen by participants. This feedback will be used to alter program content or procedures as needed.
Introduction

Program Goal

The goal of interfacing the Ryan White program with outpatient occupational therapy services at the University of Toledo Medical Center is to increase performance, quality, and safety of daily occupations in the HIV/AIDS patients served by the Ryan White Program at The University of Toledo Medical Center (UTMC).

Performance refers to the amount of occupation one does throughout the day. It is more common for the HIV/AIDS population to be inactive than overly active, and therefore people typically need to increase occupational performance.

Quality refers to how well one performs occupations; are occupations performed in the most efficient way.

Safety means reducing the risk of injury to self and others during occupational performance.

Sponsoring Agency

Interfacing the Ryan White program with outpatient occupational therapy services at UTMC will include cooperation from both the Ryan White program and outpatient rehabilitation services in order to provide appropriate referrals and occupational therapy services to HIV/AIDS patients. UTMC’s Ryan White program is a product of the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act, which supports Ryan White programs throughout the United States. The mission of the Ryan White program at UTMC is to deliver quality care to persons infected and affected with HIV through a holistic multidisciplinary approach that includes medical, psychological and spiritual components. Increasing the opportunity for occupational therapy (OT) services will add to the holistic approach already offered.
An organizational chart for UTMC’s Ryan White program and UTMC’s rehabilitation services has been provided in Appendix A and B. The Ryan White infectious disease physicians at UTMC will make occupational therapy referrals to UTMC’s department of outpatient rehabilitation services.

Investigation of Needs

To establish the need for this interface, semi-structured interviews were conducted with Ann Locher, Program Coordinator; Christie Clinton, Consumer Advocate; and Dave Kujawa, Director of UTMC’s Department of Rehabilitation Services. (For a detailed account of these interviews please see Appendix C). Informal interviews/discussions were held with Dr. Joan Duggan, Program Director; Sue Carter, Social Worker; Mary Dwyer, Family Nurse Practitioner; and Kelly Farley, OTR/L, staff OT, and Lynne Chapman, OTR/L, staff OT. Need was also established through interviews with the HIV/AIDS patients that came into the clinic between the months of January and April. (Please refer to Appendix D for interview data). The purpose of the patient interviews was to hear what the occupational challenges of the HIV/AIDS population are and whether patients are willing to go to an outpatient rehab facility to receive occupational therapy services. A copy of the interview is available in appendix E. Patients were voluntarily interviewed while they were at the clinic for their routine appointments. Using information obtained from the interviews, a list of potential needs was established. The needs address occupational performance or factors that inhibit successful occupational performance.

1. Pain management – general pain, chronic pain, emotional pain, and pain related to neuropathy are a few of the types of pain this population faces. Pain disrupts daily life for about 20-30% of the clinic population.

2. Anxiety management/Relaxation techniques – Anxiety is a normal part of these patients’ lives.
The stigma behind this illness is still so strong that patients go out of their way to make sure others do not find out their secret.

3. Energy conservation/work simplification – fatigue is a common side effect of medications, but can also be caused by the loss of weight (wasting syndrome). Fatigue was the most common complaint among patients interviewed and for some patients it was severe enough that it interfered with one’s ability to complete daily occupations.

4. Developing/maintaining habits and routines – In order for the HIV medications to be most effective, the medication needs to be taken on a regular basis and preferably at regular times. A patient could possibly be taking (4+) pills a day, and a mother or father may also be responsible for their child’s medications.

5. Home exercise program – ROM, strength, endurance, flexibility – Several of the meds result in weight gain and several patients do not participate in any physical activity. This may be due to isolation, pain, depression, or fatigue.

6. Assistive equipment – This could be simple assistive equipment such as reachers, canes, grab bars, and built up grips on utensils, or it could be more complex such as a personal digital assistant (PDA) to help with daily routines and reminders.

7. Pursuit of leisure occupations – Due to depression, the stigma surrounding HIV/AIDS, or the side effects from the drugs, many patients stop participating in the occupations they use to enjoy. They often isolate themselves from the rest of society.

8. Setting personal goals – Patients become so used to being told what they have to do, they forget they have choices in regards to occupations and goals they want to do or achieve.

9. Safety awareness – Safety can be addressed in terms of the occupations they perform and the environments they perform those occupations in. For example, identifying fall hazards in the environment.
10. Home assessments with recommended modifications – home assessments may be needed to help patients with some of the problems mentioned above. Modifications at the home might help keep a patient independent and functional for a longer period of time.

**Literature Review**

It was in June of 1981 that the first cases of what is now known as AIDS were reported in the United States (Molineux, 1997). Worldwide, over 22 million have died from AIDS since that time, over 42 million people are living with HIV/AIDS today, and 14,000 are newly infected each year (Until There’s a Cure). In the United States, there have been more than 900,000 cases of AIDS reported since 1981 and over 950,000 Americans may be infected right now, with one-quarter of those Americans unaware of their infection (National Institute of Allergy and Infectious Diseases, 2006). In 2005 Ohio reported there was an estimated 7,982 people living with HIV and 7,138 living with AIDS (Centers for Disease Control and Prevention, n.d.). More specifically, in Toledo, Ohio there was an estimated 764 people living with AIDS. Of the overall totals in the United States, African Americans represent the ethnic group with the highest percentage of HIV/AIDS cases (47%); males account for 73% of all HIV/AIDS cases; and the largest age range is between the ages of 40 and 44 (21%) (Centers for Disease Control and Prevention, n.d.).

Contrary to past stigmatization, it is now known that HIV/AIDS can affect anyone and everyone; no one is immune and there is no cure. “HIV is a retrovirus, a type of virus that contains the enzyme reverse transcriptase which allows DNA to be transcribed from RNA. The prime target for HIV is the human T4 cell, a lymphocyte that plays a key role in the immune system” (Molineux, 1997, p.194). Once infected, a person will transition through 4 stages with each stage signifying the progression of the disease and a decline in overall health due to the weakened immune system (Molineux, 1997). Longevity after being infected with the virus could
be anywhere between 10 and 43 years depending on several different factors such as time of diagnosis, adherence to medication routines, and secondary infections.

HIV/AIDS is no longer an acute illness with a death sentence, but a chronic illness that can last for several decades (Beauregard & Solomon, 2005). The progression of the disease will continually bring about new challenges both physically and emotionally. With no cure available, treatment is aimed at maintaining one’s quality of life by alleviating symptoms and preventing opportunistic infections (Molineux, 1997). The main intervention for HIV/AIDS patients is pharmacological: utilization of highly active antiretroviral therapies (HAARTs) (Galantino, 2001). It is these drugs which have transitioned HIV/AIDS from an acute illness to a chronic illness.

As effective as HAARTs are, not all symptoms and deficits of HIV/AIDS can be effectively treated with drugs. In addition, side effects are common and typically unpleasant, including insomnia, fatigue, and weight gain. An occupational therapist can assist with the management of side effects, physical changes, and the emotions that accompany these. Physically, intervention possibilities include: use of assistive equipment, teaching energy conservation techniques, safety awareness, recommending home and job modifications, making splints, positioning, and patient/family education (Weinstein & De Neffe, 1989; Molineaux, 1997; Mukand, 1991). These interventions would be used to help compensate for fatigue, insomnia, visual impairments, pain due to peripheral and central nervous system damage, shortness of breath and cardiac problems, and loss of range of motion, strength, sensation, and coordination (Pizzi, 1990; Mukand, 1991). A significant percentage of people will decline in cognitive function due to the physical problems mentioned above. In addition, people with HIV/AIDS are at risk for developing AIDS dementia complex (ADC). ADC will affect the cognitive, motor, and behavioral systems, and will progress from mild to moderate to severe
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(Gregory & Gibbs, 2002). To assist a person to compensate for impairments in cognitive functioning, occupational therapists can assist persons in creating schedule calendars and memory aids, helping develop a routine, or introducing augmentative communication tools to help with communication (Weinstein & De Neffe, 1989; Mukand, 1991). People with HIV/AIDS experience psychosocial difficulties that may include feelings of anger, fear, depression, hopelessness, anxiety, helplessness, stress, or guilt (Weinstein & De Neffe, 1989; Pizzi, 1990). These feelings may emerge due to a loss in sense of control and choice, role and habit changes, a loss of meaning and purpose in one’s life, stigmatization, or isolation (Pizzi, 1990; Mukand 1991). In addition to being a good listener, occupational therapists can teach patients stress reduction and anger management techniques, relaxation and breathing exercises, time management skills, or new vocational roles and leisure occupations (Weinstein & De Neffe, 1989; Pizzi, 1990, Molineux, 1997). “As persons with HIV/AIDS live longer, it is essential for rehabilitation professionals to recognize AIDS related disabilities and to work with each person to create the most appropriate and effective intervention plan” (Beauregard & Solomon, 2005, 115).

Occupational therapists have been involved in caring for people with HIV/AIDS since very early in the history of the disease (Molineux, 1997). “In 1986, the Physical Disabilities Special Interest Section of the American Occupational Therapy Association (AOTA) made the first national presentation on AIDS to occupational therapists” (Atchison, Beard, & Lester, 1989, p.212). Later, AOTA released a special edition of the American Journal of Occupational Therapy (AJOT) dedicated to the topic of HIV/AIDS (Atchison, Beard, & Lester, 1989). More recently, in 2007, AOTA released a draft of a statement on Occupational Therapy in the Promotion of Health and the Prevention of Disease and Disability. In this statement, three critical roles for occupational therapists in health promotion and disease/disability prevention are
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mentioned. These include: promoting healthy lifestyles, emphasizing occupation as an essential element of health promotion strategies, and providing intervention to populations (Scaffa, Van Slyke & Brownson, 2007). The HIV/AIDS population could benefit from these occupational roles in order to increase longevity and quality of life.

As evidenced in this literature review, HIV/AIDS patients are in need of services to treat/manage the symptoms and deficits that medication cannot or that medication brings about. HIV/AIDS patients need holistic services which incorporate the person, environment, and occupation into treatment approaches. Lastly, the HIV/AIDS population needs a client-centered approach to therapy so they feel they have control over one aspect of their medical treatment. Occupational therapy can provide all these services to help promote health among the HIV/AIDS population.

*Occupation-based programming*

The definition of an occupation is “the relationship between an occupational form and an occupational performance (Nelson, 1994, p.10). Occupations can encompass anything that is meaningful and purposeful to the individual (Nelson, 1994). Interfacing the Ryan White program with outpatient OT services will provide HIV/AIDS patients the opportunity to engage in occupational therapy to increase performance, quality, and safety of daily occupations that are meaningful and purposeful to each individual participant.

*Models of Practice*

The suggested model of practice to use with patients referred to outpatient OT would be the Model of Human Occupation (MOHO). MOHO is a client centered model of practice that integrates the psychosocial, biologic, and environmental factors that affect care and result in a holistic approach (Pizzi, Mukand, & Freed, 1991). It also respects lifestyle and choices of the individual, therefore goals and objectives will be a reflection of the client and more meaningful.
Three important aspects of MOHO are volition, habituation, and performance. Volition is a collection of self-knowledge that enables a person to anticipate, choose, experience, and interpret their occupational behavior (Kielhofner, 1995). Participants will be able to anticipate the types of occupation they are capable of, choose the occupations they want to work on in therapy, and interpret the impact occupational performance has on their well-being. Habituation includes one’s habits and roles (Kielhofner, 1995). Habits are important in terms of people’s daily routine which is very important for the HIV/AIDS population and their medication or symptom management. Identification of roles will allow the participants to see they are not just a person living with HIV/AIDS. Performance capacity refers to one’s underlying abilities and how they feel about those capacities (Kielhofner, 1995). A person must understand one’s physical and cognitive abilities in order to determine what occupational behavior he or she is capable of performing (Kielhofner, 1995). A person experiencing the negative impacts of HIV/AIDS needs to understand their capacity to carry out daily occupations.

Federal Initiatives and National Trends or Mandates

As a community-based program, interfacing the Ryan White program with outpatient occupational therapy services at UTMC will fulfill objectives of Healthy People 2010, a national public initiative. One goal of Healthy People 2010 is to “increase the quality, availability, and effectiveness of educational and community-based programs designed to prevent disease and improve the health and quality of life” (United States Department of Health and Human Services, 2000, p.7-11). Objective 7-10 specifically focuses on creating community health programs related to Healthy People 2010 focus areas, such as HIV (United States Department of Health and Human Services, 2000). The United States Department of Health and Human Services has identified HIV as a focus area, but is concentrating on HIV prevention. The interface does not directly relate to this specific HIV focus area, but the inclusion of HIV on the
The focus list does demonstrate the impact HIV has on our society. The interface matches up to Healthy People 2010 because it is specifically for the HIV/AIDS population, is community based, and is meant to improve health and quality of life through an increase in performance, quality, and safety of daily occupations.

Objectives

Program Goal

The goal of interfacing the Ryan White program with outpatient occupational therapy services at UTMC is to increase performance, quality, and safety of daily occupations in the HIV/AIDS patients served by the Ryan White Program at The University of Toledo Medical Center (UTMC).

Objectives

All objectives will be measured at the end of one year.

1) Program participants will demonstrate competency in the use of energy conservation and work simplification techniques for daily management of fatigue.

2) Program participants will demonstrate competency in the use of assistive equipment to increase independence in occupations of daily living.

3) Program participants will collaborate with the therapist on a home exercise program to participate in to increase strength and endurance for daily occupations.

4) Program participants will increase their overall performance according to the Occupational Self Assessment (e.g. taking care of the place I live, taking care of myself, physically doing what I need to do, managing my basic needs (food, medicine)).

5) Program participants will demonstrate an increase in their competencies in stating safely precautions relevant to their personal situations (e.g. fall hazards, medication routine).
6) Program participants will demonstrate understanding of how to set long and short term goals along with the connection between long and short term goals.

7) Program participants will demonstrate pain management techniques to reduce the level of pain as evidenced by the visual analog scale for pain.

Because a client-centered model of practice will be utilized, not all program participants will be working toward all the above objectives. Individualized intervention plans must reflect the needs and wishes of each patient, not a pre-determined list of objectives. The program evaluation for each objective will focus only on those participants whose individualized plans are consistent with the relevant objective (e.g., if 50% of the participants choose to increase safety awareness, then only these 50% will be considered in evaluating the safety-oriented objective). Nevertheless, it is expected that each participant will choose to work toward some achievement relevant to at least one of the above objectives, with many working to making positive changes relevant to several of the program objectives.

**Education and Referral of Participants**

*Education*

To educate patients and health care professionals on occupational therapy services and appropriate OT referrals, five strategies are suggested, including: HARK newsletter (when in press), patient educational dinner forums, a handout describing the profile of an ideal OT candidate, other health care professionals at the clinic, and an in-service between the two departments. The Ryan White Clinic at UTMC has a population of 635 patients who are potential participants for receiving occupational therapy services. Part of the referral strategy will be to educate patients on what occupational therapy (OT) is and how OT services can positively impact the life of someone with HIV/AIDS. Thus when patients discuss their medical needs with their health care providers at the clinic, the patients may already understand the role
of OT and possibly have an idea about whether or not OT services would be useful at their stage in the illness.

The Health Awareness Resources Knowledge (HARK) newsletter is a quarterly newsletter for those affected by HIV/AIDS. The newsletter addresses a variety of topics about HIV/AIDS, along with informing the reader about upcoming events and meetings. At the moment HARK is not in press, but staff of the Ryan White program are hopeful that it will return to press during the next year. The newsletter could be used as an educational tool to inform the HIV/AIDS community about occupational therapy services. An article could be written about specific ways occupational therapy can be beneficial in the care and management of HIV/AIDS. Article submissions are sent to submissions@hark-toledo.org. Dr. Joan Duggan along with other staff at the UTMC Ryan White program are regular contributors to this newsletter and would be useful in getting information published. There is no cost to submit an article and have it appear in the newsletter.

The University of Toledo Medical Center and the AIDS Resource Center of Toledo (ARC), formerly known as David’s House of Compassion, host educational dinners throughout the year on a variety of topics. Having an OT speak at one of the dinner forums will give patients a chance to not only hear about OT, but also ask questions and become familiar with occupational therapy practitioners in the outpatient rehabilitation department. In a community where trust is a major concern among the patient population, it will be important to market the OT as a trustworthy health care professional who is there for the best interest of the patient. Ann Locher, Dr. Duggan, Sue Carter (social worker), and Christie Clinton (consumer advocate) are all involved with the educational dinner forums and will provide guidance and support.

A handout describing the profile of ideal occupational therapy candidates will be provided for the health care professionals at the Ryan White program (Appendix F). The profile
describes how symptoms experienced by HIV/AIDS patients may affect one’s daily occupations and at what point referral for OT intervention would be appropriate.

Beneficial to the education and referral of patients are the other health care professionals who meet with the patients. All the health care professionals have been educated on what OT is and how it benefits the HIV/AIDS population. The patients who come into the clinic know and trust these health care professionals and would take their recommendations into consideration. It is also these health care professionals who are the experts on what the deficits and disabilities of HIV/AIDS are, and will be able to identify patients who are probably struggling in daily occupations.

Lastly, an orientation/in-service will include staff from the Ryan White program and the staff from the department of rehabilitation services. In-services take place in the department of rehabilitation service on the third Thursday of each month. The goal of the in-service is to not only educate the outpatient rehabilitation staff on HIV, the current investigation of needs, and the Ryan White program, but to also create an informal discussion about services that are available through the rehab department that would be beneficial to the HIV population other than just OT. The in-service date will be determined by Ann Locher and Dave Kujawa.

*Expected Number and Inclusion Criteria for Potential Participants*

The Ryan White program at UTMC is providing care to 635 patients in the Toledo, Ohio and surrounding areas. An average of 15 patients are seen at each clinic, after cancellations, no-shows, and drop-ins are accounted for. Patients have the opportunity to meet with the nurse practitioner, infectious disease physician, HIV counselors and social workers, consumer advocate, financial counselor, dietician, pharmacist, and many more. The patients eligible for receiving an occupational therapy referral will include those who are probably experiencing the mid to late stages of the illness. These patients will be experiencing numerous disabilities and
symptoms, and at an increased severity level. These professionals have been meeting with some of the patients for years and therefore are a reliable source for identifying the patients most in need of OT services.

The number of participants who will be treated during a one year period is difficult to estimate, but could possibly be between 32 and 63 patients. There are 635 patients in care and of those patients it is estimated that 5%-10% would be experiencing enough disability that OT services would be beneficial, which brings the number to somewhere between 32 and 63. Five to ten percent was estimated after conducting interviews with and observing patients at the Ryan White clinic between January and April.

Programming

*Occupational Self Assessment (OSA)*

The suggested assessment to administer to the HIV/AIDS patients that are referred for occupational therapy is the MOHO’s Occupational Self Assessment. The OSA documents utilized will include the assessment forms and follow-up forms. See Appendix G. The OSA will serve as a guide to goal setting and treatment planning, and also serve as a program evaluation tool (described below).

*Initial Evaluation*

The initial evaluation of the participant will include the outpatient OT services evaluation form (Appendix H) along with administration of the OSA. If time is available the OT and the participant will work together on setting occupational therapy goals based off of the OSA and related to the program objectives. The therapist will encourage volition (personal causation, interest, and values) in goal writing in order to make the goals more meaningful. Through observation and discussion the OT will determine if other assessments will be beneficial (e.g. home assessment, fine motor assessment). By the end of the initial evaluation the OT should be
able to set the number of sessions the participant will need to meet their goals.

*Occupational Therapy Intervention*

The occupational therapist will plan interventions that relate to each patient’s deficits/symptoms, OSA goals, and program objectives. Since the patients’ goals should be written based on MOHO’s Occupational Self Assessment, and the program objectives were written reflecting MOHO theory, all intervention should relate to the Model of Human Occupation and be client-centered.

For patients who have pain, stress, or anxiety affecting occupational performance, the occupational therapist can work on relaxation techniques, coping strategies, and occupational pacing (Birkholtz, Aylwin & Harman, 2004; Laschinger & Fothergill-Bourbonnais, 1999; Weinstein & De Neffe, 1989; Kuen Chan, Gorga, Ilaria, Damson & Jacobs, 1996; Griswold, Evans, Spielman & Fishman, 2005). Relaxation techniques can include: progressive relaxation, deep breathing, or meditation. Coping strategies can be used to control one’s perception of and reaction to stressors, and may include taking a walk, journaling, or deep breathing (St. Vincent’s Public Hospital, n.d.). Occupational pacing would include setting routines in order to balance the number and types of occupations in the day to reduce pain aggravation (Birkholtz, Aylwin & Harman, 2004).

For patients who are experiencing fatigue, the OT can teach energy conservation and work simplification techniques, CPT code 97537 (Hughes, 2004; St. Vincent’s Public Hospital, n.d.; Cusack & Phillips, 1996). Some techniques include: setting daily routines; rearranging household items so the most commonly used items are efficiently placed; or using labor-saving equipment such as electric can openers. In addition, the OT can educate the participant on how to simplify daily occupations at home or work (St. Vincent’s Public Hospital, n.d.; Cusack & Phillips, 1996).
For patients who are continually experiencing difficulty managing medication, the OT can work with the participant on creating a daily routine, CPT code 97532, which would ease the burden of this occupation. The OT will take into consideration the patient’s environments, roles, occupations, and deficits in order to determine a convenient time and way of taking necessary medication.

Assistive equipment might be beneficial to some patients, CPT code 97537. Built up grips on hand utensils will help protect joints and compensate for loss of strength or fine motor control. Reachers will help for decreased ROM that accompanies the wasting syndrome or to help conserve energy. A Personal Device Assistant (PDA) can be a memory aid especially for medication reminders. Grab bars can help prevent falls attributed to peripheral neuropathy or muscle weakness.

Modifications to one’s home may be suggested and include removing objects that could result in falls, rearranging furniture and objects for more efficient use, and installing railings or grab bars. A home assessment and modifications may also address any safety concerns the OT or patient has.

While writing the goals based off of the OSA, the OT will educate the patient on the importance of setting long and short term goals, and involve the patient in the goal writing process. During intervention the OT will work with the patient on writing personal long-term and short term goals. The patient will be able to utilize the guidance and input of the occupational therapist to set goals to work on after discharge from occupational therapy services. After the goal writing process the participant will be able to state how the short term goal is related to the long term goal.

For participants who are not engaging in enough occupation throughout the day or who cannot identify leisure occupations, the OT will brainstorm with the participant on possible
occupations that could be added to one’s daily routine. These occupations could include: past occupations abandoned after diagnosis; new leisure occupations one would like to learn; or current leisure occupations that require compensatory techniques for successful completion. The OT will also discuss with the participant why engagement in occupations is important to their overall health and how occupation can help increase quality of life. These are just a few examples of how an occupational therapist can work with HIV/AIDS patients.

Re-Evaluation & Closure to Therapy

Re-evaluation will include administering the OSA Follow-up form along with re-administering any additional assessments that were initially completed. Closure to therapy will occur if all goals and objectives are met or if the patient decides he or she is finished with therapy. Since a client-centered model of practice is being followed, a patient may decide to end their therapy sessions whenever they want, and the therapist will need to respect that decision. If a patient wishes to discontinue his or her occupational therapy sessions, a re-evaluation will still be completed along with a closure to therapy summary.

Documentation

Documentation for occupational therapy intervention will include: initial evaluation, progress notes, re-evaluation, and closure to therapy summary (described above). All documentation will be written according to documentation standards set by UTMC’s outpatient rehabilitation services. All documentation will available for the other health care professionals at the clinic to review if necessary.

Program Evaluation

Evaluation Procedures

To determine if interfacing the Ryan White program and outpatient occupational therapy services at UTMC is fulfilling the program objectives and meeting the needs of the stakeholders
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The program will be evaluated in both formative and summative ways and at a variety of times. The program evaluation timeline will begin once the first HIV patient starts their occupational therapy sessions. A program timeline is provided in Appendix K.

The program objectives will be evaluated by looking at the percentage of people who met the program objectives they chose to work on. This will be reviewed halfway through the year (approximately months 5 and 6) and then again at the end of the year (approximately months 11 and 12). Looking at these percentages will allow the Ryan White program stakeholders and the outpatient rehabilitation stakeholders to determine if appropriate referrals are being made and whether changes to intervention procedures should be adjusted. The stakeholders can also look to see if there are certain objectives that are not being met more than other objectives and therefore in need of modification.

A second evaluation process will be to look at the Occupational Self Assessment scores. A pretest-posttest no control group design will be utilized and a t-test will be run as an indicator to whether or not people increased their OSA scores. This evaluation will take place twice a year at the same time the above evaluation takes place. The OT will use the scores of participants who have already completed therapy and are no longer receiving OT services. This evaluation process will indicate whether or not occupational therapy interventions are being effective. The scores could also be an indicator of whether or not the patients are receiving enough OT intervention sessions. If the patients’ scores are not increasing by closure of therapy, then the OT may need to reconsider the number of sessions each patient receives.

The last evaluation will be a process oriented evaluation, summarized at the end of the year (months 11 and 12). The evaluation will summarize the number of people who received OT
services, the number of sessions each patient participated in, a list of the most common
intervention, and a list of OSA items most commonly chosen by participants to work on. The
summary will indicate to the OT and to the other health care professionals at the Ryan White
program at UTMC what occupational deficits are most common among the HIV/AIDS
population in Toledo, Ohio. If the interface between the Ryan White program and outpatient
occupational therapy services continues for additional years, the same process oriented summary
could be completed again. This would allow the Ryan White program to track any changes or
improvements occupational therapy services are making over time.

Each evaluation process will include having the OT review files of patients who are no
longer receiving therapy. The evaluation for the first and second evaluation process will take
place during months five and six approximately. The OT will compile data from past patients’
files, analyze the data collected, and compile it into a report to be distributed during the sixth
month. Please see Appendix I for OT the data collection form. The reports will be distributed to
all health care professionals involved with the Ryan White program at UTMC and all health care
professionals involved at the outpatient rehabilitation services department. The OT will meet
with Ann Locher, program coordinator, and Dr. Joan Duggan, program director, to go over the
reports and determine if any changes need to be made and to discuss suggestions for
improvements. Comments and suggestions from the other health care professionals will also be
taken into consideration.

This process will be repeated again during months 11 and 12 approximately along with
the process oriented evaluation summary. To help keep track of the data in the process oriented
evaluation, the OT will continuously update an excel sheet with the included information every
time a patient has completed OT intervention and been discharge from occupational therapy.
After the first evaluation in months five and six, and before the end of the year, the health care
professionals at the Ryan White program and at the outpatient rehabilitation department will have to determine if the interface is being successful for both stakeholders and if outpatient occupational therapy services should continue to be offered (Appendix J).

Letter of Support

Please refer to Appendix L for a letter of support provided by Dr. Joan Duggan, Program Director, and Ann Locher, Program Coordinator at the Ryan White program at UTMC. Dr. Duggan and Ms. Locher were chosen because they have a vested interest in the success of this program. Providing the opportunity for HIV/AIDS patients to receive occupational therapy will help increase the occupational health of this population and decrease some of the effects the progression of the disease brings about. If individuals are experiencing positive effects from engaging in occupational therapy and feeling better overall, they will hopefully continue with all medical treatments provided by the clinic. Satisfaction with occupational therapy may also influence overall satisfaction with the entire clinic. The letter from Dr. Duggan and Ms. Locher shows that the health care professionals at the Ryan White Clinic at UTMC are committed to enhancing existing services to the HIV/AIDS population.
References


In J. Mukand (Ed.), *Rehabilitation for patients with HIV disease* (pp. 283-326).


*The American Journal of Occupational Therapy, 44*, 228-231.
Interview with Ann Locher – Program Coordinator - 1/30/2007

How many patients are the clinics serving?

There are approximately 636 patients receiving treatment between the two clinics. 110 of those patients were new in 2006; which was about a 20% increase.

How are the clinics funded?

Ryan White title III and IV account for approximately $900,000.00. There are five other grants/funding sources: counseling and testing, prevention for positive, healthy relationships, AIDS foundation, and MUO foundation. MUO foundation covers what none of the other grants cover, for example food for support groups, buying someone a bus ticket, printing of the Dear Friends book.

How do people learn about the clinic or how are they referred?

There are two main networks; the local community network and the national network. All the HIV testing sites collaborate with each other and when anyone of those sites gets an HIV positive result, the site calls me (Ann) or Sue (HIV social worker) immediately. OB/GYN clinics know about the program because of education which has been done in the past at those sites. Hospitals know to send patients especially when the persons are not insured. The program tries to get people into treatment within 2 weeks of diagnosis, and a pregnant woman will be seen within 48-72 hours. The other network is an internet network through the Ryan White Care Act which supports programs across the country.

How often are patients recommended to come in?

National guidelines say a patient should be seen, on average, every 3-4 months.
There are always outliers. If a patient is doing well they may be seen every 6 months and only come in for labs. Others don’t show up or drop out of care depending on how they are feeling and therefore are seen less. At the other end are the newly diagnosed patients and pregnant women. After diagnosis the person is seen again within a week or two, and pregnant women are seen every month.

**What are some of the incentives that the program can offer in order to get patients to come in?**

Gas cards, food vouchers are big, lots of bus tokens, and pregnant women all receive a baby basket after delivery. Around Christmas we (clinic personnel) look at people’s needs and have bought clothes or heaters. We (clinic personnel) try to hook people up with the research studies because there is usually a gift card given when someone participates. At support groups we (clinic personnel) try to include some type of social component, especially for the kids. In the past we (clinic personnel) have taken them skating and to Cedar Point.

**Is there any exclusion criteria; reasons why someone could not receive clinic services?**

If a patient burns their bridges with the doctors. There are 3 infectious disease doctors; if a person is being seen by one doctor, he/she can not switch doctors and be seen by another doctor. The reason is due to some patients drug seeking. Insurance can also be a problem. UTMC does not take Buckeye insurance. The clinic can switch patients over to Paramount but that sometimes means switching primary care doctors or pediatricians which a patient may not want to do. So we (personnel at the clinic) let the patients know what the options are and let the patients choose what they want to do. The
last reason someone may be excluded is if they abuse or mistreat the staff and services.

**How do the patients get their meds paid for?**

OADAP – Ohio AIDS Drug Assistant Program. Ohio sets their own criteria for drug coverage eligibility. It is set so that someone at 500 times the poverty level is still eligible to get drugs paid for. In other states there are waiting lists and people need to wait until someone dies in order to get drug coverage. Ohio also covers payment for antidepressants and drugs needed for side effects. The meds cost approximately $15,000/year. Ohio is trying to capture the working poor, so people don’t have to stop working in order to become eligible for drug coverage. Working is so important to this population that we (health professionals) don’t want them to stop working.

**How are the patients educated on meds and the importance of a routine?**

A pharmacist meets with each person to go over side effects and drug interaction. Pill boxes are given out and phone call reminders have been done when necessary. Meds are always addressed when a person comes into the clinic. When there are problems we (clinic personnel) will work one-on-one to determine where the problem is coming from and how resolve it. For some physically swallowing the meds is difficult and for some there is a psychological component. Some people can’t swallow the pills because of what the pills mean and symbolize. It is also important to know what other meds they are taking such as, vitamins, ibuprofen, etc. And the HARK newsletter always has an article about medications.

**Is there anything you feel the patients need but are not getting?**

The need for ongoing counseling, especially in psychiatry to help with the management of medications. Housing and food are commonly a need for patients and
according to Maslow’s hierarchy of needs those have to be met first. We (clinic personnel) cannot get or expect people to manage meds and appointments if their basic needs are not first being met.

**How much interaction with health care professionals can the patients handle while at the clinic? What would be an estimate of time an OT could spend with a patient?**

It varies. Time is adjustable and the professionals shuffle around depending on the needs of a patient on that day. We (clinic personnel) can usually gauge how much a patient can handle. The patients, especially at the family clinic at St. V’s, are aware they may have to stay for awhile and are alright with that. We (clinic personnel) just don’t want to keep people so long that they miss going for their labs. On Fridays most of the clinics at the hospital end around 1pm, so pretty much any room is available for use. The patients are pretty receptive to services that will be beneficial to them.

**Approximately how many patients have problems with neuropathy or pain in general?**

Between about 20-30% pain is an issue. And the pain is usually manifested by missing appointments, lack of activity, or isolation.

**What tools are used to understand the patients’ level of pain?**

The 1-10 pain scale is used, which is inadequate especially for the people who have chronic pain.

**Are there patients that I can talk to about their needs are in regards to occupational therapy?**

Yes, we have a list of people who are always willing to talk and answer questions. Just let me know how many you want and what demographics.
After the interview:

Ann is pretty familiar with occupational therapy, but I did provide Ann with a brief overview of what OT is and how it could benefit the HIV/AIDS population. I informed Ann of what I thought some of the needs of the population were, based on literature I have read and observations I made while at the clinics. Ann then made a few additional comments.

Additional comments:

I (Ann) would like to have a session where the team can be educated on what occupational therapy is and how OT can help patients. Then the team members will be able to help identify patients that might really be in need of OT services. There are also educational dinners for the patients throughout the year where you (Sarah) could present on OT. Through these presentations the patients can learn about OT and how it will benefit them.

Interview with Christie Clinton – Consumer Advocate – 1/30/2007

Do you know what occupational therapy is?

No, not really.

~I described what occupational therapy is and some of the interventions occupational therapists use to help people. I explained that occupation does not refer just to employment but to all the things one does throughout the day. I also explained that OT can help with the things that keep people from doing an occupation, for example helping to manage pain, stay organized, or conserve energy. I shared with her some of the ways I thought OT could specifically benefit the HIV/AIDS population.

Do you think the patients could benefit from OT services?
Yes, definitely. Most of the people probably don’t think about leisure occupations or doing things for themselves. They are always being told what they have to do; they forget they have choices about things they want to do. It would also help them reflect on why they don’t do more things for themselves. Most have probably never set goals for themselves.

Is there anything else you would like to add?

No, I think that’s it.

Interview with Dave Kujawa, Director of UTMC Department of Rehabilitation Services – 4/16/2008

I informed Dave about my Capstone project and how I was trying to connect the Ryan White program with outpatient occupational therapy services. I explained the needs of the HIV/AIDS population and some of the interventions I thought they would benefit from, and how right now occupational therapy referrals are not commonly made. In order to inform the health care professionals at the Ryan White program about appropriate patients to refer I asked Dave about specific interventions and whether they would be reimbursable by insurance. For example, energy conservation/work simplification, home exercise programs, assistive devices, and so on. Dave informed me that these were all reimbursable services and commonly practiced interventions. He also stated that there are a variety of disciplines offered through the rehabilitation department that would be beneficial in the symptom management and care of HIV/AIDS, such as vocational rehabilitation, physical therapy, speech pathology, and neuropsychology. Once a month the rehabilitation department has an in-service meeting and Dave suggested having some of the health care professionals from the Ryan White program to
come over and discuss HIV/AIDS. At this time an informal discussion on how the rehabilitation department could meet the needs of the HIV/AIDS population and increase quality of life could be initiated.
Appendix D

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2. Do you have any weakness or do you feel fatigued throughout the day?

**SUMMARY:** Of the people who answered yes or sometimes, it was generally fatigue they were experiencing. Half of those people say they are fatigued all the time and half say it’s at certain times of the day.

No – 32; Yes – 27; Sometimes/Occasionally – 18

“Don’t sleep well. Mid afternoon, late evening, feel tired”
“Afternoon when kids get home”
“Fatigued in the evening”
“Get tired around 1 or 2”
“Throughout the day”
“Mid afternoon”
“Off and on. Nothing major”
“Sometimes, middle of the day”
“Might be from gaining weight”
“All the time”
“Might be meds. I also have fibromyalgia and chronic back pain”
“Weakness in legs sometimes from neuropathy”
“Maybe a little tired, but fine”
“Most of day. Never any energy”
“Tired always”
“Fatigued around midday, 6 or 7pm”
“Drained/tired throughout the day”
“Fatigued throughout the day”
“On and off throughout the day”
“Mostly job related”
“Just out of hospital last week”
“Weakness in foot – drop foot”
“Weakness in arms and legs”
“Weakness and fatigue, drug related”
“Fatigue, but rarely, between 5 and 8”
“Lack of energy in the afternoon”
“Fatigue from not getting enough sleep”
“Fatigue, always”
“Tired all day, sleeping all day, don’t go out of the house unless I have to”
“Hard to get out of bed. Starting to overwhelm me; exhausted”
“By 4pm I am fatigued”
“I have weakness and fatigue at certain times of the day”
“Get fatigued after certain activities”
“Fatigued at times”
“Sometimes fatigued from over activity”
“Weakness and fatigue comes and goes”

2a. Does it cause any problems with your ability to complete occupations during the day?

SUMMARY: Of the people who said yes or sometimes, 24 said their weakness or fatigue does interfere with daily occupations. Six people said their weakness or fatigue is not interfering.

Of those who answered yes or sometimes/occasionally above:

“Sometimes. Hard to just get up and dressed, to get motivated”
“noticed difference in house chores”
“From time to time”
“Yes, cooking in the evening”
“Have to take a break from what I am doing”
“No” - 7
“Hasn’t so far”
“Can’t walk as much”
“Sometimes. Any time throughout the day”
“Sometimes, depending on the day”
“Not usually, just sleep”
“Hard to get motivated when tired”
“Sometimes, have to force self to do what I have to do”
“Yes because I have a lot of responsibilities”
“Yes” - 7
“Sometimes” – 5
“Other people have to drive me around and make me meals”
“Just sluggish”

2b. Do you have any pain and does it interfere with your ability to complete occupations.

**SUMMARY:** The most common complaint of pain is related to pain in the lower body, followed by back pain. When asked if it interferes with their ability to complete daily occupations, 17 of 32 said yes.

Yes – 32; No – 45

“Hurts to go shopping, limits abilities”
“Achy. Standing for periods of time – laundry and dishes”
“Back pain. Can’t stand for long periods of time. Will have to go home from running errands if pain is too much”
“A little”
“Back and hip. Don’t let it get in the way of my day”
“Back and neck pain”
“Constantly. A lot”
“Back, knee, and hip. Can’t lift, bending is hard, stairs, standing, and walking long distances”
“All over. Sometimes”
“Back pain 24/7”
“Back pain”
“Slight back pain, bursitis in hip, neuropathy in arm”
“Ankles, makes it difficult to walk and stand”
“Back and head pain, yes it interferes”
“Back pain. Yes”
“Hip joints. I limp when I walk”
“Mostly legs, but at times whole body. Hurts to do anything”
“Neuropathy pain in hands and feet. Not really, just tough it out”
“Chest pain from upper respiratory infection”
“Knees”
“Knee pain. Can be irritating when walking”
“Sometimes, no, could work part-time but not full-time”
“Left arm pain from IV’s, it’s not going away and feeling like it is getting worse”
“Migraines”
“Leg pain, nerve pain”
“Arms and legs. Yes”
“All over and throughout the day. Yes”
“Stomach pain, pancreatitis”
“Hip pain”
“Neuropathy”
“Some leg pain”
“Joint and muscle pain, aches and cramps in legs, arms, and stomach”
“General all over pain”
“Knees and back”
“Continuous back pain; hurts but still doing stuff”
“Not feeling good at all”
“Ankles (arthritis)”
“Back and wrist (carpal tunnel)”
“Pulled muscle in back”

2c. How are you coping with weakness, fatigue, or pain?

**SUMMARY:** The majority of people with weakness, fatigue, or pain issues are not using healthy coping strategies. They are sleeping, taking pain meds, blocking it out, or just dealing with it. Of the people who had coping mechanisms, some included God and prayer, meditation, accepting help from others.

“Go to sleep when fatigued”
“Take a nap or coffee”
“Go sit in another room for a few minutes”
“Truck through it. Take a nap or rest”
“Pain meds” – 10
“Block it out”
“Naps” - 5
“No strategies”
“Have to take my time”
“Ignore, push out of head”
“Just deal with it” - 4
“Lot of help from kids. Lay on couch or in bed”
“Just living day to day”
“Go lay down, pain meds, go to bed”
“Block out pain”
“I’m not. I’m a couch potato”
“Get headaches and am cranky. Can’t take naps, force through it, pain meds. Did PT for hip”
“Pain meds, have trouble sleeping”
“Just sit” - 2
“Go to sleep” - 3
“Just deal with it. Sit down and don’t move. Turn to God and pray”
“Try to get a good night’s sleep. Jest deal with pain, pain meds. Going to ER when really bad”
“Possible knee surgery”
“IB profin, meditation, prayer, reading, TV, walking, music”
“Help from others”
“Just getting through it”
“Don’t”
“Lay down on the couch” - 2
“Best I can”
“Just part of life”
“Slow down, take a break, careful in cold weather”
“Watch TV”
“MRI – seeking specialist”
“Just keep going and stay motivated”

3. Can you think of anything you do throughout the day that you are limited in doing or wish you could do better? It could be in the home, at work, or in the community.

SUMMARY: Most people feel they are successful with their daily occupations. Of those who felt there were challenges, it involved performing daily living occupations, such as cleaning the house, or it was related to their motivation and energy level.

No – 44; Yes – 33

“Need to make more money”
“More drive and ambition, less fatigue”
“More motivated to exercise and stop smoking”
“Wish had more energy to do stuff. Transportation limitations”
“House chores”
“Everything”
“I only do things I know I will be successful at”
“Looking for a job”
“No motivation to do anything. Tiredness from working”
“Cleaning house and activities at home are a lot harder”
“Social life – don’t have one, difficult to get around”
“I have no memory left. Can’t remember day of week, what I had for dinner the night before. I get lost all the time, no sense of direction”
“Exercising”
“Back injury in past I have to be careful of, but I am doing everything I need to”
“Sleep is difficult”
“Wish health could be better. Worry that health is failing like it is”
“Vacuuming the floor.  Don’t like to cook as much – don’t feel like doing it”
“Bending over to get things that are down low, socks and shoes, laundry, low cabinets”
“Energy, energy level is not there”
“Endurance is low, but can do most everything”
“Memory loss”
“Keeping the house clean the way I use to.  Husband cleans now”
“Hard time getting around, shaky, bad balance”
“Being prompt to appointments’
“Gaining weight”
“Cooking more”
“Hard time concentrating or finishing tasks.  Mind wanders and I start a new task and forget about what I was doing prior”
“Cleaning, sweeping, and mopping”
“Making more money, can always do better”
“Trying to get organized and finding a place to live”
“Getting bills straightened out.  House cleaning only on weekends now. Overwhelmed with too much to do”
“Trying to get a job”
“Get frustrated easily”

4. Are you able to manage your medications among other daily responsibilities?

SUMMARY: The majority of people (62 of 77) say they are able to manage medications along with their other responsibilities. When followed-up with a second question about missing meds, 12 of the 66 mentioned sometimes they miss and explained why. There are 6 people who are not on HIV meds at this time. 10 people stated they are on HIV meds but are not taking them.

“Yes” – 62

“Struggled”
“Yes and No.  Big and I gag on them.  I don’t think they work”
“Not on meds, they don’t help”
“Bad one at that, it’s a psychological thing.  I’m good at the depression meds, but bad with the HIV meds”
“No, haven’t been taking them”
“When I have them”
“No”
“Trying”
“Haven’t been on any lately, will be a challenge”

So, no problems with missing meds?

“But I haven’t been on them for awhile”
“Well, I’m not on them at the moment”
“At times, when out of town”
“Only when I don’t have them”
“Sometimes. Don’t feel like taking them, they’re not doing anything”
“Except when sleep too long”
“On occasion, when sleep too late”
“Occasionally”
“Every so often I have forgotten, not often”
“Not lately”
“But not taking right now. I can forget often”
“Sometimes I forget”

4a. How do you manage your medications?

**SUMMARY:** The majority of people rely just on their memory to take their meds. They say it is a habit and they keep their meds on the counter, nightstand/dresser, in their room, or always in the same place; this way they remember to take them. 27 people said they take their meds first thing in the morning or right before bed in order to remember, and 15 people use a pill box.

“Routine to take at night. Kept in same place”
“No schedule or assist when on meds”
“Kept in purse. Memory”
“Take first thing in morning. Kept in my room”
“First thing in the morning. Kept in the same spot”
“One a day, 12:00, memory”
“Pill box. Knows schedule (memory) – morning and evening meds”
“Take them at the same time every night”
“Memory. Set up for morning or night. Dresser in room”
“Kept in same spot, memory”
“Kept in drawer where seen everyday”
“Pill box” - 5
“Pill container. Set up every Sunday”
“Kept on nightstand”
“All at night, right before bed”
“Right before bed” - 2
“Memory, same routine. No HIV meds yet”
“Pill box, kept in same spot”
“On night stand. Lined up for time to take”
“Memory” - 4
“Memory, keep in a bag”
“Case (pill box) filled for week”
“Pill box, set up for 2 weeks out”
“Keep them where I can see them”
“Before I go to bed” - 2
“Habit”
“Memory, in morning to get them over and done with”
“Ask roommate”
“Take 2 times/day, memory” - 3
“Take all at one time”
“Same time everyday” - 3
“Take in morning, leave on counter”
“I put the pills in cups and write on them what time to take them. I then stack the cups in the order for the day”
“Take with food and early”
“Bedtime”
“Like clockwork”
“Am/pm pill box” - 2
“Pill box for the week, am/pm”
“Containers I fill at night and take in the morning”
“Set them out”
“It’s clockwork, automatic”
“Pill container, friend”
“Memory, read bottle, no pill box right now”
“Routine, twice a day, pill box kept in pocket”
“Set out on the counter”
“Routine”
“Take in the morning”

5. At the end of the day have you been able to complete everything you planned to do that day?

**SUMMARY:** The majority of people are either not completing what they planned for the day or only sometimes completing what they planned for the day. Some make no plans to do anything and only two are overactive.

Yes – 24; No – 17; Not always/Sometimes/Mostly – 29

“Teenagers get in the way”
“Lazy, lack of motivation, depression”
“Getting to work, that’s good enough for the day”
“Kids get in the way”
“Being tired and lack of sleep get in the way, need a nap”
“Depends on what is planned for day and available transportation”
“Not always, over task, do too much”
“Kids routines get in way”
“No plans to do anything”
“Usually, very organized”
“Me (herself) and the TV”
“Get side tracked, very active”
“Laziness”
“Not always, very seldom, maybe ½ of my list”
“Don’t plan for day, what happens happens”
“Don’t really set things out to do for day. On disability. Do nothing”
“Don’t plan a lot for day”
“Don’t plan stuff for day”
“I don’t know”
“Being tired, diarrhea, getting out of bed, vomiting”
“Sleepiness, not enough time in the day”
“Hell no, but doesn’t bother me”
:Have hard time remembering what I need to do for the day. Use to-do lists”
“Don’t have anything to do during the day”
“Try not to set too many goals for day. As long as I get to work on time, I’m happy”

6. Do you set short or long term goals for yourself? Why or why not?

SUMMARY: 60 people set goals whether both, short, or long term goals. People stated they set short term goals over long term because they are easier to reach. People said they set goals because they want to achieve or accomplish something. 16 people do not set any goals because they live day by day, they have already accomplished their goals, or they do not want to let themselves or others down.

Yes (both) – 39
“Since I’ve been in prison”
“Make sure I accomplish something”
“To achieve more”
“To be successful one day. Need goals to do that”
“Short because helps work towards long term. Long term because getting older and I have an idea of where I want to be in the future”
“To have something to keep working at”
“Because can’t have everything right away, has to be built up slowly”
“Because if you don’t you won’t get where you want to go”
“To get things done”
“Want to do something. Even things I shouldn’t be doing and will pay for consequences later”
“Only way to get though the day, to have something to look forward to”
“To achieve the best”
“I’m busy and it helps me to get the things I need to get done”
“Try to, if it really needs to get taken care of”
“Want to go back to school”
“Keep me focused on what I need to do”
“Trying, but whenever I try I fail”
“It’s a habit”
“I’m a person who likes to achieve things”
“Because I don’t know what the future holds; live for today”
“For grandkids”
“Depends on what the job is”
“All the time. Things in life I want to do”
“To a certain extent. Helps me get through certain periods of time; to do my best”
“I try. See how productive my days are”
“To be successful”
“So I can continue to strive towards something, keep focus”
“Sometimes short, sometimes long. Change mind on what I want to do. Start, stop, and go back”
“Currently in school”
“Plan ahead what needs to be done”
“To get things accomplished”
“I’m a planner, that’s my personality”
“Give me something to do”
“Feel it is important in order to see where life is going and better life”
“So I know what to do throughout the week”
“Keep focused”
“Something I’ve always done”
“Because I have to”
“Car and work goals. Trying to get where I can manage and cope with my life”

Long term – 9
“Self-motivation”
“Because of condition, want to see great grandchildren”
“Keeps me motivated”
“Helps focus on future. But difficulty with reaching them”
“To make a change in something. Something different each year”
“Long term, want to see grandkids grow up”
“Can take time to get done with goals, and I’m not in a rush”
“Goal to raise son right, make sure he gets a good education”

Short term – 12
“Easier to reach than long term”
“Because can remember short term”
“Very short. Don’t want to let anyone down”
“Plan ahead for two weeks. Have had AIDS for 22 years, don’t know how much time is left”
“Long term goals would never get done”
“Short, have to go day by day, less overwhelming”
“Short, lot of lists that I can then accomplish”
“I don’t look too far ahead”
“Short term when I have goals”
“Short because I want to finish tasks. Long term foals not usually met”
“I don’t want to overwhelm myself”

No – 16
“Live day by day”
“Don’t know what those are”
“A lot on mind, don’t know”
“Hard enough just to get through the day. Depressed”
“Not recently. Because of situation, unsure about things. Don’t know what to expect”
“Tired of letting self and others down”
“Don’t have any”
“Too old”
“Go day by day”
“No. Already completed the ones I had”

7. Do you pursue leisure occupations? Why or why not?

SUMMARY: About 1/4 of people said they do not pursue leisure occupations (things they enjoy, do for fun, hobbies). Of the people who do pursue leisure occupations, the occupations tend to be solitary (reading, computer games, music, TV, drawing). Some visit with friends, play with grandkids, or help family members.

Yes – 49
“Computer games, music. Play dominoes with friends”
“Read, talk on the phone”
“Draw, everyday”
“Read, listen to music”
“Read, listen to music, play cards”
“Play cards about every 2 weeks”
“Drink with girls. Go out”
“Out with friends, luncheons. To park with kids”
“Watch TV. Don’t listen to music anymore, know that is a sign I am depressed”
“Computer, swim, go out to dinner and movies. Because of grandkids”
“Every Sunday go to dinner and movie with friends”
“Sports and games with kids”
“Watch TV”
“Play guitar and 30 different instruments, sew, read, crochet, cat”
“Takes mind off of other things”
“Go to basketball games”
“Shoot pool, watch movies/TV, cook”
“Movies, fishing, nature walking, play with kids. They are fun to do”
“Watch movies, cook, sew”
“Watch TV since back in Toledo”
“Church, cooking. Because we have to eat, it’s a source of income, because of family dinners”
“Bowling and shooting range”
“Play drums and draw, since I was a kid”
“Woodworking”
“Fishing, golf but not much. Right eye lost sight and left eye is blurry”
“Stress reliever”
“Reading” - 5
“Socializing”
“Vacations, not much else”
“I enjoy them, manage stress, socialization”
“Shopping, cause I like it”
“Decorating around the house, concerts with nieces/nephews. I’m a homebody, I think I should do more”
“Play in a band, sports”
“Sew. It relaxes me”
“Play cards, time with nieces and nephews”
“Music, dancing, sport activities. Not much time though to do”
“Gardening, computer”
“Working out at gym”
“Read, needlework, travel when I can to see kids. For enjoyment, it’s relaxing, something to do other than TV”
“Living life, life is an art”
“Time consumed with kids, sometimes I scrapbook”
“Music”
“Sometimes. I get bored and like to do them”
“Yes, for sanity reasons”
“Word search books”
“Trying to learn things to do with son. Retreats twice a year, church, and bible study”
“To treat yourself to fun things”

No - 19
“Home-body. Kids main focus”
“Not so much anymore. Friends are gone. I’m a caregiver to someone. Don’t read much anymore, mostly quiet time”
“Pain”
“Because I can’t run anymore which I use to enjoy”
“No, just computer and reading”
“Not much because of financial situation”
“Not usually because of time. Bingo occasionally”
“If I had the time”

7a. (question added on) Do you work?

No – 40; Yes – 21; volunteer - 3

8. Have you experienced any falls or accidents while performing daily occupations?

SUMMARY: Of the people who have had accidents it was usually tripping, falling, or losing balance.

No – 53

Yes – 24
“Sprained knee when getting up to quick; was just in hospital for pneumonia”
“Playing basketball with younger guys”
“Everyday. Neuropathy from knees down. Lots of trips”
“Running into things around the house. Off balance, knees go out”
“Fell down steps at home”
“Trip while walking. Twisted left foot while out shopping”
“Not really, but lose balance a lot and difficulty getting up because of hips”
“Fell and twisted ankle, tripping while walking”
“Once”
“In earlier years when involved with more risk taking behaviors. (lost 2 front teeth)”
“Almost fell a couple of times”
“A couple of smashed fingers and hands – work related”
“Seizure”
“Trouble with neuropathy and fell a lot years ago, nothing recently”
“Trip a lot but never fallen”
“Little bit dizzy and light headed”
“Hit my head a lot”
“Equilibrium is sometimes off”
“I was having seizures”
“Not recently. A little clumsy, I feel like I have a mobility problem. No speed and that gets in the way”
“Once, I was in the hospital for a few days”

9. Do you exercise? Why or why not?

SUMMARY: Most people do not exercise. Four don’t want to lose weight, stating they are too skinny right now and trying to gain weight. People stated laziness, lack of motivation as reasons as to why they didn’t exercise. Several also stated that walking and climbing the stairs was exercise enough. Of the people who do exercise the most common type was walking followed by weights.

No – 49
“Don’t want to lose any more weight”
“Going to start. Weight training”
“Too cold to walk”
“Don’t know. Up and down the stairs is exercise enough”
“Lazy” - 4
“I walk a bit everyday”
“Don’t know. Other priorities”
“Trying to gain weight”
“Holidays, laid off of work, like food”
“Need to know the right kind of exercise for my condition”
“Hard to get around. Just getting dressed is hard”
“No motivation”
“Not enough, when not it pain”
“I think I should start though”
“Stairs are difficult”
“No clue. I do some work related exercise”
“Ankle pain”
“Because constantly walking, no car”
“Too cold outside. Just don’t, pain”
“Not into it, being lazy”
“Don’t know”
“Because of back condition”
“Just don’t, no finances to join a club”
“No reason to”
“No energy”
“Not at the moment, would like to, don’t have balance and coordination”
“Only work related exercise, nothing outside of work”
“Not lately, can’t hardly walk”
“As soon as it warms up I will be walking”
“Don’t want to lose weight, too skinny”
“Stress”
“Hate it, boring”
“Use to, but now too lazy”
“I have a little one to run after”
“Too tired”
“Pregnant”
“Busy, and can’t afford it”
“Going to get into it, hard to keep at it”
“Don’t have energy but going to start”
“Just don’t, haven’t given it any thought”
“Achilles tendon injury; putting on shoes can be difficult”
“I just don’t, but want to”
“Need to gain energy and pounds first and then will start working out”

Yes – 21
“Because of dog, have to walk”
“But not much”
“Sometimes”
“Keep weight under control”
“Because it helps heart and I’m overweight”
“Try to every now and then”
“I go with my son”
“Keep healthy”
“For my back”
“Keep in shape, lose weight”
“But not much this winter”
“Don’t want to gain any weight, in a wedding”
“Sometimes because I know it makes me feel better. I don’t exercise as much as when I was younger. Don’t want to join a gym”
“I’m 43 and trying to compete with 20 yr olds”
“Something to do, keep body in shape”
“Cause I’m getting fat”
“To stay in shape”

9a. What kind and how often?

“Walks daily”
“Walking 2 times/week”
“Cycling class once a week”
“Walk daily”
“Walk but not a lot”
“1/2 mile twice a day with dog”
“Sit-ups, arms, and legs”
“1/2 hour per day”
“Walk a lot”
“Bike, but get tired fast”
“Aerobic and weights”
“Sit-ups and squats”
“Walk, weather permitting, 2 times/week”
“2 times/week”
“Weights and squats”
“Weights, walking, bike – 20-30 miles”
“Gym, 4 times/week”
“Gym, a couple times a week”
“5 days of cardio and 2 days of resistance”
“Pilates, core, gazelle, 4 times per week”
“Walk a lot”
“Up and down stairs, walking”
“6 days/week. 40 min cardio and 20 min weight training”
“Just day to day activities”
“Walk, once or twice a day”
“Walk dog, 2 times/day”

10. Have you ever had anyone come into your home for help or assistance?

No – 60; Yes – 17

10a. Did you find them helpful?

“Yes, nurse who changed dressings. Family and kids come over and help most”
“Yes. Family assistance”
“No. Irritated that I couldn’t do what the person wanted me to do”
“Got on nerves”
“Yes, it was a nurse”
“Yes” – 9
“After surgery. In the beginning”
“Yes and annoying”
“Just family, and they were helpful”

11. Would you be comfortable with having an occupational therapist come into your home? If yes, more than once, and if no, why not?

SUMMARY: Most people stated they are comfortable with an occupational therapist coming to their home if they are in need of OT services. Most people also stated they would be comfortable going to an outpatient facility for OT services if they needed to. People answered yes more quickly to the OT coming to the home versus going to an outpatient facility. People tended to be hesitant about saying yes I would go to an outpatient facility, but would go if they really needed OT services.

Yes & Yes - 69
“As long as they are helpful”
“If I really needed it” - 3
“As long as daughters aren’t there”
“Whatever necessary”

Yes but just once - 2

No – 2
“I don’t live alone”
“No reason as to why”

Maybe – 4
“Depends on the person and my comfort level”
“Maybe, have to think about it”
“Depends on who it is and the service they are providing”
“Not sure”

11a (question added on) Would you be comfortable going to an outpatient facility to receive occupational therapy services?

Yes – 41; No – 3; Probably – 4; Don’t know - 2

“Possibly, depends on the therapist, if it was one-on-one”
“Probably not feel comfortable but eventually would accept it”
“If I needed to”
“If covered by insurance”
“I know most of the people in town”

11b (question added on) What do you spend most of your day doing, what consumes most of your time?
SUMMARY: Work and leisure occupations consumed most of people’s day. Seven people are spending most of their days cleaning up around their house. Only 5 cannot think of what keeps them busy, stating they are doing nothing or watching TV most of the day.

“Downtown library to study”
“House and kids”
“Getting meals ready”
“Trying to remember what I forgot”
“Laying around”
“Sleeping, napping”
“Taking care of others”
“Caregiving”
“Trying to figure out how to make more money for a car”
“Cleaning” - 2
“Household chores and organizing”
“TV” – 9
“Boredom”
“Nothing. Computer, library, reading”
“Nothing”
“Mental health therapy”
“Time with grandson. When the weather is nice I go fishing”
“With wife, live in the country”
“Smoking cigarettes”
“Taking care of self, ADL’s. Taking care of others – home care”
“Cleaning up around house”
“Computers, research time, phone, work related stuff”
“Working and school work, helping with homework”
“School” - 2
“Trying to eat and get better”
“Starting a lot of things, but I’m never finishing them”
“Helping others (family members)”
“Driving other people around, personal taxi driver to friends”
“Computer” - 2
“Taking care of pets”
“Sleeping” - 2
“Work and hobbies”
“Thinking about work”
“Baby”
“Church and computer”
“Work and recreational time”
“Working” - 10
“Cooking, cleaning, and talking to ARC”
“Work and studying”
“Watching TV and watching kid”
“Straightening house, TV”
“Spending time with sister and helping her out”
“Dealing with mother’s cancer”
“Reading and watching TV. In the summer, outdoor activities”
“Looking for a job”
“Physical activities”
“Women groups”
“Kids”
“Love to cook”
Appendix E

Interview Questions for HIV/AIDS Patients

Occupational therapy helps people to stay independent and functional by working on occupations that are meaningful and purposeful to the client. Occupations are all the things one does throughout the day; occupations can be related to your self-care, work, or leisure pursuits. Meal preparation, bathing and dressing, driving, going to work, cleaning, grocery shopping, and playing cards are all examples of occupations. When a person has difficulty completing occupations, an occupational therapist will work with a person to find a solution to the problem.

Occupational therapists believe environmental, social, behavioral, cultural, and physiological characteristics can impact one’s ability to be independent and enjoy the quality of life.

1. Do you have any questions about what occupational therapy is?
2. Do you have any weakness or do you feel fatigued?
   2a. Does it cause any problems with your ability to complete occupations during the day?
   2b. Do you have any pain and does it interfere with your ability to complete occupations.
   2c. How are you coping with weakness, fatigue, or pain?
3. Can you think of anything specific you do throughout the day that you are limited in doing or wish you could do better? It could be in the home, at work, or in the community.
4. Are you able to manage your medications among other daily responsibilities?
4a. So no problems missing meds?

4b. How do you manage your medications?

5. At the end of the day have you been able to complete everything you planned to do that day?

6. Do you set short or long term goals for yourself? Why or why not?

7. Do you pursue leisure occupations? Why or why not?

8. Have you experienced any falls or accidents while performing daily occupations?

9. Do you exercise? Why or why not?

9a. What kind and how often?

10. Have you ever had anyone come into your home for help or assistance?

10a. Did you find them helpful?

12. If you were in need of occupational therapy services would you be comfortable going to an outpatient rehab facility to receive those services?

13. Would you be comfortable with having an occupational therapist come into your home? If yes, more than once, and if no, why not

13. What do you spend most of your day doing? What consumes most of your time during the day?
Appendix F
Occupational Therapy Patient Profile

Does a patient need occupational therapy services?
An ideal OT candidate will have one or more of these symptoms and be willing to participate in occupational therapy services at an outpatient rehabilitation facility. The person probably has poor coping mechanisms or a limited number of coping mechanisms.

Fatigue: Does it interfere with the person’s ability to manage and complete their daily occupations? Are they keeping up with their daily responsibilities at work and home (cleaning, cooking, running errands)?

Pain: Is the person experiencing increasing levels of pain while performing occupations? Is the person avoiding occupations because it causes pain or increases pain levels? Are pain meds not alleviating pain completely?

Safety: Are there safety concerns related to weakness or mobility in the home and/or environment (e.g. fall hazards)?

Exercise: Is the person exercising, do they want to exercise? Have they attempted exercise programs and been unsuccessful? Are they concerned with the type of exercise appropriate for them?
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<th>No</th>
<th>Don't know</th>
<th>I'm not sure</th>
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<tr>
<td>Question 2:</td>
<td></td>
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</tr>
<tr>
<td>Question 3:</td>
<td></td>
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<tr>
<td>Question 4:</td>
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<td></td>
</tr>
<tr>
<td>Question 5:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Appendix G**

**Occupational Self Assessment**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>I'm not sure</th>
<th>It's not applicable</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question 2:</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Question 3:</td>
<td></td>
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<td></td>
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<tr>
<td>Question 4:</td>
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<td></td>
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</tr>
<tr>
<td>Question 5:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note:** If any item does not apply, circle it and move on to the next. For each statement, check how true or false it is for you.
<table>
<thead>
<tr>
<th>Activity</th>
<th>Would Like to Change</th>
<th>Possible Interests</th>
<th>How Do I Interact with Others?</th>
<th>The Interactions are Important</th>
<th>Would Like to Change</th>
<th>Possible Interests</th>
<th>How Do I Interact with Others?</th>
<th>The Interactions are Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Connecting with others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socializing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Misfit (continued)**

**Occupational Self-Assessment**

**Name:**

**Step 1:** Insert the steps above that apply to you.

**Step 2:** Insert the steps above that apply to you.

**Step 3:** Insert the steps above that apply to you.

**Step 4:** Insert the steps above that apply to you.

**Step 5:** Insert the steps above that apply to you.
### My Environment

**Occupational Self-Assessment Form**

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>Problem</th>
<th>行动计划</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel comfortable in your environment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel supported by your environment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel respected by your environment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel safe in your environment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel appreciated by your environment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel valued by your environment?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Step 1:** Below are statements about your environment. Where you feel a problem, place a check mark in the box. For each statement, circle the number that best describes how you feel.

1. I feel comfortable in my environment.
2. I feel supported by my environment.
3. I feel respected by my environment.
4. I feel safe in my environment.
5. I feel appreciated by my environment.
6. I feel valued by my environment.

**Step 2:** Cross out 2 things that you feel you could change.

- [ ] I feel comfortable in my environment.
- [ ] I feel supported by my environment.
- [ ] I feel respected by my environment.
- [ ] I feel safe in my environment.
- [ ] I feel appreciated by my environment.
- [ ] I feel valued by my environment.

- [ ] I would like to change the place I live and the care I receive.

**Step 3:** Check the box if you need any assistance to make changes.

- [ ] Yes, I need assistance.
- [ ] No, I can do it on my own.

**Step 4:** Provide any additional comments or suggestions.

---

**Home-Based OT for HIV/AIDS Population**

- [ ] People who care about me
- [ ] My children
- [ ] My friends
- [ ] My neighbors
- [ ] Opportunities to do things I like
- [ ] Things I need to be productive
- [ ] The basic things I need to live
- [ ] The things I need to be safe
- [ ] The things I need to be healthy
- [ ] The things I need to be independent
- [ ] The basic things I need to learn
- [ ] The things I need to live
- [ ] The things I need to work
- [ ] The things I need to study
- [ ] The things I need to be a part of a community

---

**Name:**

**Date:**
# Occupational Self Assessment Follow-up Form

| Name: | Date: |

### Step 1: Below are statements about things you do in everyday life. For each statement, circle how well you do it, if an item does not apply to you, cross it out and move on to the next item.

<table>
<thead>
<tr>
<th>Task</th>
<th>Lot of Problem</th>
<th>Some Difficulty</th>
<th>Well</th>
<th>Extremely Well</th>
<th>Not so Important</th>
<th>Important</th>
<th>More Important</th>
<th>Most Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concentrating on my tasks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical doing what I need to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking care of the place where I live</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Taking care of myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking care of others for whom I am responsible</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Getting where I need to go</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing my finances</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing my basic needs (food, medicine)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expressing myself to others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Getting along with others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identifying and solving problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxing and enjoying myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Getting done what I need to do</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Having a satisfying routine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Handling my responsibilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being involved as a student, worker, volunteer, and/or family member</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing activities I like</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working towards my goals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making decisions based on what I think is important</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accomplishing what I set out to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effectively using my abilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Step 2: For each statement circle how important this is to you.

<table>
<thead>
<tr>
<th>的重要性选项</th>
<th>Lot of Problem</th>
<th>Some Difficulty</th>
<th>Well</th>
<th>Extremely Well</th>
<th>Not so Important</th>
<th>Important</th>
<th>More Important</th>
<th>Most Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Important</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Occupational Self Assessment Follow-up Form

**My Environment**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date:</th>
</tr>
</thead>
</table>

**Step 1:** Below are statements about your environment (where you live, work, or go to school, etc.). For each statement, circle how this is for you. If an item does not apply to you, cross it out and move on to the next item.

<table>
<thead>
<tr>
<th>There is a lot of problem</th>
<th>There is some problem</th>
<th>There is good</th>
<th>There is extremely good</th>
<th>This is not so important to me</th>
<th>This is important to me</th>
<th>This is more important to me</th>
<th>This is most important to me</th>
</tr>
</thead>
<tbody>
<tr>
<td>A place to live and take care of myself</td>
<td>lot of problem</td>
<td>some problem</td>
<td>good</td>
<td>extremely good</td>
<td>not so important</td>
<td>important</td>
<td>more important</td>
</tr>
<tr>
<td>A place where I can be productive (work, study, volunteer)</td>
<td>lot of problem</td>
<td>some problem</td>
<td>good</td>
<td>extremely good</td>
<td>not so important</td>
<td>important</td>
<td>more important</td>
</tr>
<tr>
<td>The basic things I need to live and take care of myself</td>
<td>lot of problem</td>
<td>some problem</td>
<td>good</td>
<td>extremely good</td>
<td>not so important</td>
<td>important</td>
<td>more important</td>
</tr>
<tr>
<td>The things I need to be productive</td>
<td>lot of problem</td>
<td>some problem</td>
<td>good</td>
<td>extremely good</td>
<td>not so important</td>
<td>important</td>
<td>more important</td>
</tr>
<tr>
<td>People who support and encourage me</td>
<td>lot of problem</td>
<td>some problem</td>
<td>good</td>
<td>extremely good</td>
<td>not so important</td>
<td>important</td>
<td>more important</td>
</tr>
<tr>
<td>People who do things with me</td>
<td>lot of problem</td>
<td>some problem</td>
<td>good</td>
<td>extremely good</td>
<td>not so important</td>
<td>important</td>
<td>more important</td>
</tr>
<tr>
<td>Opportunities to do things I value and like</td>
<td>lot of problem</td>
<td>some problem</td>
<td>good</td>
<td>extremely good</td>
<td>not so important</td>
<td>important</td>
<td>more important</td>
</tr>
<tr>
<td>Places where I can go and enjoy myself</td>
<td>lot of problem</td>
<td>some problem</td>
<td>good</td>
<td>extremely good</td>
<td>not so important</td>
<td>important</td>
<td>more important</td>
</tr>
</tbody>
</table>

**Step 2:** Next, for each statement circle how important this aspect of your environment is to you.
Appendix H

MEDICAL UNIVERSITY OF OHIO AT TOLEDO
UNIVERSITY MEDICAL CENTER

REHABILITATION SERVICES
OUTPATIENT OCCUPATIONAL THERAPY EVALUATION

☐ INPATIENT  ☐ OUTPATIENT

DATE:  TIME:  DIAGNOSIS:

HISTORY

HOME:

EQUIPMENT:

<table>
<thead>
<tr>
<th>LEFT</th>
<th>UE FUNCTION</th>
<th>RIGHT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RANGE OF MOTION</td>
<td></td>
</tr>
<tr>
<td></td>
<td>STRENGTH</td>
<td></td>
</tr>
<tr>
<td></td>
<td>COORDINATION</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TONE</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SENSATION</td>
<td></td>
</tr>
</tbody>
</table>

PAIN:

COMMENTS:

<table>
<thead>
<tr>
<th>FUNCTIONAL MOBILITY</th>
<th>ACTIVITIES OF DAILY LIVING</th>
</tr>
</thead>
<tbody>
<tr>
<td>POSTURE:</td>
<td>BATHING:</td>
</tr>
<tr>
<td>BALANCE:</td>
<td>GROOMING:</td>
</tr>
<tr>
<td>MOBILITY:</td>
<td>BATHING:</td>
</tr>
<tr>
<td>ENDURANCE:</td>
<td>UE DRESSING:</td>
</tr>
<tr>
<td>RED MOBILITY:</td>
<td>LE DRESSING:</td>
</tr>
<tr>
<td>TRANSFERS:</td>
<td>HOMEMAKING:</td>
</tr>
</tbody>
</table>

COMMENTS:

LEISURE:

<table>
<thead>
<tr>
<th>VISION/PERCEPTION</th>
<th>COGNITION/BEHAVIOR</th>
</tr>
</thead>
</table>

COMMENTS:

PATIENT GOALS:

<table>
<thead>
<tr>
<th>PROBLEM AREAS</th>
<th>GOALS</th>
</tr>
</thead>
</table>

Signature:
### Appendix I

#### Data Collection for Ryan White Occupational Therapy Patient Participants

<table>
<thead>
<tr>
<th>Patient &amp; Date</th>
<th>Initial OSA score</th>
<th>Final OSA score</th>
<th># of Intervention sessions</th>
<th>Objectives met (yes or no)</th>
<th>OSA Item(s) chosen to work on</th>
<th>Type(s) of Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>20</td>
<td>18</td>
<td>17</td>
<td>16</td>
<td>15</td>
<td>12</td>
</tr>
</tbody>
</table>

#### Summary

<table>
<thead>
<tr>
<th>OSA score comparison (t-test)</th>
<th>Average # of sessions</th>
<th>Percentage of people who met objectives</th>
<th>Most common OSA Item(s) chosen</th>
<th>Most common intervention types</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6 months</th>
<th>1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>OSA score</td>
<td>comparison</td>
</tr>
<tr>
<td></td>
<td>(t-test)</td>
</tr>
<tr>
<td>Average # of</td>
<td>sessions</td>
</tr>
<tr>
<td>people who</td>
<td></td>
</tr>
<tr>
<td>met objectives</td>
<td></td>
</tr>
<tr>
<td>Most common OSA</td>
<td>Item(s) chosen</td>
</tr>
<tr>
<td>Item(s) chosen to work on</td>
<td></td>
</tr>
<tr>
<td>Most common intervention types</td>
<td></td>
</tr>
</tbody>
</table>
Appendix J

Ryan White and Department of Rehabilitation Stakeholders
Program Evaluation Questionnaire

Interface between the Ryan White program and outpatient occupational therapy services

1. Are occupational therapy services positively impacting Ryan White patients?

2. Are appropriate referrals being made?

3. Are HIV patients following through with their appointments?

4. Any suggestions for improvement?

5. Any questions or concerns?
Appendix K

Program timeline for interfacing the Ryan White program with outpatient occupational therapy services at UTMC

Orientation/in-service: The department of rehabilitation services at UTMC has an in-service the third Thursday of each month. Health care professionals from the Ryan White program will present to the outpatient rehab department about the Ryan White program and HIV/AIDS. An informal discussion will take place about services that are available through the rehab department that would benefit the HIV/AIDS population.

~PROGRAM EVALUATION~

Months five/six – half way through the year
Evaluation of program objectives: The percentage of people who met their program objectives compared to the percentage of people who did not meet their program objectives.
Evaluation of OSA scores: A pretest-posttest no control group design. A t-test will be run as an indicator to whether or not patients increased their OSA scores.

Months eleven/twelve – after one year
Evaluation of program objectives: See Above
Evaluation of OSA scores: See Above
Process oriented evaluation: Summarizing the number of people who received OT services, number of sessions each patient participated in, a list of the most common interventions, and a list of OSA items most commonly chosen.

*Note: The program evaluation timeline will begin when the first HIV/AIDS patient begins their occupational therapy sessions.
April 18, 2007

Dear XXXXXXXX

This letter is written in support of the project to investigate establishment of a home-based occupational therapy program for persons with HIV. The target population is to be consumers who are currently being treated through the Ryan White Program at the University of Toledo Health Science Campus.

Based on the findings of a needs assessment conducted between January and May of 2008, an Occupational Therapy Program will be developed to meet the needs of patients facing functional limitations as a result of their HIV infection. Consumers will be educated about the services available through any of three routes: 1) the consumer educational dinners, 2) articles in the HARK consumer newsletter, and/or 3) one on one education by staff in the clinic.

Referrals to the program will be based on a clinic-based assessment by an occupational therapist. A plan of care will be developed in conjunction with the AIDS Resource Team and implemented by the Occupational Therapist.

We recommend funding for this project through the HRSA HIV/AIDS Bureau Special Projects of National Significance (SPNS) grant options.

We welcome this opportunity to expand services to the consumers served by the Ryan White HIV Program at the University of Toledo Health Science Campus.

Sincerely,

Joan M. Duggan, MD, FACP
Associate Professor of Medicine and Physiology, Pharmacology, Metabolism & Cardiovascular Science
Medical Director, Ryan White Program

Ann W. Locher, MSN, RN, ACRN
Coordinator, Ryan White Program

Infectious Diseases
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419.383.4228 Phone • 419.383.2847 Fax • www.bsc.utoledo.edu