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Applying the Model of Human Occupation : three community-based case studies of individuals with HIV/AIDS

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Applying the Model of Human Occupation:
Three Community-based Case Studies of Individuals with HIV/AIDS

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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. As such, the Capstone Dissemination is not formal research.

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Abstract

Purpose: Given the persistent incidence of HIV/AIDS (Center for Disease Control, 2010; Center for Disease Control, 2008), community-based occupational therapy services are needed to address multiple occupational problems of this population. Three case studies are presented.

Method: Clients were recruited through recommendation by an infectious disease physician with a Ryan White program in Toledo, Ohio. Clients participated in up to 12 total therapy sessions and at least one follow-up session two weeks after discharge. The Model of Human Occupation was used as a foundation for the therapeutic process.

Results: Client #1's deficits included home and financial management, pursuing leisure, mobility, organization, and problem-solving. In general, his assessment scores did not improve from evaluation to discharge. Client #2's challenges included IODLs, community involvement, and transitioning to independent living from a SNF. His OSA, MOHOST and SIGA scores all improved significantly from evaluation to discharge, with OSA overall competence score improving from a 68/100 to a 72 and indicating an increased sense of volition. Client #3's deficit areas included coping with fatigue, childcare/play, home management, and pursuing meaningful and purposeful occupations, specifically writing. In general, her OSA, MOHOST and SIGA scores improved from evaluation to discharge, with significant improvements noted in MOHOST subsections related to environment.

Conclusion: Findings suggest a need for continued exploration of home- and community-based occupational therapy interventions for individuals with HIV/AIDS. Additionally, results illustrate that MOHO promotes the development of occupation, meaning, and purpose with this population in a community-based setting.

Introduction

Approximately one million people in the United States are living with HIV, and an estimated 56,300 people become infected each year (Center for Disease Control, 2010). Current data suggest that the HIV/AIDS epidemic is more severe than anticipated, with homosexual and bisexual men of all races and African American men and women identified as the most at-risk groups (Center for Disease Control, 2008; Hall et al., 2008). Individuals with HIV/AIDS often experience various physical and psychosocial deficits affecting quality of life, including fatigue (Lerdel et al., 2011), chronic pain and challenges to mobility (Wantland et al., 2011), peripheral neuropathy (Nicholas et al., 2010), depression and anxiety (Wagner et al., 2011; Gonzalez et al., 2012), sleep disturbances and self-care impairments (Hughes, 2004).

Currently, few studies exist that explicitly explore the relationship of occupational therapy services and HIV/AIDS. Aside from several studies tracking outcomes of work programs for those with HIV/AIDS, only a handful of case studies have been previously published. O'Rourke (1990) provided occupational therapy services to an individual who became HIV positive through intravenous drug abuse, and Bedell (2000) explored daily life for eight gay men living in New York City. Finally, Braveman and Suarez-Balcazar (2009) identified patterns of social justice and community resource utilization for two individuals with HIV/AIDS.

The Model of Human Occupation (Kielhofner & Burke, 1980) addresses both physical and psychosocial deficits, emphasizes client growth and change, and takes into account the strong impact of the dynamic environment on volition. This model was chosen as appropriate to facilitate therapy with clients with HIV/AIDS (Pizzi, 1990).

The plan was to recruit three clients through recommendation by an infectious disease physician with a Ryan White program in Toledo, Ohio. The physician recommended clients who

had reached out for help and who displayed a wide range of clinical and social features often seen in persons with HIV.

Client #1

Client #1 was a 57 year-old Caucasian male who had been HIV positive for approximately 27 years. He had borderline personality disorder, major depressive disorder, chronic back pain, cervical root neuropathy, COPD, lipoatrophy, lipodystrophy, neck pain, shoulder pain, and spinal stenosis, and underwent a C4-C7 cervical laminectomy three months prior to beginning home-based occupational therapy.

Evaluation

Assessments utilized for all clients at initial evaluation included the Occupational Self Assessment (OSA) (Baron, Kielhofner, Iyenger, Goldhammer, & Wolenski, 2006), the Model of Human Occupation Screening Tool (MOHOST) (Parkinson, Forsyth, & Kielhofner, 2006), and the Self-Identified Goals Assessment (SIGA) (Melville, Baltic, Bettcher, & Nelson, 2002). For client #1, main areas of deficit revealed through assessments, specifically the OSA and MOHOST, included independence with home management, financial management, pursuing leisure occupations, driving, mobility, organization, personal responsibility, and problem-solving. His OSA value score was 49/100, indicating that his perception of how important occupations were was very close to his perception of competence when completing them. See Table 1 for comprehensive results of initial assessments for client #1.

Client #1 reported his sexual orientation as homosexual. In regard to volition, he demonstrated that self-reflection played a strong role in his life, yet indicated that he did not trust himself completely when making important decisions. He also seemed to judge himself negatively in regard to typical occupational performances around his home. He demonstrated a

consistent spontaneous interest in telling his personal narrative, even when already in the midst of another occupation or topic, tending to become fixated on self-analysis that prevented him from completing the necessary planning to act upon motivations for occupation. (For example, at one point the client recalled a story about admitting himself to a drug and alcohol rehabilitation facility for gays, lesbians, bixsexuals, and transgenders, as opposed to completing the occupation of cleaning a ceiling fan.)

Client #1 reported that he had been essentially on his own for most of his life without family support, causing him to have to become more responsible for himself at an early age. He reported having been incarcerated in 1995 as a result of committing assault, having a history of severe drug and alcohol addiction, and still using alcohol and marijuana, though less often than in the past. He expressed finding significant meaning, purpose, and self-efficacy in his ability to overcome difficult life events, yet appeared vulnerable to change and potential judgment from others, disorganized, and somewhat anxious over the state of his future. Though he reported certain valued goals, such as continuing advocacy work or wanting to drive again, his reported daily habits did not match these desires. For example, he also reported that he still frequently visited the bar to drink with friends and had turned down a neighbor's offer to take him driving.

The most meaningful and purposeful roles for client #1 discussed during evaluation were centered on being a friend to those in his social group, caring for his two cats, and participating in work as a local HIV/AIDS advocate. Though client #1 was without the support of family, he reported having close friends and neighbors that would check up on him and a consistent relationship with a psychotherapist at Ryan White, as well as excellent support from social workers and other staff. At initial evaluation, he expressed interest in many occupations to be worked on in therapy, ranging from self-care to home care to leisure to work, though was not

able to conceptualize how these occupations would fit into a daily routine.

Client #1 tended to be candid when providing information, yet inconsistent and scattered during conversation. For example, he reported that he always needed to use a cane when walking around his home, then expressed walking a mile down the street to the library the week before with no device. He also initially reported using a shower chair that he could not locate within his apartment when asked; when found in a corner beneath a stack of boxes, it was obviously broken, yet the client reported that it would be safe to use.

Client #1 reported regularly occurring pain and fatigue during occupations, and was a fall risk. A standardized fall risk assessment (Guralnik et al., 1994) was also administered, with results indicating that the client had impaired balance. Client #1 also had decreased total body strength, numbness and tingling of the hands and feet, decreased fine motor skills, impaired range of motion in his neck in all planes of movement, and back pain and lipodystrophy that affected his posture significantly, inhibiting participation. The client described his physical deficits as sometimes making him feel “trapped in a cage.”

The client’s most important environmental setting was his apartment, which he reported leaving in winter only occasionally. Occupational forms of the client’s home were over-challenging, and his environment was very cluttered and dirty at initial contact. The client himself noted these problems but was generally unable to address them until they arose to a level of being an emergency, as with soiled laundry. He reported that his social group of friends provided support when needed, though sometimes inconsistently. Primary areas of concern identified by the “My Environment” section of the OSA included client #1 lacking “people who do things with me” and “opportunities to do things I value and like.”

Interventions

All client goals were established through collaboration and client self-identification, using both OSA scores and SIGA ratings. (SIGA ratings occur on a 0 to 10 scale, with 0 being totally unable to complete an occupation and 10 being able to complete an occupation in the best manner possible. “Overall” indicates the score for perceived efficacy related to all items that were rated combined.) Goals for all clients changed slightly throughout the occupational therapy process, with final SIGA ratings reflecting these changes.

For client #1, initial goals were set to focus on improving occupational performance with home management (SIGA rating: 5/10) and financial management (2/10), pursuing a craft as a hobby (6/10), fall prevention (5/10), and transportation with a focus on motor aspects (5/10), including increasing neck and back range of motion. Overall SIGA rating: 6/10.

Client #1 participated in a total of six therapy sessions over the course of 12 weeks. In addition, he participated in scheduled telephone calls three times, beyond simple appointment-making. These telephone calls, described below, should be considered part of occupational therapy. Prior to the second session, the client reported that he had fallen when getting up to go to the bathroom during the night, but was unsure what had caused the fall. He verbalized having previous falls in the past due to what he reported as side effects of HIV medications, such as temporary balance impairment, dizziness, and general lethargy. The client was advised to see his physician immediately, and the focus of therapy sessions were consequently shifted to account for fall prevention education as a priority. The client was educated about how to safely get up from a fall and methods of fall prevention, and the client’s home environment was evaluated for potential fall risks.

Mobility concerns were also addressed along with fall prevention, and the client was

provided with several home exercise programs to facilitate increased total body strengthening, increased endurance during occupations of daily living, improved balance, and decreased pain, which the client had been experiencing more frequently post-fall. Neck range of motion exercises were especially emphasized to address the client's goal of preparing for driving. The client was encouraged to fill out an exercise log to track consistent participation. Though the client verbally reported completing his exercise programs throughout the duration of occupational therapy sessions, his exercise log showed only three entries when checked closer to discharge. Functional neck range of motion as observed during cooking or cleaning occupations improved slightly as therapy progressed, though such improvements might not have been a direct result of home exercise programs. The client also regularly reported improvements with pain across various sessions, which he attributed to "stretching and moving around more often."

Another session consisted of the client creating a monthly, itemized budget, as a primary area of deficit identified at evaluation was financial management. Though the client required some guidance and input to prioritize areas of spending, he was easily able to create a budget on his computer with minimal verbal assistance, saying, "Now the hard part will be sticking to it." This quote is typical of other self-descriptions indicating that the volitional process often did not lead to actually experiencing his choices. Rather than move forward after creating his budget, he began to search his computer for personal writings describing his past choices and experiences.

Despite frequent re-direction, the client repeatedly returned to therapy sessions discussing his personal narrative, and it was clear that his desire to examine the past often short-circuited the occupation at hand. There seemed to be a lack of balance between reflecting and doing. As an attempted solution, time was spent during various sessions reflecting on how the client's past actions could correspond with forming a meaningful and purposeful future (Barrett, Beer, &

Kielhofner, 1999). Time was also scheduled for hands-on doing.

Yet another therapeutic occupation the client completed was crocheting, chosen by the client to be a craft of interest that would facilitate exploration of hobbies and leisure, and also address use of fine motor skills and hand manipulation in the presence of decreased sensation. While crocheting, the client demonstrated some fine motor deficits and some frustration with the level of challenge of the occupation, saying, “Come on fingers, work!” Though the client also lacked some self-awareness of his occupational performance in not recognizing his mistakes, he was able to ask questions and ask for help, and reported finding meaning and purpose in the occupation and wanting to continue it in the future. “It will be a good way to pass the time.” Despite this interest and intention, however, observation during subsequent home visits did not indicate continued pursuance of this craft.

Over the course of therapy, client #1 frequently cancelled scheduled appointments while stating that he was not feeling well. A tentative interpretation is that he was trying to cope with depression by avoiding being with someone who would elicit, however inadvertently, his negative self-judgments. Though he was never directly asked to explain himself, he seemed to do this automatically even when being encouraged to engage in hands-on, concrete occupations.

Outcomes

After six in-home therapy sessions, client #1 experienced what he perceived to be significant anxiety brought on by catastrophic changes that occurred suddenly in his life within the span of a few days, causing him to request to end therapy. These changes as he reported them included attempting to drive and being highly unsuccessful, learning that a neighbor was moving away, speaking to an ex-lover and having a negative conversation that “drew up memories,” and speaking with his former employer who told him that he had filled the client’s former position as

a floral delivery truck driver.

Staff at Ryan White confirmed that this was a typical cyclical nature for client #1, and that he often had periods where he felt very overwhelmed and withdrew from all interaction. Discharge assessments were administered to client #1 after discussion of these recent life changes, and he agreed to participate in follow-up phone calls for a few weeks. Discharge scores reflect his feelings of extreme lack of volition at the time of completing the assessments.

Client #1's MOHOST and OSA scores at discharge were similar to initial scores. Some OSA rating changes occurred, however, perhaps coinciding with the volitional and environmental changes the client experienced close to the time of rating. For example, at initial evaluation, client #1 rated the item "taking care of others for whom I am responsible" as not applicable, yet rated this item as done well and as being more important at discharge, demonstrating inconsistency in the client's environment, habits, and roles. Progress was seen with OSA competence ratings of items such as "handling my responsibilities" and "getting where I need to go."

Client #1's SIGA scores remained essentially the same at discharge as well, with the exception of the item "fall prevention," which increased from a score of 5/10 to a 6/10. The client reported that all SIGA items rated were still goals to be worked on, saying, "I just haven't been feeling very good lately, so I don't know if these scores are going to be a true picture of how I do normally. It's just been rough lately. I feel like I don't care about anything at all and everything seems sort of stuck and hopeless right now."

Follow-up telephone calls. Three follow-up phone calls were completed with client #1, who reported feeling much less stressed and more "under control" than at discharge. The client described attending his psychological counseling appointments more frequently and getting

support to utilize coping skills to deal with sudden changes in his environment and social group. He reported that he continued to have back and neck pain, though he was beginning to wean off pain medication and had been performing his home exercise programs to the best of his ability. Though client #1 sounded during these phone calls much more like he had prior to the multiple catastrophes, it is possible that he was engaging in impression management in attempt to be supportive of the overall project.

Recommendations. The client was provided with final recommendations, including continued occupational therapy, following up with his primary care physician regarding medical intervention, obtaining home health physical therapy services for neck range of motion, and inquiring with his social worker about obtaining Lifeline© for continued fall prevention awareness. It was also recommended that the client continue writing his personal narrative to focus on his future, try to attend psychological counseling more regularly, and continue pursuing advocacy work that brings him meaning and purpose.

All services, including OT, must be sensitive to client #1's narrative history and his patterns of behavior, including his cycle of outreach, followed by withdrawal in the face of setbacks (some of which were the result of overestimation of his abilities, for example his wish to drive), and gradually ending with continued outreach. Ideally, there should be telephone contacts during periods of withdrawal and a strong focus on occupational adaptation during periods of outreach, in order to maximize client #1's occupational potential.

Client #2

Client #2 was a 50 year-old African American male who had been HIV positive for approximately 12 years, and had neuropathy, transverse myelitis, low back pain, urinary retention, and impaired mobility secondary to generalized weakness. Client #2 had lived in a

skilled nursing facility for approximately two years, and had just moved into his own apartment two weeks prior to beginning home-based occupational therapy.

Evaluation

For client #2, main areas of deficit revealed through the OSA and MOHOST included independence with instrumental occupations of daily living, community involvement, organization of the home, transitioning to new occupational forms and roles since leaving the nursing home, developing routines, and meeting the occupational demands of his environment. His OSA value score was 78/100, indicating that he perceived most occupations in general as being of high importance. See Table 1 for comprehensive results of initial assessments for client #2.

Client #2 identified himself as bisexual. Related to volition, he had good insight into his strengths, though required some encouragement to identify areas of difficulty. He verbalized thinking that he would be efficacious during various types of occupational performances if given the opportunity, though he had not had the chance for a long time since living in the SNF. The client expressed some longing for his higher level of independence in the past, and some negative feelings toward his current deficits. Client #2 reported having support from family members who lived nearby and from The Ability Center of Toledo, which provided case managers and volunteers on an as needed basis to assist with transitioning to home. Even so, the client reported a significant inability to “get motivated,” especially since his recent move from the SNF.

Client #2’s state of transition from a setting noted for passivity (a nursing home) to his own apartment left him with habits, roles, and occupational forms within an environment that was in the process of changing. Primary areas of concern identified by the “My Environment”

section of the OSA included lacking “the things I need to be productive” and “opportunities to do the things I value and like.”

The client reported normally having some fatigue throughout the day, and occasional low back pain. The client was friendly and personable, and demonstrated good self-awareness and safety awareness when utilizing both a standard walker and/or a power wheelchair for functional mobility around his home. Strength was decreased due to generalized weakness, though range of motion was within functional limits.

The client had regular positive social support from family members, case managers, social workers, and volunteers. He expressed doubt as to how he was going to fulfill his role as son to his mother, and as brother to his sister. Transportation was an issue. He saw himself as potentially having a role in the larger community but did not have a clear path in establishing that role. He lacked routines not only in terms of family-oriented occupations but also in instrumental occupations of daily living, such as laundry and shopping. Client #2 seemed open to change and exploring new aspects of his identity, though seemed unsure and in need of support and guidance to achieve these parts of change and identity.

Interventions

For client #2, initial goals were set to focus on improving occupational performance during instrumental occupations of daily living such as laundry (SIGA rating: 0/10), cooking (5/10), and grocery shopping (7/10), organization of the home and daily routine (6/10), and community involvement (1/10). Overall: 7/10.

Client #2 participated in a total of 12 therapy sessions over the course of 12 weeks. After the first few therapy sessions, the client demonstrated safety and independence with valued instrumental occupations such as cooking, taking out the garbage, sorting laundry, and simple

cleaning. He reported that an initial lack of perceived self-efficacy in these occupations was due to not having had the opportunity to complete them for years. After quick success with these types of occupations, therapeutic priorities were shifted to center on transitioning to conquering unpacking the various boxes around the home, to setting up daily routines, and to occupations outside his apartment. At this point, client #2 was definitely in a benign cycle of success, with associated increases in personal causation.

A tub transfer bench, hand-held showerhead, and non-skid mat were obtained for client use in his bathroom to promote continued safety during self-care. In order to make the client's new home environment more personalized and familiar, client-directed occupations were designed to facilitate problem solving, planning, organization, and time management. With minimal physical assistance, for example, the client unpacked and successfully set up his desktop computer, as well as organized a space in which to use it. The client also successfully unpacked, sorted, and organized items taking up the entire space of his apartment's spare bedroom with minimal physical assistance, reporting that this was a source of great relief of anxiety and stress during his period of transition. Because organization of the spare bedroom was what the client identified as his biggest challenge since moving into his own apartment, completing this occupation with competence significantly increased his sense of volition and self-control, also increasing his confidence to try and to complete other occupations outside his home.

Therapeutic occupations to facilitate increased community involvement required the client to independently plan community outings, such as traveling in his power chair to a nearby grocery store to complete shopping, utilizing the public bus system for individuals with disabilities to go to a fast food restaurant for lunch, and attending a trip to the movies. The client successfully carried out all community outings with supervision only, utilizing planning skills,

safety awareness, and problem solving independently. These community occupations also allowed the client to test his sense of self-efficacy with transportation, handling money, and following a schedule during his transition from the SNF. He reported, “I feel like I can just go do things again. I can just go get out on my own and live my life and I’ll be okay.”

Finally, a significant part of therapy sessions with client #2 was promoting self-advocacy. Methods of self-advocacy were discussed during almost every session in relation to that day’s specific therapeutic occupations as a means of instilling in the client the long-term habit of continuing to be his own advocate. For example, one therapy session consisted of the client making a list of helpful strategies to use when completing self-identified tasks that could be challenging due to requiring self-advocacy, such as taking the initiative to call and check up on the progress of his food stamps application, or trusting his judgment and instincts when deciding to seek out the services of a different home health care agency than he was utilizing at the time.

Outcomes

After 12 weeks and 12 sessions, client #2 was discharged. The client’s OSA competence score improved from initial evaluation to the time of discharge, specifically from a score of 68/100 to a score of 72, indicating that the client increased his sense of volition and personal causation and gained an improved perception of his own competence during occupations. Additionally, the client’s score of value increased from a 78/100 to an 84, perhaps indicating that at the end of therapy services the client’s level of meaning and purpose about everyday occupations had increased. Successful transitioning to a personalized home environment with more independence than existed in the skilled nursing facility assisted the client in gaining volition and identity.

Client #2’s MOHOST scores improved mainly in areas related to volition as well,

including progress with his ability to make choices, select interests, develop a routine, exercise responsibility, and appraise his own abilities.

SIGA scores on the majority of items for client #2 also improved from initial evaluation to discharge, including: laundry from a score of 0/10 to 1/10, grocery shopping from 7 to 10, cooking from 5 to 9, showering safely from 7 to 10, organization from 6 to 8, and physical movement/exercise from 7 to 10. Though the client reported being “much more involved outside my home,” his SIGA score for community involvement remained a 1 at discharge, no change from initial evaluation, indicating that this is still a goal for client #2. His overall SIGA score improved from a 7 to a 9.

Two-week Follow-up. One brief home visit was completed with client #2 for follow-up. The client reported that he was doing well, and had followed through on some of the “projects” initiated during in-home OT services, such as successfully obtaining food stamps and successfully switching home health agencies. Client #2 also reported that he had lost his cell phone, and had taken the necessary steps to have a new one shipped to his home. The client also reported that a neighbor who wanted to borrow money had approached him, but he declined to lend her funds. “I just feel like I have the nerve to look out for myself, you know, and be more forward with people if I have to. I think it’s good. I’m doing good.”

Recommendations. Recommendations were made for the client to continue seeking social support from his family and medical providers, building relationships with neighbors and friends, and participating in community occupations. The client was also advised to continue pursuing progress on current goals, such as obtaining Internet services for the computer workspace to increase community access. Additionally, client #2 was reminded to continue habits emphasized during OT, such as basic exercise techniques to complete from a seated

position and fall prevention strategies. Overall, the client was reminded of the importance of self-advocacy and in exercising volition during occupations, and was advised that he was making good progress that should be nurtured through self-advocacy during all decisions, whether medical or non-medical. The client expressed understanding the importance of his own participation in continuing to develop a sense of identity.

Client #3

Client #3 was female, 28 years old, and African American, and had been HIV positive for approximately 8 years. She also had anxiety, major depressive disorder, fibromyalgia, generalized pain, obesity, migraines, and fatigue.

Evaluation

Client #3 identified herself as heterosexual. Main areas of deficit revealed through the OSA and MOHOST included energy conservation, childcare and play, independence with home management, and pursuing meaningful and purposeful occupations, specifically writing. Her OSA value score was 68. This rating (significantly higher than the OSA competence score) indicated that the client's perception of how important occupations were did not match her perception of successful performance. See Table 1 for comprehensive results of initial assessments for client #3.

Related to volition, the client alluded to feeling a lack of control over portions of her life, especially recurrent inconsistency with her home environment. The client was a clear communicator, though somewhat timid with vocal expression initially. She expressed a strong sense of personal responsibility, meaning, and purpose toward taking care of her five year-old daughter, and verbalized wanting to be a better mother than her own mother was. However, the chaos in her environment, the resulting lack of predictable routines, and the wasting of precious

energy as she improvised as best as she could ultimately led to a profound problem of volition, a feeling of hopelessness, that no matter what she did she would make no difference. For example, she wanted to take her daughter to Cedar Point, an amusement park about 50 miles from her home, and she said tearfully that she had failed to do so because she just couldn't.

The client reported valuing creativity, expression, and morality. She discussed having significant fatigue that impacted daily occupations, more severe in the winter months and in the evenings. The client recalled feeling constantly tired since she was a teenager, feeling her fatigue get worse since giving birth, and having anxiety that often impeded occupational performance. The client's strength and range of motion were within functional limits, though she reported not being able to utilize motor skills to their full potential due to fear of fatigue. She expressed sadness that she had lost the capacity to enjoy and succeed in basketball. The client described her fatigue as being "like a heavy weight on my shoulders bringing me down."

Client #3's occupational forms were chaotic and unstable, as she and her daughter moved back and forth each week between three homes: her grandmother's home, an apartment she occasionally shared with her sister who, she said, had a history of drug problems, and an apartment held by the client's daughter's father, with whom there was no committed relationship. In addition, a fourth home was a possibility, for just her and her daughter. The client reported having few friends within her social group outside of family or people she knew from support groups and volunteering. Primary areas of concern identified by the "My Environment" section of the OSA included lacking "a place where I can be productive," "opportunities to do the things I value and like," and "places where I can go and enjoy myself."

She reported feeling pressured by family members to consistently clean and/or pick up after her daughter, even when her energy did not permit. She reported that this pressure was

particularly strong when she stayed with her daughter's father. When staying with her grandmother, she would often become the caretaker of her very active nephew when her sister was unable to watch him. Client #3 also reported feeling a lack of control over the state of her health and the state of her body, impacting her various perceived roles and habits. The client appeared scattered, and for example, was unable to problem-solve how she would go about scheduling her day in order to make sure she got to take a nap.

Interventions

For client #3, initial goals were set to focus on increasing energy conservation and improving occupational performance during home management occupations such as cooking (SIGA rating: 4/10 in AM, 4/10 in PM), cleaning (7/10 in AM, 1/10 in PM), and dishes (7/10 in AM, 3/10 in PM), during childcare and play occupations (7/10 in AM, 4/10 in PM), and during leisure (5/10 in AM, 0/10 in PM), specifically writing (6/10 in AM, 2/10 in PM). Overall: 6/10 in AM, 2/10 in PM.

Client #3 participated in a total of five therapy sessions over the course of six weeks. Almost all of the sessions addressed energy conservation across all aspects of the client's life, including home management, childcare and play, and leisure. One therapeutic occupation focused on the client creating an energy conservation schedule by analyzing her daily priorities, considering the factors that made her fatigue worse or better, and taking into account various other therapy goals and how they related to energy and fatigue. For example, during formation of the energy conservation schedule, the client reflected on typical play patterns of her five year-old daughter and how they factored into the client's own day. In addition to developing more organized and scheduled play times for her daughter, the client was able to plan daily naps for herself during her daughter's already scheduled nap times as well as brainstorm play occupations

she could complete with her daughter when feeling particularly fatigued.

After making the schedule, the client reported feeling that she had more control over her body and therefore over her daily routine, when before she felt helpless. Additionally, through the schedule, the client was able to concretely see how her fatigue impacted every aspect of her daily life. Throughout the therapy sessions, the client reported using the energy conservation schedule consistently and feeling “more calm, awake, and not so crazy.” The client also reported improved performance with home management occupations such as cleaning and dishes, areas of deficits on initial evaluation, since having more energy and endurance due to the schedule.

As the client gained an increased sense of control over her fatigue, she reported finding more time to address her goal of writing, an occupation that she found very meaningful and purposeful. The client reported admiring works by authors writing about empowerment for women, for children, and for African Americans in general. She disliked literature that that focused on angry confrontation or on topics that she perceived as being immoral, such as detailed sexual encounters. Another therapy session, therefore, was designed to facilitate creating an ergonomic computer workspace for writing based on provided education about body positioning and ergonomic techniques as a means of promoting joint protection, minimizing pain, and reducing fatigue. The client was successful in creating the workspace, but unsuccessful in maintaining it since she continued to move around between three home environments each week.

This overall instability of the client’s home environment was also discussed frequently during therapy sessions, as her continuous moving around from home to home with her daughter significantly threatened her ability to follow the energy conservation schedule. Prior to beginning home-based occupational therapy, the client was planning to move into her own home, yet had not taken any steps toward enacting this plan.

As with Client #1, there were problems in scheduling appointments. Sometimes she did not return telephone calls; sometimes she cancelled appointments. Sometimes she forgot appointments unless reminded the day before or the day of the appointment, or did not know where she would be at the time of the appointment. These problems seemed to be due to both environmental chaos and fatigue.

By the end of the therapy sessions, the client successfully moved into her own home with her daughter and began the process of unpacking, transitioning, and settling in. Though no initial therapy goals related directly to the client moving into her own home, client #3 reported that consistently discussing the importance of stability and consistency in an individual's environment, as well as the impact of the environment on energy conservation, did contribute to her "finally getting motivated to go ahead and get us out of that situation and into our own place."

Outcomes

Client #3's final assessments were administered after six weeks elapsed. The client's final OSA competence score improved from 49/100 at initial evaluation to 53 at the time of discharge, indicating that she increased her sense of volition and personal causation.

Additionally, the client's score on OSA value items significantly decreased, from 68/100 at initial evaluation to 47 at discharge, indicating that the client placed less value at discharge on many of the volitional items listed. An interpretation of this is not that she valued personal causation less, but that she felt less anxious and overwhelmed during daily occupations. In other words, she downgraded her expectations to match her newly emerging perception of personal capacity. The client appeared to be learning how to prioritize her occupations in a way that was more manageable.

Environmental scores greatly improved on the MOHOST at discharge, since the client had moved into her new home. Results suggest that the physical space of the environment at discharge much more adequately met occupational demands and better facilitated occupational performance, as well as facilitated improved relationships within the client's social group.

Finally, SIGA scores on the majority of items still applicable at discharge improved as well. Examples include: cooking (AM) improved from 4/10 at evaluation to 6/10 at discharge; dishes (PM) from 3 to 5; leisure (AM) from 5 to 7, leisure (PM) from 0 to 3; and overall scores for all items from 6 to 8 (AM) and 2 to 4 (PM). The client expressed that writing and childcare/play were goals that she planned to continue addressing.

Two-week Follow-up. One follow-up phone call was completed with client #3, who reported being completely settled into her new home with her daughter. The client also described that she was trying her best to follow her energy conservation schedule, and that though she still felt tired throughout the day, she could clearly notice the benefits of planning occupations ahead of time and utilizing consistency within her environment to her advantage.

Recommendations. Only two recommendations were made, to focus on the most acute issues with potential long-term complications. First, the client was to continue following the energy conservation schedule as consistently as possible, including scheduling time for writing. As part of this recommendation, a home that is stable physically in terms of objects, and stable socially in terms of the relationship between the client and her daughter, can facilitate energy conservation across predictable occupational forms. The second recommendation was to utilize a planner to maintain regular attendance of her medical appointments, which she struggled with during the course of therapy sessions.

Discussion

Overall, each client participating in the case studies experienced changes in volition and identity in his or her own unique way. Though prior case studies of individuals with HIV/AIDS using MOHO have focused on work, our three case study clients were not prepared for employment. Kielhofner & Barrett (1998) wrote that occupational therapy that focuses primarily on vocation does not evoke meaning and purpose in all individuals. MOHO is applicable to all occupational forms and settings challenging people with HIV/AIDS whether or not a formal workplace is a client setting.

Client #1 struggled with the relationship between volition and habituation. He had adequate awareness of his physical capacity, limitations, and personal values, yet he was unable able to translate these aspects of volition into daily life in the form of habits and roles. The inconsistency between his intentions and actions revealed by the conclusion of the 12 weeks was so great that it suggested that the client's initial self-presentation of possessing self-control and self-efficacy was misleading. For individuals with HIV/AIDS, periods of increased anxiety, change, or stress, such as the occurrence of abrupt change that client #1 experienced, can force increased awareness of the gap between volition and habituation and threaten an individual's entire sense of identity (Braveman, Kielhofner, Albrecht, & Helfrich, 2006).

Clients #2 and #3 were challenged mainly by their environments, in which initial occupational forms presented over-challenges to performance. Client #2 successfully transitioned to independent living after residing in a SNF for two years, when typical SNF stays resulting in safe transition to home tend to be approximately 90 days (Arling, Kane, Cooke, & Lewis, 2010). The client went from having essentially no volition to living in a completely independent environment. Though this drastic change initially threatened client #2's volition and habituation,

it also opened up new opportunities that he was able to take advantage of through expanding social support. Client #2's change in environment also resulted in the strengthening of personal causation, perhaps through his gaining reassurance that the qualities and characteristics that he already possessed could be useful and purposeful once again.

Client #3's major challenge was the presence of inconsistent home environments that interacted in a negative way with her performance capacity, specifically fatigue. This interaction made habituation, including habits and roles related to energy conservation, childcare, home management, and leisure, almost impossible. The client had to draw on her sense of personal causation to accept the reality that her multiple homes were a negative influence on roles, and was then able to adjust her sense of identity accordingly through new habits and roles. Because an individual's environment influences his or her ability to develop new skills and increase volition (Kielhofner, Braveman, Fogg, & Levin, 2008), client #3's change in environment was a positive influence on her identity.

Because clients in the HIV/AIDS population tend to lack adequate social support and coping skills (Atkins et al., 2010), their environments may at times remain disorganized and stressful, increasing their risk for non-compliance with medication regimens, medical appointments, and any rehabilitation services in which they are participating (Catz, McClure, Jones, & Brantley, 1999; Giordano, 2011). Even so, there is a clear need for occupational therapy to provide services to individuals with HIV/AIDS that address all aspects of life, particularly in the home- and community-based environments in which those with HIV/AIDS frequently experience the majority of challenges.

Though community-based care, especially with individuals with HIV/AIDS, is rare within the field of occupational therapy, it "inevitably draws therapists into dealing with the

contexts in which clients work, play, and do their activities of daily living....” (Kielhofner et al., 2002, p. 428). The Model of Human Occupation suggests that community-based environments promote the development of occupation, meaning, and purpose in perhaps the most pure and natural forms, unrestricted by the required schedules or methods present within most structured healthcare systems.

In order to ensure the continued growth of occupational therapy within new and necessary practice settings, interventions with individuals with HIV/AIDS should be further explored. As there remains no cure for HIV/AIDS, over two decades after the onset of the disease, home- and community-based care of this population is still a relevant, rewarding, and critical area of practice.

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Table 1: *Initial Evaluation Assessment Results for Clients*

	Client #1	Client #2	Client #3
Age	57	50	28
Gender	Male	Male	Female
Years HIV positive	27	12	8
OSA*: Competence Score	48	68	49
MOHOST**: Motivation for Occupation	Appraisal of Ability: Allows Expectation of Success: Allows Interest: Allows Choices: Inhibits	Appraisal of Ability: Allows Expectation of Success: Allows Interest: Allows Choices: Allows	Appraisal of Ability: Facilitates Expectation of Success: Inhibits Interest: Inhibits Choices: Allows
Pattern of Occupation	Routine: Not seen Adaptability: Not seen Roles: Allows Responsibility: Inhibits	Routine: Inhibits Adaptability: Not seen Roles: Allows Responsibility: Inhibits	Routine: Inhibits Adaptability: Allows Roles: Allows Responsibility: Inhibits
Interpersonal/ communication	Non-verbal skills: Allows Conversation: Facilitates Vocal expression: Facilitates Relationships: Not seen	Non-verbal skills: Facilitates Conversation: Facilitates Vocal expression: Facilitates Relationships: Allows	Non-verbal skills: Facilitates Conversation: Facilitates Vocal expression: Allows Relationships: Allows
Motor Skills	Posture/Mobility: Inhibits Coordination: Allows Strength/Effort: Allows Energy: Inhibits	Posture/Mobility: Inhibits Coordination: Allows Strength/Effort: Allows Energy: Allows	Posture/Mobility: Facilitates Coordination: Facilitates Strength/Effort: Allows Energy: Inhibits
Process Skills	Knowledge: Not seen Timing: Allows Organization: Inhibits Problem-solving: Inhibits	Knowledge: Not seen Timing: Facilitates Organization: Allows Problem-solving: Allows	Knowledge: Allows Timing: Allows Organization: Inhibits Problem-solving: Inhibits
Environment	Physical space: Inhibits Physical resources: Inhibits Social groups: Not seen Occupational demands: Not seen	Physical space: Allows Physical resources: Allows Social groups: Facilitates Occupational demands: Inhibits	Physical space: Inhibits Physical resources: Inhibits Social groups: Inhibits Occupational demands: Inhibits

*Possible OSA scores range from 21 to 84 if the client rates all items. If some items are not rated, scores are plotted on a visual key and range from 0 to 100. Clients #1 and #2 left some items unrated, while client #3 rated all items.

**MOHOST ratings are in regard to occupational participation and are based on clinical observation during one point in time.

Appendix A

Documentation: Client #1

Initial Occupational Therapy Home Health Evaluation – 01/20/2012

57 year-old male, Caucasian

PMH: HIV+ (per client, for 27 yrs.), borderline personality disorder, major depressive disorder, chronic back pain, cervical root neuropathy, COPD, HLD, HTN, lipoatrophy & lipodystrophy, osteoarthritis (isolated to ankle and foot), asthma, A-fib (controlled), neck pain, shoulder pain, spinal stenosis, tinnitus/hearing loss. S/P C4-C7 cervical laminectomy; per client and chart, was in hospital followed by temporary stay in nursing home for rehab for approximately 1 month. (Per client, had occupational therapy services in the nursing home to “work on my shoulder... They made me do all these exercises and it just made my shoulder hurt worse.”) Client reports having rotator cuff deficits and pain. Per chart on 01/06/2012, client reports will have to have another surgery to correct neck.

Psychosocial: Per client and chart, has been seeing CNP through Ryan White Program for approximately 2 yrs. to address borderline personality disorder and coping and has made significant gains. Per client, has a hx of being hospitalized for psychiatric reasons (e.g. checked self in to LGBTQ rehab facility after learning that client was not going to die immediately from HIV). **Meds:** Takes Intelence and Truvada for HIV; oxycodone-acetaminophen 5 mg every 12-24 hrs for back pain. *[See chart for complete list of meds.]*

Personal History: Sexual orientation: homosexual. Per medical chart on 9/28/11, not currently sexually active. Currently, +tobacco, +marijuana and +ETOH; client reports a hx of drug abuse, including heroin and crack cocaine but reports does not use anymore. Per client, was incarcerated in 1995. Client reports having some higher education. Was previously employed by computer software company, then by a florist as a delivery driver. Per client, stopped working a few yrs ago d/t inability to drive safely (secondary to C-collar, limited neck and head ROM, and side effects of pain medication). Client does not desire to return to full time employment at this time. Volunteers doing advocacy work for HIV/AIDS funding and legislation. Client reports having no family, but has good social support from friends and peers within social group.

Summary of Results of OSA: Top 4 identified therapy priorities:

1) Increasing independence with ODLs (e.g. cleaning the home, doing the dishes, etc.) by increasing general strength and endurance, 2) Financial management, 3) Pursuing leisure occupations, 4) Increasing independence with transportation (e.g. driving, preparation for driving) – *See OSA in file for complete OSA form and scores.*

Summary of Results of SIGA: Overall (all four tasks): 6/10; Housework and minor home maintenance: 5/10, Financial management: 2/10, Pursuing crafts and hobbies: 6/10, Independence with transportation (e.g. driving): 5/10 – *Additional goals and occupations will receive SIGA scores as they arise.*

Current Status:

VOLITION

Personal Causation: Client has good insight into strengths and weaknesses. Was able to quickly respond to OSA questions and recognize problem areas, including explaining why these areas were problematic (e.g. lack of consistent financial responsibility). Client also

has insight into deficits (e.g. Borderline Personality Disorder, ETOH abuse) and how they affect daily life. Client was also able to identify situations where occupational performance was not efficacious because of lack of support from others in the environment or social group (e.g. client attempting to continue to publish HIV/AIDS newsletter after 2 yrs. of prior success). Client indicates that he does not trust himself completely when making important decisions regarding money, and also seems to judge himself negatively in regard to his occupational performance with home maintenance and basic home management tasks. Per client, has been essentially on his own for most of his life and without family support, causing him to have to become more responsible for himself at an early age without parental guidance.

Values: advocacy (for self and for causes deemed important, e.g. HIV/AIDS advocacy), productivity and personal responsibility (e.g. the need to become more independent and self-sufficient around the home), approval from others (e.g. client reporting not wanting people to think he “just sits around at home getting stoned all day”), continuous insight and analysis of self (e.g. client expressing wanting to think about situations that occur and why)

Interests: reading information online (e.g. news), reading books, watching TV, online gaming, participating in advocacy volunteer work for HIV/AIDS

HABITUATION

Roles: caregiver to pets (two cats), friend, partner/ex-partner, advocate, former student, former employee, patient (medical and psychological)

Habits: *Will continue to assess.*

PERFORMANCE CAPACITY

Communication/interaction: Client able to communicate reasonably and logically. Communicates significant information voluntarily and without prompting; follows conversation and interpersonal interaction adequately. Appropriate body language. Somewhat flat affect with occasional smiling. Wears glasses; near-sighted.

Motor skills/Process Skills: Client rated pain a 2/10 while at rest. Pain estimated to elevate to a 5/10 during occupations, such as standing to wash the dishes or vacuuming the carpet. Per client, typically takes 10 minute rest breaks in between episodes of pain before returning to tasks. Per client, improved head, neck, and BUE ROM since laminectomy, but still impaired. Per client, has balance deficits that cause difficulty with everyday occupations. *Will continue to assess motor and process skills during subsequent tx sessions (using MOHOST and clinical reasoning skills).*

Environment: Lower level apartment with approximately 5 stairs to enter. No stairs inside apartment. Clutter and limited space inside apartment. No laundry facilities on site. Close and accessible social network. *Will continue to assess.*

Attempt Note

1/24/12 – 9:15 a.m.

Per client, needed to cancel therapy session for today d/t having fallen last night; was taking “sleepers” [meds] which made him feel dizzy. Got up in the middle of the night and tripped and fell. Per client, “didn’t know how to get up from the fall and am in a lot of pain.” Client reported being sober of ETOH and drugs at the time of incident. Per client, has fallen x2 prior in the past, both before most recent surgery in October. Client educated re: going to the doctor if pain continued. Will continue to assess fall risk status and provide education re: fall prevention during next OT session, rescheduled for 1/26/12.

Progress Note

1/26/12, 1 p.m. to 2 p.m.

Subjective report by client: Client reported being in pain (5/10) today d/t fall earlier this week. Since pain has not subsided, plans to make doctor's appointment today immediately following OT tx. Pain remained at 5/10 during movement and occupational performance.

Summary of interventions carried out/goals addressed: Education provided re: fall prevention techniques and how to get up properly from a fall to ensure joint protection, proper body mechanics, and safety. Provided two handouts on fall prevention. Client verbalized understanding. Assessed home environment through clinical observation and client self-report—client owns shower chair (not in working order) and reports using “some of the time,” also owns straight cane and reports using primarily when walking outside or traveling outside the home. Very high (approximately 2.5 ft) tub to step over in bathroom. Completed getting in and out of tub safely with SBA. Recommended grab bar for shower wall and consistent use of safe, functional shower chair. Client educated re: general safety in the home (e.g. wearing shoes or socks with tread, drying wet areas of the floor, minimizing clutter, watching out for cats on the ground, turning on lights in hallways to improve visual awareness, etc.) Completed kitchen occupations (un/loading cans from kitchen shelves to counter; functional mobility approximately 6 ft to kitchen stool to obtain cans and put back on shelves; bending/stooping to lower shelves to lift pots and pans to counter and back)— in approximately 10 min w/o rest breaks. Guralnik screening tool completed (*see results in motor skills section below*).

VOLITION

Personal Causation: Also reported having difficulty with meal prep occupations lately d/t back pain from recent fall; called friend to assist with meal prep last night. Client expressed that on average, is able to complete making simple meals I. Client continues to express some self-negativity and self-judgment re: cleanliness of home, presence of bugs in kitchen. Client also reported “walked downtown this weekend and was completely exhausted afterward”—per client, distance was approximately 1.5 miles; client exhibited sense of pride and accomplishment when describing this walk. During assessment of balance, client reported having a DUI in 2003—reported, “I told the cop that I couldn't even do those balance sobriety tests while sober, and I proved it in court too”— Client demonstrated a sense of accomplishment after completing the balance screens.

Values: cleanliness of home, self-advocacy for healthcare needs (e.g. pain management, checkup after recent fall)

Interests: Expressed interest in potential leisure occupations such as woodworking, fixing clocks, and staining glass. Discussed practicality of these occupations within context of home environment. Client reported would “like to just go and walk around Michael's and just see what is there and available.” OTS will continue to explore smaller versions of these craft occupations for client.

HABITUATION

Roles: Friend, patient/client

Habits: Client reported having no problems with medication management and adherence at this time. See “Volition” section for additional overlap with habits.

***Results of MOHOST falling under VOLITION and HABITUATION:**

(Rated based on MOHOST categories and procedure: F= facilitates occupational participation, A= allows occupational participation, I= inhibits occupational participation, R= restricts occupational participation, N/S= not seen)

Motivation for Occupation:

Appraisal of Ability: A

Expectation of Success: A

Interest: A

Choices: I – especially in regard to financial management and work goals

Pattern of Occupation:

Routine: N/S

Adaptability: N/S

Roles: A

Responsibility: I

PERFORMANCE CAPACITY (from MOHOST)

Interpersonal/communication:

Non-verbal skills: A

Conversation: F

Vocal expression: F

Relationships: N/S

Motor Skills:

Posture/Mobility: I – slight trunk flexion of posture during functional mobility; limited neck mobility in all planes of movement

Coordination: A

Strength and Effort: A – decreased strength BUE, especially in planes of shoulder flexion, extension, and horizontal abduction (MMT B shoulders 4- ; MMT all other planes BUE 4+ ; MMT BLE WFL)

Energy: I – per client report of general occupational performance during a typical day

*Results of Guralnik: 3 non-severe injury falls in the past two years. Grip strength average 80.67# B hands. Vision screens not completed d/t client currently possessing a valid driver's license. Balance test= 4 points, Measured walks= 3 points, Chair stands= 1 point. Total= 8 points.

Process Skills:

Knowledge: N/S

Timing: A

Organization: I

Problem-solving: I – reassurance needed for problem-solving re: home safety decisions

Environment:

Physical space: I

Physical resources: I

Social groups: N/S

Occupational demands: N/S – will continue to assess

Attempt Note

02/02/2012 – 9:00 a.m.

Client called and reported having severe back pain. Expressed: “I think I slipped another disc.” Was educated that OT session could focus on occupations such as financial management and education that would not include movement. Client reported wanting to be in bed and rest. Has doctor’s appointment for back this coming Tuesday (per client, this was the earliest he could get in for an appt); will call on Tuesday to reschedule.

Progress Note

02-23-12, 1:00 p.m. to 3:00 p.m.

Subjective report by client: Per client, has been in communication with his boss at the florist re: returning to work in April full-time as a delivery driver. Reports has been adhering to neck AROM and stretching program given by OTS and is noticing improvements in his neck ROM. Is gaining confidence in his potential ability to drive and has talked to friends about helping him look for a car within the next few months. Would like to purchase a used car in the month of April—plans to save his money and prepare until then; will continue doing neck exercises and lower back stretching. Reports MD wanting to wean off pain meds within the next month or two as well, which will also improve his confidence with driving (per client report). Client also reports that he cancelled his initial evaluation last week with physical therapy (as referred to by neurology MD) d/t his cold and is still unsure if he wishes to pursue it. “I would rather that they come here [to his home] because it’s just so much easier. But I’m willing to give it a shot. The thing about it is I would have access to the gym with all the equipment that I don’t have, but then I think that I could just go to the Y and pay \$25 a month to do the same thing myself. I guess I’ll have to see.” Client also reported this week that he has begun to work on a grant with a few other HIV/AIDS advocates.

Recent updates on Ryan White medical charts:

Feb. 7th

Note from Neurology: “Pt comes in today for routine f/u and c/o new mid back pain started 2 weeks ago suddenly. No associated trauma. Pain aggravated by movement. Started at 8-9/10 now improving to about 5-6/10. No new motor or sensory deficit. No recent bowel or bladder incontinence. Still having cervical and back pain

Pt was referred to pain management clinic but was refused because he was smoking pot/marijuana

Still smoking 5-6 cigarette/day and drink 3-4 beers or shot daily.

Tobacco use current tobacco user, Daily alcohol use 1 to 3 drinks per occasion, Weekly alcohol use 1 to 7 drinks per week” – **Client did not report having fall that resulted in back pain to MD, as noted in chart re: “no associated trauma.”**

Note from Psych:

“Pt says that he is not feeling well. He says that he injured his back. He says that believes that he has injured two more disks in his back. Pt fears that he will now have to have more surgery. Pt says that he has been feeling like he is becoming emotionally unraveled. Pt is tearful in session. Pt says that he and friend have had a conversation and have worked through some of their differences. Pt expressed feelings of loneliness. Pt says that he has a great deal of difficulty getting out of the apartment. Pt has few friends other than at the bar.” – **Will attempt to address community involvement goal and getting client out of the house during OT.**

Most recent labs: CD4 absolute 638 cells/cu mm blood, CD4 percent 42%, Viral load 77 copies/ml blood; Severe lipodystrophy

Client attended appointment with general internal med on Feb. 23rd for severe productive cough + sputum—coinciding with cancellation of OT session last week d/t client report of having a severe cold and being in pain.

Summary of interventions carried out/goals addressed: Followed up with client re: adherence to exercise programs, pain levels, and general health since last OT session. Returned book of memoirs to client and explained concept of “personal narrative”—inquired about whether client had ever written extension of narrative to include future or whether or not client would be open to doing so. (Client reported has been working on a memoir that he would like to turn into a book for the last few years off and on—“I have notes here and there, and it’s a work in progress.” Client did not offer to allow OTS to read; will continue establishing therapeutic rapport before addressing this topic further.) Facilitated crocheting occupation with VS and min A by OTS Meghan for a few mistakes during second step of crocheting. Demonstrated and recommended additional fine motor occupations (e.g. sorting coins, buttons, stringing beads) for client to complete on own to assist in gaining additional B hand dexterity and fine motor control. Educated on smoking cessation and potential options. (OTS Meghan initiated during casual conversation, as she is a former smoker and spoke to client re: additional options, such as an electric cigarette or nicotine patches that she has used in the past. Client receptive. Expressed that he was trying to cut back and has recently decreased his amount of cigarettes, but still continues to smoke.) Followed up with COPD education re: COPD exacerbation due to smoking.

VOLITION

Personal Causation: See subjective report section above re: improvements and continuations of previous behavior related to personal causation. Client continues to vocalize certain aspects of volition that he may or may not actually act upon. Client’s self-efficacy continues to be high, especially in relation to his habits and roles, and in relation to his occupational performances based on these habits and roles (i.e. actual performances do not match self-report in a completely consistent manner). For example: During crocheting occupation, client said things such as, “There, I think I have it now,” or, “Oh, okay, I see how to do it” though he continued to make significant mistakes that needed correction.

HABITUATION

Habits: some habits emphasized this week by client include: smoking, alcohol use

PERFORMANCE CAPACITY

Interpersonal/communication: Client was very open and communicative with OTS Meghan—very candid with personal history and with self-reflection... consistent with attitude of client when first meeting OTS and OTR during initial eval; again attempting to portray himself in a positive manner and to prevent any forms of perceived judgment or negative opinions

Motor Skills: Client demonstrated fine motor deficits during crocheting occupation—somewhat of an over-challenge for client. Two steps to crocheting—chaining, and single crocheting—client was able to complete chaining I (a just-right challenge) but not the single crocheting step. Noted shaking in B hands, client wringing hands, fingers fumbling. Educated client re: taking breaks and reeducation process of muscles and nerves during fine motor occupations and motor learning. Client became frustrated, saying “Come on fingers, work!” Per clinical reasoning, if

client had not been talking during crocheting and was able to utilize more sustained attention skills, perhaps client would have been more successful during occupational performance. Lack confidence that client will continue crocheting occupation on own. Will follow up. Will explore other methods of hobbies and leisure.

Process Skills: Lacked some self-awareness of occupational performance during crocheting occupation in not recognizing mistakes; able to ask questions and ask for help but not self-correct mistakes accordingly

Environment: Re: physical environment—client cleaned off coffee table in living room and moved into the center of the room. Also obtained a small sofa and placed in living room—removed plastic chairs. (This also applies to volition/personal causation re: client wanting to clean and organize his home environment.) Per client, received help from friend with moving and placing furniture.

Progress Note

03-01-12, 1:00 p.m. to 2:30 p.m.

Subjective report by client: Per client, did not go to PT this morning due to feeling in too much pain. Has given money to his friend and friend's girlfriend to hold for him (cash) to later be used as a down payment on a car. Texted friend yesterday to tell him he found some potential cars on Craigslist, but friend never responded. Per client, has never let friend hold money for him before and does not know what will happen. Expressed again strong desire to buy car, drive, and return to work.

Summary of interventions carried out/goals addressed: Focused on assessing progress re: neck AROM, and adherence to BUE home exercise program and low back stretching program. Slight improvements noted in neck AROM, especially re: comfortably maintaining more neutral positioning when at rest—per client, also noticing improvements. Client completed neck ROM program during OT session. Client had questions re: if he was performing PT home exercise program for neck correctly—educated re: correct positioning and methods for completing exercises. Educated re: time limit for using heat modality (heating pad) and precautions with heat. Planned to focus on kitchen and cleaning occupations for next week.

VOLITION

Personal Causation: Client reports certain increases in self-efficacy during occupational performance, such as being able to stand for longer periods of time while performing occupations in kitchen, taking fewer rest breaks, no longer using cane during functional mobility, and noticing improvements in neck ROM. Client also reports is continuing to wean off pain meds. However, most clinical observations of client's environment do not match his verbal report, demonstrating a discrepancy between personal causation in client's mind vs. his actions—e.g. client reported doing PT home exercise program yesterday, though sheet of checkmarks indicating that client performed exercises was not filled in. Client also reported not being able to crochet during this past week, due to “becoming frustrated when my left hand just doesn't want to work.” Per client, did complete some fine motor occupations recommended previously by OTS, e.g. sorting coins, picking up coins from a flat surface. When asked if he wanted to explore a different craft or hobby occupation, client reported, “I think right now I just want to stick to the sorting coins, which is something I know I have to do to function.” Client educated re: additional ideas, such as stringing buttons, doing beadwork, or working with clay to address fine motor skills—OTS offered to bring client materials to work with, but client again declined, indicating that he would continue with the coins (which seems to be meaningful to him) and perhaps work up to trying to crochet one day in the future. (Crochet materials observed on coffee table in living room.) Client also declined doing the dishes as an OT occupation, reporting that he currently has no dish soap and has to buy some. “It's the first of the month so my SS check should be coming through soon, and then I can get [my friend] to take me to the store and get all the cleaning supplies.” Client continues to exhibit excuses as to why he does not wish to perform certain hands-on occupations, and seems to tell OTS what he feels he should be saying. Per clinical reasoning, doubtful that client is doing coin sorting occupation as he reports.

HABITUATION

Habits: Marijuana paraphernalia out on table this date, though client not using in presence of

OTS. Cancelling appointments is clearly emerging as a habit for client—e.g. with OTS in the past, with PT recently.

PERFORMANCE CAPACITY

Interpersonal/communication: During this week and last week's session, client is noted to have some perseveration re: his surgery in October—continues to talk about it in great detail, repeating some of the same information he provided last week to OTS; wanting to show pictures of surgery procedure, etc. – At times, client clearly wishes to distract from the hands-on occupation occurring with conversation, perhaps out of habit, when he finds something challenging or perhaps physically painful.

Motor Skills: See prior comments re: motor skills improvements

Process Skills: Client continues at the same level re: process skills, where he places high emphasis on self-reflection and on analyzing his own behavior in a way that he deems meaningful

Environment: Change in client's social group environment recently, as client reports he has a date this Saturday—also reports wanting to make sure his apartment is more clean for his date [This also relates to personal causation and values], despite having already seen his date's apartment which is “even worse and more messy than mine is.”

DISCHARGE

3/8/12, 1 p.m. to 2 p.m.

Subjective report of client this date: Client contacted OTS this morning requesting to drop out of the case studies. At the time, client reported that he was in too much pain and “can barely walk.” Agreeable to OTS coming over to discuss it. Upon further discussion, client clearly in a state of occupational change (per MOHO, this might be considered transformational change, perhaps bordering on catastrophic change, especially when considering client’s mental health status).

Relevant changes discussed re: volition, habituation, and performance capacity: Client in a clear state of anxiety and emotional distress; tearful throughout most of OT session. Reports that he lost his job with the florist, which was previously being held for him while he “recovered.” (Spoke with manager, and manager is downsizing his business and needs to make cuts.) Client had a strong attachment to returning to work, and though this was not an OT goal, other OT goals were designed to work toward an ultimate goal of returning to work in the eventual future (e.g. HEPs, driving goals, organizational goals)—clear sense of hopelessness re: working. Client did not want to discuss further options for returning to work at this point. (Became clearly even more anxious thinking about the prospect of having a new and unfamiliar job.) Client then reported that he was making progress on the goal of getting back to driving—was doing his neck stretches and feeling good, had taken the planned steps to obtain a car, and found support with a friend who could help him. Went to look at a car this past week and decided to take it for a test drive—the first time client had driven in approximately one year. Per client, drove around a residential block about two times and decided that he was not safe to drive; reported could not feel his feet against the gas pedal or the brake d/t loss of sensation secondary to neuropathy. (To date client has never reported this level of severity of numbness and tingling in his feet and/or hands; per client, was always able to maintain feeling to pressure, touch, and temperature and performed regular checks of skin integrity on hands and feet. Was not evident during functional mobility. Now questioning whether or not this severe BLE neuropathy contributed to client’s falling during beginning of case study?) Client very upset at the prospect of possibly never being able to drive again. Began to cry and said, “I always knew it might be possible that I would end up in a wheelchair” re: recent decline with functional mobility. Client reports has been using cane all the time, both outside and inside the home. (Prior to this session client was completing functional mobility safely, per OTS, w/o straight cane.) Client reported will not be attending physical therapy any longer until he can find out more information about pain from PCP. Feels overwhelmed. Has not attended since initial PT eval about 3 weeks ago. Client also reported not attending counseling at Ryan White for the last 5 weeks. “I think maybe things are just not straightened out enough in my head.” Reported feeling stressed over recent encounter with ex-lover. Reported going to the bar and having 3 beers and 2 shots in the span of 2 hours, and followed this comment with the statement “I didn’t really feel very much like drinking that night.” Client reports has not been engaging in consistent use of alcohol, however. Client reported that neighbor (who sometimes help client cook or keeps him company) is also moving out of the apartment complex in the next few weeks. Finally, client also reports having recent distress over treatment from pharmacy at re: pain meds—“They just think I am some sort of drug addict who just wants the meds. I am so sick of being treated like that because some people have real pain that they have to live with every day. I told them I will just go back to [other hospital].”

That's where I was before for spinal problems... I would have no problem with that." Reported that PCP would not distribute any more pain meds and that client obtained them from ID doctor (at Ryan White Clinic).

Unknown which of the various recent changes in client's life are causing the most anxiety and emotion, though perhaps the combination/interaction of all of them. Client very resistant to idea of continuing OT. Explained that perhaps this is the time that client could most benefit from OT, when his deficits are most severe, but client feels strongly that he needs to wait to see PCP and remain at home and rest. "I just can't do anything. I just can't. It just hurts too much. Everything is too much. It's not your fault and I appreciate your help, and I'm sorry I can't be of more help. Right now I just have to try and take care of myself." Explained connection between taking care of oneself and OT, changing goals, client-centeredness, etc. Client remained tactfully resistant. "In the beginning [of home OT] I had lots of hope, but there is only so much my body can do. I just hope they tell me it's osteoarthritis or something all through my body and not another spinal problem." Client has met several of his goals (see goals section below) though this is not reflected by changes in SIGA or OSA scores.

Client with clear sense of apathy toward all parts of life this date. As especially evident today, a very large gap exists between client's own perception of his occupational performance and his actual abilities. This has been noticeable on prior occasions (e.g. through client's report of having no problems cleaning apartment but apartment is in complete disarray), but most noticeable today re: report of driving incident. This significant discrepancy between perception and actual ability exists perhaps due to client's borderline personality disorder, or perhaps due to elevated sense of self-efficacy based on client's prior abilities and performances before surgery and illness. Furthermore, client has a somewhat warped perception of what is required to obtain results with occupational performance. (e.g. seems to expect that he will just get better without putting in work, or seems to expect that neuropathy will just go away or strength will just increase without actually doing exercises regularly. Perhaps has greater sense of ambivalence re: getting better than had previously displayed?)

Per clinical observations, client continues to demonstrate clear inconsistencies with actions vs. verbal report. (e.g. tells OTS he is feeling horribly and cannot walk and has not gone anywhere in days, yet reports going to the bar, looking at a car, and making plans to go to see his friend who recently had hip replacement surgery at the hospital tomorrow) Clear emergence of psychological deficits and their impact on client's occupational performances (especially under conditions of stress)—extreme inconsistencies with self-reports in general. (e.g. Client reports feeling hopeless and helpless one minute, and the next minute reports that he will be able to overcome all obstacles. Client reports not having done his exercises because of pain, but then later reports that he has been doing them consistently and correctly. Client reports improving since initial eval with energy and fatigue management, but these changes are not reflected by SIGA or OSA scores.) Client is clearly fixated on recent negative experiences, and is allowing them to impact his perception of progress thus far; unable to accurately assess his occupational performances while in a state of high emotion and stress. Also seems to be fixated on his surgery this past October—most clear today, though this fixation was present at last 2 OT sessions in addition to today's. Today showing OTS very detailed pictures of surgery and wanting to talk about surgery at length, even in the midst of a completely different conversation. Perhaps

suggestive that client is fixated on the surgery as the primary source of blame for everything that has gone wrong since then in his life (as opposed to taking personal responsibility, assuming self-efficacy, or personal causation).

***Note:** Though it cannot be assumed that client is “faking” or is not in real pain, it is important to consider whether or not client has exaggerated his current level of pain or current level of environmental stress in order to provide what he considers to be a legitimate justification to end participation in the case studies. Based on previous experience with client, he tends to want to prove that he is proficient at self-analysis and at understanding himself and his environment... simply ending participation because he no longer felt like it or because he met his goals might seem too simple to him; he seems to want to be a “good example” of an HIV patient. Client was very apologetic to OTS, saying, “I’m sorry I couldn’t help you and it had to end like this” in a tearful and dramatic manner. Client seems to be seeking approval while simultaneously wanting to maintain a sense of control.

Tx provided this date: Provided emotional support and encouragement to client as needed. Provided client with additional information re: occupations to encourage increased visual motor coordination, fine motor skills, and balance. Encouraged to continue HEP provided re: neck AROM and back stretching as tolerable, non-weight bearing. Reinforced fall prevention education previously provided. Recommended client look into Lifeline service for maximum safety/fall prevention. Client able to demonstrate and verbally report fall prevention information with I. Recommended that client utilize cane at all times during functional mobility. Facilitated client thinking and/or planning support from outside sources (e.g. friends, neighbors) daily to provide assistance with ODLs, transportation, etc. Provided client with further recommendations for discharge. (See recommendations section below.) Informed client of 2-week follow-up via phone. Client agreeable and appreciative.

Summary of Results of OSA: See OSA data summary sheet in client’s chart for full results. Client’s OSA scores remained fairly similar, with some discrepancies that coincide with client’s recent volitional and environmental changes—e.g. on initial eval, client rated item “taking care of others for whom I am responsible” as N/A, yet rated item as done well and more important on D/C. During initial eval, rated item “being involved as a student worker, volunteer, and/or family member” as done well and being not so important; did not rate this item on D/C (perhaps indicative that to client, this role is no longer existing in his life). Of particular interest in relation to volition, client’s competence rating of the items “taking care of myself,” “getting done what I need to do,” “effectively using my abilities,” “taking care of the place where I live,” and “identifying and solving problems” each decreased by one increment. Some of these items also increased in level of importance. Progress was seen with competence with items “handling my responsibilities” and “getting where I need to go.” Additionally, client completed the OSA D/C form with the item “working toward my goals” crossed out and deemed N/A—when questioned about this item, client reported tearfully, “I just feel so much uncertainty right now.” After discussion with OTS re: definition of goals, goals that can still be worked on and achieved, client rated the item. Comparison of overall scores is as follows:

Initial OSA scores: Competence: 48 (Error=3), Value: 49 (Error=3)

Final OSA scores: Competence: 46 (Error=2), Value: 48 (Error=3)

Summary of Results of SIGA: See SIGA form in client's chart for complete results of SIGA at D/C. Overall, all client's scores remained the same or decreased, with the exception of the item "fall prevention," which increased from a 5 to a 6. Client's score for "overall" decreased from a 6 to a 5. Per client, all SIGA items rated are still goals to be worked on, and none of the items were rated inaccurately at initial eval. Also per client, perception of how well client is able to perform items rated today at D/C were greatly affected by client's current state of decline in health.

MOHOST:

VOLITION and HABITUATION:

(Rated based on MOHOST categories and procedure: F= facilitates occupational participation, A= allows occupational participation, I= inhibits occupational participation, R= restricts occupational participation, N/S= not seen)

Motivation for Occupation:

Appraisal of Ability: A **I** (bolded items are current scores, vs. scores during initial eval)

Expectation of Success: A **A**

Interest: A **I**

Choices: I **I**

Pattern of Occupation:

Routine: N/S **I**

Adaptability: N/S **A**

Roles: A **A**

Responsibility: I **I**

PERFORMANCE CAPACITY

Interpersonal/communication:

Non-verbal skills: A **A**

Conversation: F **F**

Vocal expression: F **F**

Relationships: N/S **A**

Motor Skills:

Posture/Mobility: I **I**

Coordination: A **A**

Strength and Effort: A **A**

Energy: I **A**

Process Skills:

Knowledge: N/S **A**

Timing: A **A**

Organization: I **I**

Problem-solving: I **A**

Environment:

Physical space: I **I**

Physical resources: I **I**

Social groups: N/S **A**

Occupational demands: N/S **I**

Recommendations: Provided client with recommendations, including: make sure he attends scheduled appointment with PCP within the next few weeks, continue AROM and stretching HEP as tolerable, inquire with PCP re: home health physical therapy (vs. client going to physical therapy clinic), inquire with social work re: obtaining Lifeline. [Will follow-up with social work at Ryan White.] Also recommended that client continue writing memoirs/a future narrative, try to attend psychological counseling more regularly, and continue pursuing advocacy work that brings him meaning and purpose.

Goal Status:

STG: To be met in 5 weeks

- Client will complete neck and back ROM stretches and exercises (5/7 days per wk during the 5th wk) with I, in preparation for improved occupational performance during driving.
- **Met**
 - Client has a strong desire to drive but lacks self-confidence due to (self-reported) decreased neck ROM, frequent back pain, and balance deficits
- Client will prepare a simple monthly budget with VS. – **Met**
 - Client has a strong sense of awareness that he lacks financial management skills; reports being in debt and not being able to hold onto cash from week to week. Lowest ranked item on OSA.
- Client will correctly verbalize at least three basic monthly budgeting techniques, with I. – **Met**
 - See above
- Client will complete balance and strengthening programs with VS, in preparation for IODL. – **Not Met**
 - Collaboration by OTS and client based on client reporting that balance deficits inhibit client's ability to drive and that general weakness, fatigue, and lack of endurance affects performance on IODL; reinforced after learning that client also had a fall that was related to balance deficits
- Client will initiate beginning to create a meaningful item of his choosing by crocheting, with VS. - **Met**
 - Edited 2-14-12 from general craft to specifically crocheting; client has previous experience crocheting but forgets how and expressed interest in finding something new to "pass the time" while at home. Also applies to any deficits with fine motor skills due to client's B hand neuropathy.
- Client will demonstrate at least three correct fall prevention techniques, with I. - **Met**
 - Added 1-26-12 after learning client had recently fallen and after assessing home environment for fall risks

LTG: To be met in 10-12 weeks

- Client will take three necessary steps (self-identified) toward obtaining and/or driving a car, with VS. - **Progressing**
 - Client has a strong desire to drive but also lacks resources (e.g. does not own a car); expressed wanting to take steps toward buying a new car and using it to help him be more active in the community and more independent during IDOL

- Client will successfully manage basic finances for approximately one week with I, per self-report. - **Met**
 - See STG explanation above
- Client will decrease the frequency of rest breaks taken during IODLs, including doing the dishes, cleaning the fan, and vacuuming, from approximately every 10 minutes to every 15-20 minutes. - **Met**
 - A long-term expansion of related STG re: balance and strengthening programs, demonstrating any potential improvements made with increased strength, and improved energy levels and endurance to allow client to better perform the three priority IODLs of his report (dishes, fan, vacuuming)
- Client will successfully complete 100% of a meaningful item of his choosing by crocheting, with I. – **Not Met**
 - See STG explanation above
- Client will write an expanded and current personal narrative to include most recent past experiences and expectations for the future, with I. - **Progressing**
 - Added 2-14-12 after client presented OTS with already written personal narrative during last tx session

Progress Note

3-22-12, 4:00 p.m. to 4:20 p.m.

Subjective report by client: Client reports is feeling a lot better since last OT session, and is feeling a lot less stressed. Reports having found social support with friends to assist with coping over not being able to drive, and has been taking more walks with friends and enjoying the nice weather. "I always perk up a little bit when the weather gets nicer." Reports has had a counseling appointment that helped him address stress and anxiety, and has scheduled another counseling session for next month. Has been writing as a means of coping as well. Has been in contact with social workers from Ryan White re: attending support groups and continuing advocacy work. Client did not bring up issue of returning to work or feeling anxious about this topic. Reports has been trying to complete exercise/stretching program, though has decided not to return to PT services. Latest MD appointments with positive results; MRI scans show no new spinal problems contributing to pain. Per client, is completely off pain medication and is feeling a lot better. Still having some low back pain, but is managing it with occasional OTCs, e.g. Advil PRN.

Summary of interventions carried out/goals addressed: Phone session to discuss progress and current status. Client aware and agreeable to continuing phone sessions over the next few weeks when possible.

VOLITION

Personal Causation: Client this week continues to display emphasis on self-reflection and analysis; demonstrates demeanor of having regained control over his life in the last two weeks with little outside assistance, yet said several times during phone conversation, "I just hope things stay this way." Can infer that client is aware of the cyclical nature of his feelings of emotion, anxiety, and impending catastrophe in his life and environment. Questionable whether or not client is attempting to comply with what he perceives the "correct" responses to OTS questions should be, or if he is actually feeling better. Can infer that client is most likely doing better, but perhaps not quite as 100% as he is describing, in that he still has feelings of anxiety and chaos at times. Reports going out and "partying recently for about nine hours, and I was hurting after that and regretted it... too much standing up and walking around and my body felt it." Continues to use alcohol as a means of coping.

Values: Client clearly values maintaining appearance of control in his life

HABITUATION

Roles: No noted changes since last session

Habits: No noted changes since last session

PERFORMANCE CAPACITY

Interpersonal/communication: No noted changes since last session

Motor Skills: Per client, improved; improved levels of pain and increased mobility with less pain

Process Skills: No noted changes since last session

Environment: Finding new social support in group, since neighbor has moved out; is spending more time with friends that live down the street

Appendix B

Documentation: Client #2

Initial Occupational Therapy Home Health Evaluation – 01/27/2012

50 y.o. M, African American

PMH: HIV+ (per client, since before 2001), GERD, neuropathy, urinary retention, syndrome of inappropriate vasopressin secretion. Lab work from 7/14/2011: CD4 count 402 cells/cu mm blood 18.09%, VL 214 copies/mL blood. Per client, was hospitalized in 2008 and was then referred to a SNF by PCP d/t determination that client could not be safe in home environment (e.g. when climbing stairs, performing ODLs, etc.) Client D/C from SNF (same stay since 2008) approximately one week ago and is currently transitioning to independent living in 2-bedroom W/C accessible apartment (with ramp entry). Has power chair, straight walker and straight cane. Received PT in the SNF and was D/C from PT d/t meeting all goals (per client report); did not receive OT in SNF. Was I with self-care in SNF. Currently not receiving home OT/PT. Meds: Takes Prezista for HIV; oxycodone-acetaminophen and Lidoderm (5% patch) for pain. *[See chart for complete list of meds.]*

Personal History: Sexual orientation: bisexual. Per chart on 7/14/11, currently sexually active. +Marijuana “on rare occasion.” Unemployed. Client reports having completed college courses bringing him to approximately junior undergraduate status. Client does not drive. Has TARPS card. Per client, has good social support from mother who lives close by, and from other services such as Homechoice and the Ability Center of Toledo. Client’s father passed away within the last two years while he was in the SNF.

Summary of Results of OSA: Top 4 identified therapy priorities:

1) Increasing independence with ODLs and IDOLs, including: showering, cooking, grocery shopping, laundry, and basic home management (e.g. taking out the garbage), 2) Increasing community access and involvement (e.g. through computer use; trips to art museum, movies, restaurants) 3) Increasing daily motivation to accomplish goals re: organization and developing a routine, 4) Accessing educational opportunities– *See OSA in file for complete OSA form and scores.*

Summary of Results of SIGA: Overall (all tasks): 7/10; Laundry- 0/10, Grocery shopping- 7/10, Cooking- 5/10, Showering- 7/10, Community involvement- 1/10, Organization in the home and with daily routines- 6/10, Getting daily physical movement and exercise- 7/10– *Additional goals and occupations will receive SIGA scores as they arise.*

Current Status:

VOLITION

Personal Causation: Client has good insight into strengths. Was able to quickly respond to OSA questions and recognize potential areas for improvement, including explaining why these areas were important to him. Required some encouragement to identify areas of weakness and/or struggle. Client verbalized feeling that he would be efficacious during occupational performances when given the opportunity, since he has not had the opportunity for a long time since being in the SNF (e.g. during SIGA ratings client rated some items by prefacing “When I do go grocery shopping, I know I’ll be okay” or “Well, I guess right now it would just be a 1 because I haven’t done it yet”). Client expressed

appreciation for the interactions and help he has received from others (e.g. the Ability Center). Some minor longing for the past or negative feelings toward current occupational performance deficits could be inferred (e.g. when asked what he would like a typical day to be like, responded by saying “I would really like to just get in my car and drive wherever, but that’s probably not going to happen any time soon.”) Client also reported several times an inability to adequately “get motivated” to complete daily tasks or goals and identified this as one of the main areas in which he needs and wants assistance—will continue to assess how this lack of motivation might affect other areas of the client’s life. It can be inferred that client’s recent move from a SNF to home has also affected his sense of volition, self-motivation, and perspective of control of his daily life, as he is currently adjusting to newly gained independence and decreased accountability to others.

Values: self-advocacy (e.g. when taking medications on time, attempting to get his own apartment after living in a SNF), the ability to work well with others to accomplish goals (e.g. the Ability Center), cleanliness and tidiness (as evidenced by apologizing that his home was messy and cluttered), independence and self-sufficiency (evidenced by strong sense of communicating that he could probably successfully do things on his own when given the chance)

Interests: using a computer for online access, education (was pursuing a degree in Communications), spending time with family (mother, niece), community involvement (e.g. art museum, movies)

HABITUATION

Roles: son, uncle, former college student, patient/client, community member

Habits: It can be assumed that since client’s recent move from the SNF, his sense of habits are in the process of changing. *Will continue to assess.*

PERFORMANCE CAPACITY

Communication/interaction: Client able to communicate reasonably and logically. Follows conversation and interpersonal interaction adequately. Appropriate body language. Friendly and personable; smiling and laughing. Wears glasses.

Motor skills/Process Skills: Client reported normally having some fatigue throughout the day and some low back pain; expressed that symptoms and med side effects do not typically interfere with daily function. *Will continue to assess motor and process skills during subsequent tx sessions (using MOHOST and clinical reasoning skills).*

Environment: W/C accessible apartment with ramp entry. Some clutter inside apartment but adequate space to maneuver around. Laundry facilities on site. Close and accessible social network. Client is currently transitioning to a home environment after being in a SNF for approximately two years, causing significant changes in his physical environment, as well as his sense of social support and access to social groups (e.g. perhaps socialization was more readily available in the SNF). As he gains familiarity with his new environment, client’s sense of volition will perhaps change as well.

Progress Note

02-01-12, 1:00 p.m. to 2:30 p.m.

Subjective report by client: Reported being appreciative of help provided by OTS and by the Ability Center. At beginning of tx session was frustrated with this morning's trip (driven by his older brother) to the pharmacy, where he thought he was getting refills on all his meds, but received only two.

Summary of interventions carried out/goals addressed: Discussed status of assistance from the Ability Center of Toledo with obtaining DME for bathroom—client reported Tiffany from the Ability Center had received message from OTS and will bring handheld shower, shower seat, and additional grab bar this coming Monday. Per client, Tiffany will also be bringing co-workers from the Ability Center to assist with other household tasks, such as organizing extra bedroom. Discussed use of TARPS to travel to medical appointment yesterday; client reported no problems using services, though felt it somewhat unnecessary since hospital/MD clinic is such a short distance from his apartment. Expressed wishing he could ride his power chair there, but not being sure or confident it would make it all the way so will continue to ride TARPS. Discussed client calling pharmacy and asking about medication delivery option. Completed kitchen occupation of washing dishes, with straight walker and S. Completed simulated trip to the laundry facilities, which client had not yet accessed; client carried full laundry basket and laundry detergent on lap in power chair and opened all doors with I. Expressed: "I probably wouldn't have found where that was without you telling me to look around the corner, even though my brother tried to tell me where it was. Now I can do some laundry. Thank you." Educated on seated exercises to do from armchair or couch for BUE—two soup cans use for weights, as client's free weights are in storage in extra bedroom currently. Discussed importance of working on one thing at a time so as not to feel overwhelmed, re: organizing extra bedroom—assisted client in carrying two boxes to living room for him to sort through. Assisted client in plugging in computer modem and monitor; client will search for missing computer cords in box. Ended tx session with client sorting through boxes to determine what he might like to give away vs. keep.

VOLITION

Personal Causation: Client is insistent that once he can "get motivated and get started" with organization of apartment and completion of tasks that he will get everything completed very quickly. Client reported being the type of person that prefers to work for long, consecutive periods of time on a task until it is complete, rather than doing it a little bit at a time. Client alluded to being stressed and somewhat overwhelmed, then seemed to self-correct by reassuring himself that "it will all get done." Continues to appear self-critical, especially re: home organization.

Values: Being neat and organized-- Client expressed: "I used to be so much for cleanliness, very fastidious. Now I just walk past that room and I feel disgusted."

Interests: computers and online access—client reported "I really used to love getting online" and expressed possibly buying a laptop instead of the current desktop that he has in order to provide him with better computer access

HABITUATION

Roles: brother—client expressed that he currently has one older brother; previously had another older brother as well but he passed away approximately one year ago from heart disease secondary to HTN; Indicated re: brother driving him to pharmacy this morning, “Since I don’t drive I have to take what I can get.” [also applies to volition]

Habits: +tobacco this date, though not listed in medical chart or information obtained during initial eval; Re: social appropriateness of habit, client said to OTS, “You don’t smoke, right?” and sprayed air freshener into the air; took last drag of cigarette then put cigarette out. [also applies to values—manners, social acceptance, being polite]

***Results of MOHOST falling under VOLITION and HABITUATION:**

(Rated based on MOHOST categories and procedure: F= facilitates occupational participation, A= allows occupational participation, I= inhibits occupational participation, R= restricts occupational participation, N/S= not seen)

Motivation for Occupation:

Appraisal of Ability: A

Expectation of Success: A

Interest: A – within own environmental restrictions

Choices: A

Pattern of Occupation:

Routine: I

Adaptability: N/S

Roles: A

Responsibility: I

PERFORMANCE CAPACITY (from MOHOST)

Interpersonal/communication:

Non-verbal skills: F

Conversation: F

Vocal expression: F

Relationships: A

Motor Skills:

Posture/Mobility: I

Coordination: A

Strength and Effort: A

Energy: A – one rest break taken during washing dishes occupation; client very aware that rest break and sitting was warranted

Process Skills:

Knowledge: N/S – Will continue to assess.

Timing: F

Organization: A – Based on observation of volition and personal causation, client would most likely rate himself lower on this item. Client is not disorganized when environment is set up for easier access; may need assistance creating this sort of environment.

Problem-solving: A

Environment:

Physical space: A

Physical resources: A

Social groups: F – re: family, outside services (e.g. The Ability Center)

Occupational demands: I

Progress Note

02-8-12; 1:00 p.m. to 2:30 p.m.

Subjective report by client: Client reported that one of his close family members had passed away unexpectedly a few days ago, and that he was “currently trying to deal with that.” Per client, services will be this weekend and family members are coming to help him with transportation and with coping.

Summary of interventions carried out/goals addressed: Tub transfer bench and handheld shower were delivered by the Ability Center earlier this week but had not been assembled. Assisted client in problem-solving and assembling shower chair. Set up shower chair in bathroom; also set up non-skid mat and shower curtain. Marked position on floor with electrical tape where shower chair should remain. Marked diagonal position on far wall of shower where second grab bar will be installed. Educated client re: cutting shower curtain around tub transfer bench to allow for maximal safety re: water spillage and preventing falls. Client will call apartment maintenance to assist with removing current showerhead and with installation of handheld shower. Client informed of potential benefits of altering door hinges for door to swing out of bathroom the opposite way, allowing for more space and increased safety in bathroom. Client reported would ask maintenance about this. Client completed occupation of taking out garbage with I. Client was given a copy of some of his OT goals; discussed overall nature of goals in OT, that they will change, importance of communication during goal-setting, importance of self-report with tracking progress, etc.

VOLITION

Personal Causation: At the end of the OT session client reported: “I feel like we really got something accomplished today.” After reviewing his goals client reported: “I feel like I already do a lot of this all the time. Do you want to see me do it?”—indicating that client does feel a continued sense of volition and personal causation that he can be independent on his own, as evident during initial eval; however, also indicates appreciating help in completing tasks—e.g. “I couldn’t have done it without you” re: shower chair assembly. In relation to recent death in the family, client said, “I am trying to get this place organized but my mind has just been elsewhere lately with everything going on.” Client indicated some feelings of self-blame and negativity toward himself for letting his emotions or grief get in the way of his occupational performances on everyday occupations.

Values: family, productivity, independence, organization

PERFORMANCE CAPACITY

Interpersonal/communication: Client asking more questions today about OTS opinion (e.g. “I was thinking of putting this mat by the door; what do you think?”). Client also problem-solving out loud and providing practical reasoning and explanations. During setting up of bathroom, client voluntarily repeating back information provided by OTS and demonstrating clear understanding (e.g. “So, the grab bar will go there where the tape is, and I can use that mark on the floor for the bench if I ever have to move it.”)

Motor Skills: Client took approximately 3 breaks during OT session to rest. Client able to safely

use walker for functional mobility around apartment. Client able to safely lower himself to the floor to work on a challenging occupation (e.g. assembling shower chair) during kneeling or sitting; able to safely get back up to couch surface. Some fatigue noted but no shortness of breath, sweating, etc.

Process Skills: Good sense of self-awareness by client as to the state of his fatigue, or if his environment was offering an over-challenge vs. a just-right challenge. Good problem-solving during occupations, including adjusting to changes in sub-occupations and to challenges arising within environment.

Environment: Small size of bathroom continues to be an environmental challenge to client, as he cannot use his walker to go into the bathroom and instead must bear weight onto the door handle. Social group clearly providing support (from family) this week (e.g. niece took client's winter coat to the drycleaners so he would have it for upcoming funeral).

Progress Note

2-15-12, 1:00 p.m to 2:30 p.m.

Subjective report by client: Client reported that visiting RN and HHA will be coming approximately 12 hours per week. Client unsure what he would like HHA to focus on in addition to assisting him with cleaning. (Discussed some possible options with client, and typical HHA job description.)

Summary of interventions carried out/goals addressed: New STGs created based on what client wanted to address this date—Facilitated client problem-solving during occupation of putting items from boxes away in master bedroom (e.g. hanging clothes, sorting items to donate to Goodwill, moving boxes, unpacking, etc.). Assisted client with disposing of small broken cabinet in dumpster at client's decision-making and direction and taking boxes of clothing to Goodwill. Checked status of bathroom DME—second grab bar installed in shower (suction grab bar). Handheld shower yet to be installed, pending assistance from apartment maintenance staff. Will bring tools to next week's session and re-assess bathroom DME.

VOLITION

Personal Causation: Reported, "I know it looks like nothing has really been touched since the last time you were here, but since that funeral I've just sort of been hanging out not doing much." – Client continues to display negative self-judgment toward the status of organization and cleanliness in house. Demonstrates improved hopefulness for the future in response to assistance being provided. (e.g. "Thanks for all the help. I feel like it's really starting to come along. I have more space to move around!") Client is progressing and meeting goals. Client also demonstrates clear sense of volition and personal causation re: self-initiating tasks based on suggestions from support system—e.g. remembered the need to ask the maintenance staff at apartment complex about showerhead and door hinges from last session, followed up with home medication delivery services, is pursuing Food Stamps with Job and Family Services (has filled out paperwork), etc. Client easily and quickly able to make decisions regarding what clothing or items to give to Goodwill versus which items to keep—did not appear anxious or stressed over these decisions when minimal support was provided. Seems to need initial push to begin occupations re: organization, but is successful continuing them and completing them with assistance. Client also expressed calling TARPS to try and get a bus to take him to the bank to cash a check; TARPS informed him that he needed to plan trips at least one day in advance with their services. Client seemed somewhat frustrated but able to adjust; could infer that client had learned and will adjust his behavior accordingly in the future in a successful and productive way.

Values: cleanliness, working with others to complete goals and occupations, the need for making continuous progress in some capacity

Interests: When unpacking swim trunks, client expressed some interest in potentially doing water aerobics or water therapy classes at a YMCA – Will continue to discuss and explore.

HABITUATION

Habits: Easily taking care of immediate needs (e.g. food, self-care, sleep) but struggles with

addressing more complex occupations (e.g. cleaning, laundry, etc.)

PERFORMANCE CAPACITY

Interpersonal/communication: Excellent collaboration to complete occupations and excellent insight of self in relation to others and in relation to environment during problem-solving

Motor Skills: Continued fatigue, but able to complete all occupations by utilizing good body mechanics and energy conservation techniques with minimal rest breaks

Process Skills: Good self-awareness, problem-solving abilities during occupations

Environment: Continued improvements with organization and environmental stability; continues to have positive social support within social group (though, per client, support can sometimes be a slow process—e.g. family members are often busy and it takes them a while to respond to client's needs)

Progress Note

02-22-12, 1:00 p.m. to 2:15 p.m.

Subjective report by client: Per client, feels that HHA has been coming too much and he “doesn’t have that much for her to do... I feel bad because I know she’s getting paid, but I think I might call [the home health agency] and ask them if they can send her only twice a week or something.” Client expressed wanting to walk to the shopping center by his apartment in his power chair and wanting to buy some items at the store. Asked OTS to walk with him, then remembered that HHA was coming. Decided he could not make it back in time for when she arrived and changed his mind about going. Reported that HHA drove him to the store last week and he would ask her to again this date.

Summary of interventions carried out/goals addressed: Facilitated client problem-solving and provided encouragement to enable client to complete occupation of setting up computer. Since last week, client had successfully sorted through a box containing cords and electronic equipment. With min A from OTS, client successfully set up computer station including modem, monitor, keyboard, and mouse. Educated client about methods of obtaining Internet services in order to have additional access to the community, leisure, education, etc. Will follow up. Met HHA and explained OT briefly. Planned to set up a TARPS outing for next week (e.g. shopping, or leisure outing), since client has only taken TARPS independently to hospital/MD clinic and no farther. Will call client on Monday or Tuesday of next week to plan TARPS outing in more detail. Client agreeable.

VOLITION

Personal Causation: Client seems to have a somewhat improved sense of personal causation, especially in regard to decision-making; appears more confident in decisions and makes them in a more authoritative manner (e.g. tells OTS what he would like to do and asks for specific help, instead of expressing himself in a manner where he asks OTS what he should do first); is also able to make decisions noticeably faster. Able to change his mind when needed and with good reason (e.g. today with not going shopping if not enough time). Client is also improving with being aware of what he needs to do (e.g. go to Job and Family Services to discuss food stamps situation, since calling has not been working) and is aware of the steps needed to achieve these goals—however, client does continue to display some continued sense of avoidance toward occupations and tasks that he finds difficult and overwhelming (e.g. organizing extra bedroom or actually finding the time to go to Job and Family Services) yet seems to understand that he needs to keep working on gaining personal causation—in his words, “fully settling in” to his environment.

HABITUATION

Roles: (can also apply to values and interests) When setting up client’s computer (which had not been used in approximately three years, per client report) observed four or five usernames on the main login screen, three with a strong sexual connotation—indicating that perhaps client had a previous role of maintaining Internet relationships or meeting new people online. Client has previously reported that he “used to enjoy being online” and that he spent a large amount of leisure time in this manner, especially when sick. Various usernames indicate that when client was physically unable to participate in other occupations, spending time online as a means of

communication was meaningful and purposeful to him, and relevant to his sense of identity as well as to his sense of maintaining a social group and social environment.

Habits: Client demonstrated high emphasis on the habit of smoking this week—Normally does not smoke during OT sessions but today said, “I’m so sorry, I just have to smoke today.” No further discussion about current level of stress or potential stressors.

PERFORMANCE CAPACITY

Process Skills: Continues to exhibit good problem-solving skills, and improved sense of accuracy with self-awareness of self and environment

Environment: Excellent support continues from various organizations, such as The Ability Center (sending a volunteer to assist client with moving heavy objects in extra bedroom at the end of this week, such as a weight machine); Remains unclear what sort of social group client has in his environment outside of family members. When asked about friends, client expressed that he had many friends in the nursing home, but right now mostly he just sees his family since moving out of the SNF. Did not offer more specific information or details at this time.

Progress Note

02-29-12, 1:00 p.m. to 3:00 p.m.

Subjective report by client: During session, as progress began to be made, client reported “Yeah, wow, it’s so nice to have space... my own space.” At the end of session, client reported, “Thanks so much, I couldn’t have done it without either of you!”

Summary of interventions carried out/goals addressed: Met Tiffany from the Ability Center and volunteer/rec therapy student. Discussed client goals, including finding a buyer to purchase weight set in client’s closet. Developed plan for client to clean and organize extra bedroom in apartment. Facilitated organization, problem-solving, and decision-making processes during cleaning and organizing of extra bedroom. Client completed approximately 80% of extra bedroom organization. Planned for TARPS outing next OT session.

VOLITION

Personal Causation: Client exhibits increasing confidence in occupational performance and increased self-efficacy, e.g. during decision-making with sorting items from extra bedroom—took less time to sort these items than did when sorting items before in master bedroom, demonstrating clear improvements. Client also expressed sense of control and personal causation, choosing a few boxes to go through on his own after OTS and volunteer had left. Client still demonstrates some sense of being overwhelmed and/or anxious in the face of large or complex occupations, but demonstrates improved sense of personal causation when he knows he has help and support, even in the form of mere verbal encouragement. Client also demonstrated increased assertiveness this week, expressing to OTS, “I actually really wish I could keep that weight set, if only there was some place to put it. But I just don’t see how. I mean, I just bought it about a year ago.” OTS discussed options of rearranging extra bedroom with client in order to allow room for weight set. Suggested that client think about rearranging room vs. selling weight set, and form a decision by next week. (Will follow-up and assist client with rearranging room if needed.) Either way, will test client’s sense of volition and personal causation by OTS not providing opinion or input re: decision about weight set. Will discuss reasons for final decision next week. Client did not seem anxious or stressed by the chance to make this decision on his own, which also demonstrates improvement with personal causation since initial eval.

Values: Client demonstrated sense of meaning attached to many of the personal items he came across when sorting and organizing, such as old records, VHS tapes, family photographs, an old jacket, exercise equipment, a large glass mirror, a Cuckoo clock, etc. Client expressed, “All these things had meaning at one point. They’ve been in storage so long.” Client clearly demonstrated sense of self-awareness about how environments and parts of life change, how people adjust to them, and how objects represent phases of people’s lives and represent meaning, but do not dictate meaning. [Also relates to process skills.] In this way, client seems to value self-reflection and memories, while still maintaining a sense of privacy and control over his environment and personal items.

Interests: Client also shared with OTS an Internet deal he received in the mail that he was interested in looking into. Reported would call the company to address his questions. While

sorting through items, found a box of old records and said, “Maybe I could sell those on E-bay? I used to go on E-bay all the time.”

HABITUATION

Roles: Client’s brother present at the beginning of session, watching TV and drinking a beer in living room. Brother remained for approximately one hour while OTS and rec therapy student were present. Left when HHA arrived.

Habits: Continues to consistently smoke cigarettes

PERFORMANCE CAPACITY

Interpersonal/communication: Observed that client and HHA have little interpersonal communication or interaction. This week was the second time observing HHA and client interact; somewhat of a language barrier, as English is the HHA’s second language. Client is somewhat reluctant to delegate tasks to HHA as well [also relating to volition and personal causation]—after organizing extra room, various pieces of furniture needed to be cleaned before being used. Client noted that these items needed to be cleaned and expressed, “I can just clean those later,” though HHA was present and cleaning the client’s bathroom that was not dirty and per client had just recently been cleaned.

Motor Skills: Client tolerated approximately 2 hours of moderate exertion (e.g. bending, stooping, picking up bags, standing, changing positions, etc.) with very minimal rest breaks—rest breaks consisted of sitting down on bed and sorting through boxes. Observed some improvements re: endurance during occupational performance and re: level of energy since initial eval, perhaps based on client completing ODLs and IODLs in his home vs. with assistance in the SNF.

Process Skills: Continues to demonstrate good problem-solving and logic

Environment: Environment of apartment continues to improve in organization and cleanliness

Progress Note

3-7-12, 1 p.m. to 4 p.m.

Subjective report by client: Client reported cancelling HHA for today as he was planning TARPS trip to Job and Family Services with OTS. Also reported not wanting HHA for so many hours per week, especially because “sometimes she just sits there, after she vacuums and does a few dishes. And normally it doesn’t even really need vacuuming at all. I mean, I hate to get her in trouble but I think I need to do something about that.” Also reports wanting HHA to drive him to grocery store or bank and HHA telling client it is not part of her job description. Reported being frustrated “that I can’t even get, like, a stamp or something. Just a stamp to mail a letter” without help if HHA is unable to take him. Client also reported getting electric bill for \$156 for one month, well over the amount he had anticipated. Client called electric company to inquire. Client reports will call Internet service provider this week.

Summary of interventions carried out/goals addressed: Client completed planning of outing to Job and Family Services using TARPS system with I. Accompanied client on trip and observed client demonstrating safety, planning, organization, and problem-solving skills with I. Educated client re: smoking cessation and encouraged client to continue taking an active role in management of his daily occupations (as he has been, e.g. calling the electric company when a problem arose). Facilitated formation of alternate plan if HHA is unavailable for transportation, e.g. TARPS, asking client’s brother or niece to drive him. Will continue to encourage/facilitate client gaining Internet service, calling to inquire with HHA’s company, and deciding what to do with weight set in client’s master bedroom closet. Priority plan for next week: rearranging furniture in extra bedroom to see if weight set will fit inside adequately, to better help client make decision about selling.

VOLITION

Personal Causation: Client continues to demonstrate improvement re: personal causation through improvement in his confidence with decision-making abilities. Before, perhaps client would have not said anything to anyone re: HHA not completing tasks up to client’s satisfaction; now, however, he is able to speak up about his thoughts and feelings and take the correct steps to communicate them to the correct people. (e.g. plans to call home health service and ask for more information) Client also went to leasing office to discuss maintenance making repairs on his bathroom w/o prompting or assistance, when before client might have simply let such repairs go. Client also showing improvement re: decreased procrastination with accomplishing tasks, and an improved sense of control over his life and environment. Perhaps after client accomplished the occupation of organizing his extra bedroom, other occupations seem less challenging—as the extra bedroom was a large source of client’s anxiety, accomplishing this may have been a huge confidence booster for client. Clear improvements re: independence with occupations. Even client’s selecting Job and Family Services as his outing on TARPS demonstrates his improved understanding of organization and his increased ability to prioritize—instead of choosing a leisure outing, client chose to focus on his more immediate needs (e.g. food). Still continues to have some apprehension with initiating tasks (e.g. deciding what to do with weights) but is better able to prioritize needs and take care of more important ones on own, while saving other ones that are less of a priority for when client has outside help and support.

Values: Can infer that client places significant value on following rules and/or staying out of trouble (perhaps because of negative past experiences?) E.g. client saw sign on door that he interpreted as no one being allowed to stand outside of door; client became somewhat preoccupied with security guards passing by, waiting for them to say something to client and OTS about standing outside door (though they never did). Client also smoked a cigarette while at the facility, instructing OTS, “You go ahead back inside, because I want to smoke this and I need to be a certain distance away from the building.”

Interests: As there was extra time after speaking with Job and Family Services before TARPS returned for pick up, client initiated walking to Wendy’s for lunch. Seemed to very much enjoy being out and around other people; no observed anxiety or discomfort. Client laughing a lot this OT session. Can infer that client found meaning in feeling a renewed sense of participation in a community, especially after being in SNF.

HABITUATION

Roles: Client is perhaps beginning to think of himself as a member of a community again after being out today (emerging role)—some excitement noted when client expressing that he feels a sense of accomplishment. “We got a lot done today.” Client very pleased that TARPS driver did not ask him to redeem a ticket, meaning that he can ride TARPS more frequently for a cheaper price—additional incentive to continue to take it to farther destinations. Also, client observing certain buildings that had been torn down or changed during the bus ride—commenting on these changes, indicating further sense of attached meaning and connection to community.

PERFORMANCE CAPACITY

Motor Skills: No fatigue noted throughout outing outside client’s home today—tolerates use of power chair well; no accessibility challenges noted

Process Skills: Excellent planning and organization this week

Environment: Seems to function well within social environment

Progress Note

3-14-12, 1 p.m. to 2:15 p.m.

Subjective report by client: Client reported being very displeased by HHA. Per client, received copies of time sheets from home health agency on which HHA had listed various items that she had not actually completed with client, most of which he does not even require assistance with (e.g. “Incontinence care,” and “toilet transfer”). Client called agency and requested that HHA not come in this week. Client also reports that Jobs and Family Services (where client and OTS went last week to get food stamps) has not contacted him as promised to continue the process. Client reported sending in necessary paperwork and still has not heard back. Reported some low back pain (3/10) for which client reported had taken one pain pill this date, PRN. Reported pain was “not too bad, and feeling better.”

Summary of interventions carried out/goals addressed: Client completed functional mobility to mailboxes and back with walker + supervision, after writing out checks to pay some bills and wanting to mail them. Discussed meaningful occupations (per client) that he has completed so far this week (e.g. cleaning furniture items that were dusty from extra bedroom, putting items in closet, going grocery shopping, going to the store by himself). Client inquired about strategies for dealing with HHA situation. Educated on possible options. Collaborated with client to make plan for client to communicate with agency about getting a new HHA, followed by possibly contacting his main case manager about potentially selecting another home health service. Facilitated client making list of tasks that he can complete on his own the rest of this week, including calling Internet service provider, refilling prescriptions by phone and having them delivered to his home, putting money on his laundry card, doing laundry, calling Jobs and Family Services, calling re: home health care needs, calling Tiffany from the Ability Center re: man who called about purchasing weight set, having brother bring over DVD player to set up.

VOLITION

Personal Causation: Client dictating the direction of the OT session today. Wanting to get organized and determine all that he needs to complete this week. Reported: “You helped me get motivated to do these small things that I just need to do.” Client finding clear meaning in enjoying the weather, and in challenging himself to use his walker outside for short distances with supervision. Client continues to improve re: knowing what he wants to accomplish, and continues to improve with determining how to access help as well. Per client, “So next week I’ll have a plan before you get here of what I want to do. I may as well use you while you’re here for the next few weeks. I’ll make sure my W/C is charged up.” Client exhibiting confidence and security with actions and with increasing independence. Continues to adjust gradually to small things in the home environment... e.g. reported wanting fresh air—“I wish I could just leave the door open.”—OTS suggested opening windows, which had a screen. Assisted client to open windows and arrange path for him to reach windows. “Thanks! I couldn’t have done it without you. I was just used to winter. And to windows that didn’t open much at the nursing home. It feels so nice. Fresh air!” When asked about general feelings of progress thus far (informally), client reports feeling that the “big things are under control” and that it’s just “a matter of keeping up with everything.” Seems less outwardly anxious and stressed when faced with challenging tasks.

Values: People who are trustworthy, people who “respect me” (per client)—especially apparent when discussing HHA; independence—clear also with HHA discussion, as client reporting “I can just do that myself”

Interests: Being outdoors in the nice weather

HABITUATION

Roles: Seems to have improved sense of self-advocacy, taking on the role of self-advocate for his own healthcare much stronger than before

PERFORMANCE CAPACITY

Process Skills: Problem-solving skills continue to improve

Environment: Physical environment continues to improve; some instability re: social environment with HHA this week, as client must rely on family members more or on himself to use TARPS—reports that he feels confident and able to use TARPS, but wishes there were a more convenient way. (i.e. to go to the bank to cash a check, TARPS drops him off and leaves, and he ends up waiting there for it to return for much longer than it would take him just to stop at the bank quickly)

Progress Note

3-20-12, 1:00 p.m. to 2:30 p.m.

Subjective report by client: Client reports is still frustrated by HHA situation, but has been in contact with the home health company this week and has told them of his dissatisfaction. Has obtained number of a contact who can recommend a new home health agency; will call them tomorrow and ask for another agency who will allow their HHAs to drive clients to store, bank, etc, as client has identified that this is his priority need with the HHAs.

Summary of interventions carried out/goals addressed: Per OTS request last week, client had entire session for today planned. Client with power chair charged and ready to go upon OTS arrival. Client completed occupation of traveling from apartment to store to obtain basic grooming items in power chair, with I. Client then decided to travel from store to gas station to obtain additional items, and from gas station to fast food restaurant to purchase lunch. Client then independently decided it was time to return to his apartment, as he had been consistently monitoring power chair's charge without prompting. Stopped twice on the way back to apartment to allow power chair to regain some charge.

VOLITION

Personal Causation: Excellent problem-solving skills, planning skills, organizational skills—client continues to seem to feel more comfortable taking charge of situations, making choices independently, and justifying his thinking and reasoning. Client also requires less prompting to discuss problems that have arisen since last session, as well as analyzing solutions. Client continues to appreciate help and assistance—"I couldn't have done it without you today! I just wanted to make sure I could get that far. I think next time I'll just go to one store, and then the chair's charge will stay longer." After session, client assessing what was successful or unsuccessful about occupational performances during session, commenting on what might have gone differently, etc.

Values: Client clearly places a high value on safety, as was consistently monitoring his chair's power and discussing methods of traveling to the store in the safest manner. OTS + client concluded that the ideal solution would be to have HHA who might drive client to the store. Discussed benefit of being driven to the store and shopping himself, as opposed to giving HHA money and a list to do the shopping for him; discussed occupational nature of doing own shopping and making own choices, dealing with changes, meaning, and purpose in making own decisions. Client clearly values independence in this way, and ability to make own decisions.

Interests: Wendy's spicy nuggets ☺

HABITUATION

Roles: Remain consistent since last session

Habits: Remain consistent since last session

PERFORMANCE CAPACITY

Interpersonal/communication: Remain consistent since last session

Motor Skills: Reports no pain today; minimal fatigue. Per client, feeling good and “enjoying the weather, feeling energized because of the weather”

Process Skills: As noted above, problem-solving and organizational skills improving

Environment: Remains consistent since last session

Progress Note

3-28-12, 1:00 p.m. to 2:00 p.m.

Subjective report by client: Client reported that he had a friend from the SNF come to visit him last week unexpectedly. His friend reported that she had moved out of the SNF down the street from the client; had called the SNF asking for him and the SNF had given her the client's address so she came to visit.

Summary of interventions carried out/goals addressed: Facilitated client doing laundry occupation—traveled to leasing office, loaded money onto laundry card, did load of laundry, loaded more money onto card, etc. Also completed taking out the garbage. Ran into a neighbor on the way back from the dumpster who client also knew from the SNF; the neighbor lived in the apartment directly behind client, and reported was going to the store but was going to come back to visit client that afternoon. Client and neighbor discussing methods of efficiently charging power chairs, traveling to nearby grocery store, swapping advice about methods of transportation, etc. Client also talked to landlord at leasing office while loading laundry card, and was informed that the apartment complex hosted Bingo for residents to win prizes and discounted rent. Client verbalized being excited and plans on attending this coming week.

VOLITION

Personal Causation: Continues to display increased confidence with making choices, increased sense of control over self and environment, etc.

Interests: Plans for movie outing next week

HABITUATION

Roles: Beginning to embody the role of friend, neighbor, and acquaintance to those in the environment around him; expanding his social group and developing new relationships

Habits: Desire to form additional habits of increased community involvement

PERFORMANCE CAPACITY

Interpersonal/communication: Noted increased confidence re: communicating with others, communicating with strangers, etc.

Environment: See previous comment re: expansion of social group

DISCHARGE

4/4/12, 12:00 p.m. to 5:00 p.m.

Subjective report of client this date: The client reports feeling like he has accomplished a lot over the last few months. “We have done so much. I certainly don’t miss the nursing home. I really appreciate our visits and I feel like I can take care of what I need to take care of.”

Relevant changes discussed re: volition, habituation, and performance capacity: The client’s report on standardized assessments and his verbal report when asked specifically about progress on his goals indicates that he has made gains in volition and personal causation as well as decreases in anxiety. Organization, especially of the environment, has improved, leading to improvements with problem-solving and planning skills. “I feel much more capable. I still have some more things to get done and take care of, but I’m definitely on my way!”

Tx provided this date: Facilitated the client planning a community leisure occupation to the movies, including looking up the movie times, calling TARPS ahead of time to schedule, utilizing time management, organization, and problem-solving skills. The client was able to correctly respond to unplanned changes in scheduling or in the environment during this leisure occupation with independence.

Summary of Results of OSA: See OSA data summary sheet in the client’s chart for full results. Overall, the client’s OSA competence scores improved from initial eval to the time of D/C, indicating that the client increased his sense of volition and personal causation, and indicating that the client has an improved perception of his own competence during occupations. Additionally, the client’s scores of value items increased, indicating that the client currently places more value on many of the volitional items listed on the OSA. This is perhaps indicative that client’s level of meaning and purpose about everyday occupations has increased, and that transitioning to a personalized home environment from the skilled nursing facility assisted the client in gaining value and self-identity.

Comparison of overall scores is as follows:

Initial OSA scores: Competence: 68 (Error= 3), Value: 78 (Error= 3)

Final OSA scores: Competence: 72 (Error= 3), Value: 84 (Error= 4)

Summary of Results of SIGA: See SIGA form in the client’s chart for complete results of SIGA at D/C. Overall, the client’s SIGA scores on the majority of items improved from initial eval to time of D/C. Examples include: laundry from a score of 0/10 to a 1/10, grocery shopping from a 7 to a 10, cooking from a 5 to 9, showering safely from a 7 to a 10, organization from a 6 to an 8, and physical movement/exercise from a 7 to a 10. Though the client reported “I am much more involved outside my home now” his SIGA score for community involvement remained a 1 at D/C (as it did during initial eval), indicating that this is still a goal for him. His overall SIGA score improved from a 7 to a 9.

MOHOST:

VOLITION and HABITUATION:

(Rated based on MOHOST categories and procedure: F= facilitates occupational participation, A= allows occupational participation, I= inhibits occupational participation, R= restricts

occupational participation, N/S= not seen)

Motivation for Occupation:

Appraisal of Ability: A (bolded items are scores at D/C vs. initial eval) **F**

Expectation of Success: A **F**

Interest: A **F**

Choices: A **F**

Pattern of Occupation:

Routine: I **F**

Adaptability: N/S **F**

Roles: A **A**

Responsibility: I **A**

PERFORMANCE CAPACITY

Interpersonal/communication:

Non-verbal skills: F **F**

Conversation: F **F**

Vocal expression: F **F**

Relationships: A **F**

Motor Skills:

Posture/Mobility: I **A**

Coordination: A **A**

Strength and Effort: A **A**

Energy: A **F**

Process Skills:

Knowledge: N/S **A**

Timing: F **F**

Organization: A **F**

Problem-solving: A **F**

Environment:

Physical space: A **F**

Physical resources: A **F**

Social groups: F **F**

Occupational demands: I **A**

Recommendations: The client should continue seeking social support from his family and medical providers, building relationships with neighbors and friends, and participating in community occupations. The client should also continue pursuing progress on current goals, such as obtaining Internet services to increase community access and looking into getting a new home health agency. The client was also reminded of basic exercise techniques to complete from a seated position, and fall prevention strategies were reinforced. Finally, the client was reminded of the importance of self-advocacy and in asserting himself during occupations and goals.

Goal Status:

STG: To be met in 5 weeks

- Client will complete basic exercise routine (5/7 days per wk during the 5th wk) with I, to facilitate increased pain management and tolerance of occupational performance in preparation for IODL. - **Progressing**
 - The client reported pain and frequent fatigue/lack of energy during IODL, and expressed wanting to develop a more consistent routine and “be more motivated” to stick with it.
- Client will correctly verbalize at least three examples of energy conservation education techniques, with I. - **Met**
 - See STG above re: fatigue.
- Client will correctly verbalize at least three examples of fall risk prevention education techniques, with I. – **Met**
 - The client is transitioning to home from previously living in a SNF for two years, and reported that he has never had a fall before. He wants to make sure to maintain safety in his new home and new environments.
- Client will successfully complete at least one IODL occupation (e.g. grocery shopping, laundry, cooking, and/or basic home management) per day, 5/7 days per wk during the 5th wk, with VS. - **Met**
 - This goal relates to the common theme of the client transitioning from a SNF to home and wanting to ensure safety, independence, and a sense of volition in his new environment.
- Client will successfully arrange for and utilize TARPS bus system for medical appointments with mod I, 2/3 trials. – **Met**
 - The client does not drive, and a major part of his independence depends on navigating the TARPS bus system.
- Client will increase SIGA score related to cleaning and/or organization of extra bedroom in apartment by at least one point, with S. - **Met**
 - A general goal for the client is organization, particularly in regard to organizing/cleaning the extra bedroom of his apartment. He also expressed the desire to increase personal causation in this way. The current disorganization of the extra bedroom causes the client stress and anxiety, and seems to embody his tendency to self-criticize regarding his current inability to be completely independent. Organizing this room is a priority, as the client desires it to be clean very much but reports lacking the personal causation to complete this task himself. Organizing this room would greatly increase the client’s sense of personal causation and his confidence in his ability to be independent in his home overall. Furthermore, it would decrease his stress levels and increase his sense of volition, which could then be carried over to other occupational performances (e.g. ODLs, IODLs, leisure, etc.).
- Client will put away contents of boxes in master bedroom, with S. – **Met**
 - Added 2-15-12, after the client expressed that this is what he wanted to do this date, as the clutter was beginning to bother him and he was feeling overwhelmed.
- Client will dispose of old clothes, a small cabinet, and several boxes he no longer wants, with S. – **Met**
 - Added 2-15-12, see explanation from previous STG. These items had been sitting in the client’s apartment since he moved in about a month ago and expressed wanting them out to feel more organized.

- Client will set up computer and computer workstation with S. – **Met**
 - Added 2-22-12, after the client found missing computer cords and wanted to set up computer.

LTG: To be met in 10-12 weeks

- Client will complete full shower safely (by self-report), 2/3 trials, with mod I and correct use of DME. - **Met**
 - The client reported having difficulty with showering and wanted to ensure maximum safety. Upon initial eval, the client was in the process of working with an outside organization to obtain DME for his shower and was interested in trialing it and getting help making any necessary adjustments.
- Client will increase SIGA scores related to IODLs by at least one point, including: grocery shopping, laundry, cooking, and basic home management. - **Met**
 - See related STG above. This goal relates to demonstration of increases in volition re: living at home after transitioning from SNF.
- Client will successfully complete steps needed to plan, navigate, and participate in at least one community outing of his choice, with mod I. - **Met**

This goal relates to the STG of using TARPS for medical appointments above. Because the client would like more community involvement, his access to community outings and occupations also depends on the TARPS system.
- Client will increase SIGA score related to cleaning and/or organization of extra bedroom in apartment by at least two points, with S. - **Met**
 - See related STG explanation above. This goal will require actual support (as opposed to only verbal support) by OTS since the client is physically unable to lift or move some items in the room.

Appendix C

Documentation: Client #3

Initial Occupational Therapy Home Health Evaluation – 01/30/2012

28 year old female, African American

PMH: HIV+, depression, anxiety, major depressive disorder (recurrent, moderate), fibromyalgia, generalized pain, HLD, obesity, migraines

Per client, lack of energy and high fatigue levels are more severe in the winter months and in the evenings. Also per client, remembers feeling constantly tired since she was a teenager, and feeling her fatigue get worse s/p giving birth to her daughter 5 yrs. ago.

Psychosocial: Per chart, currently receiving psychological services from CNP at Ryan White. Reports is doing well on psych meds and taking them as directed. Per chart on 10/14/11, was fearful about leaving the house and afraid to be around people. Same date, psych note reports client being “re-traumatized by a book she read with a sexual abuse theme.” Per client, participates in support groups through the Ryan White Program. **Meds:** Takes Nexium, Topamax, Trazodone, and Venlafaxine for depression. *[See chart for complete list of meds.]*

Personal History: Sexual orientation: heterosexual. Per chart on 2/18/11, not currently sexually active. –Tobacco and –substance use. Highest level of education: high school. Currently unemployed. Client has a car and drives. Client has one daughter (5 yrs.). Client currently switches back and forth between living with her child’s father and her own grandmother and father; client’s nephew (age similar to client’s daughter) also sometimes stays at client’s grandmother’s house. Per client, is currently attempting to move into a family-owned house in another independent location. Also reports was recently living with sister but had a falling out over financial issues. Client currently volunteers doing HIV/AIDS testing and education. Client reports having few friends outside of family and people she knows from support groups or volunteering.

Summary of Results of OSA: Top 4 identified therapy priorities:

1) Home management (e.g. increased independence with and energy for cooking, dishes, cleaning, laundry, etc.), 2) Childcare/play (with daughter), 3) General energy conservation and fatigue management, 4) Pursuing writing– *See OSA in file for complete OSA form and scores.*

Summary of Results of SIGA: **Note: The first numbers in each category denote SIGA rating if occupation were completed in the morning, and the second numbers denote SIGA rating for occupations done at 7 p.m. at night.*

Overall (all tasks): 6/10, 2/10; Cooking- 4/10, 4/10, Cleaning- 7/10, 1/10, Dishes- 7/10, 3/10, Childcare/play- 7/10, 4/10, Leisure (e.g. basketball)- 5/10, 0/10, Writing- 6/10, 2/10– *Additional goals and occupations will receive SIGA scores as they arise.*

Current Status:

VOLITION

Personal Causation: Client alludes to feeling a lack of control over portions of her life currently, such as confusion over where she is currently living, what her potential choices of other home environments might be, etc. Clearly feels a strong sense of responsibility toward taking care of her daughter; expresses wanting to be a better mother to her daughter than her own mother was to her. Reports that her father is currently involved in her life

(e.g. helped her get a car, lives with her while at her grandmother's), but seems more attached to her grandmother concerning interpersonal relationships (based on observation of client interacting with her father briefly during eval). Client also reports that many people in her life (e.g. grandmother, father of her child) are very "neat" and tidy re: the home environment, and alludes to feeling pressured to consistently clean and pick up after her daughter even when her energy and fatigue levels do not permit. Reports "I'm pretty much on my own" re: moving into a new home, even though family and social support are present. Client also clearly feels a lack of control over the state of her health and the state of her body—during discussion of what types of occupations she might like to do with her daughter, began to cry when saying "I'm only 28 and I can't even take my daughter to Cedar Point. I can't walk around Cedar Point; I'd be so exhausted." This lack of control over one's own body might in turn affect the client's view of her relationship with her daughter, i.e. potentially causing her anxiety or uncertainty about responsibilities related to motherhood. Client seems to exhibit more of a sense of control when talking about writing. Is able to clearly express ideas and opinions about what she would write about, why it is important, etc.

Values: family, being a good mother, selflessness and putting the needs of others (especially daughter) before herself, having a calm and relaxed demeanor (e.g. expressing that in the past she worked on being able to "let things go," such as her daughter's toys or not always doing the dishes; also, controlling outward emotions- "My grandmother tells me not to cry"), creativity and expression (e.g. passion for writing), moral values- especially re: adolescents (e.g. reporting wanting to write prose that limited violent words targeted at African American youth)

Interests: spending time with/playing with daughter, helping with daughter's education, writing, basketball, video games (e.g. fitness video games), reading, volunteering

HABITUATION

Roles: mother, granddaughter, daughter, sister, aunt, girlfriend/partner, volunteer, writer, patient/client

Habits: *Will continue to assess.*

PERFORMANCE CAPACITY

Communication/interaction: Client communicates significant information voluntarily and without prompting. Sometimes expresses thoughts in a confusing, rushed manner and with some anxiety. Talkative, sweet, and seemingly trusting in demeanor. Fidgeting during most of conversation. Client tearful at one point (in discussion about taking care of daughter) and apologizing for crying. Reports having some difficulty with vision d/t fatigue and eyestrain.

Motor skills/Process Skills: Client reports generalized low back pain, and displays physical signs of R shoulder pain (e.g. rubbing shoulder). Reports most severe physical deficits as being lack of energy and constant fatigue. Observed slow speed during functional mobility. MMT observed to be WFL (e.g. client lifting and holding textbook). *Will continue to*

assess motor and process skills during subsequent tx sessions (using MOHOST and clinical reasoning skills).

Environment: See earlier section of eval re: personal history. Client's home environment is very fluctuating and unstable; currently has four options of living situations, and has yet to decide on one permanent one. Tends to stay with grandmother when she feels particularly ill. Per client, is currently debating whether to move out into family-owned home or to stay in her child's father's home on a more permanent basis. Has social support from various social groups, to the point that it might be overwhelming and/or swaying for client. *Will continue to assess.*

Attempt Note

02-10-2012 – 10 a.m.

Client called OTS to reschedule OT tx session for this date, assuming tx session was scheduled for 10 a.m. (At the time of phone call, client was heard going through McDonald's drive thru.) Informed client that tx session was actually scheduled for 1 p.m. Per client, has moved into new family-owned home and is in the process of organizing things. Will proceed with therapy sessions from now on in client's new home environment.

OTS (while at Ryan White Clinic) noticed that client had medical appointment scheduled for this date at 12:40 p.m. Called client back and informed. Client expressed not remembering medical appointment, but realized importance of going. Rescheduled OT session for this coming Monday, Feb. 13th. Will discuss organization of schedule and use of planner during next OT session.

Since initial eval, new client information obtained (through interdisciplinary discussion with Ryan White staff) includes: HIV transmission occurred for this client approximately 8 yrs ago when client was 20; transmitted from partner who previously knew he was HIV+ and did not inform client. This partner is the father of client's child. Child is HIV negative. Per Ryan White CNP, client's partner is not abusive but is a negative influence on client's life.

*Evident that client is struggling with volition and personal causation—e.g. cancelling OT appointment by providing reasoning that is clearly contradicted by client's actions, not remembering medical appointments with Ryan White. However, client is also clearly attempting to improve her sense of personal causation over her home environment and living situation by moving into her own home. Will continue to assess client's level of home environment stability.

Progress Note

2-13-12, 10:30 a.m. to 11:30 a.m.

Subjective report by client: Goal is to be moved into new house by the 1st of March. Per client, “I don’t know if that will happen, but that’s my goal at least.” Until then, will be living back and forth between grandmother’s and partner’s house. “My daughter keeps asking me when we are going to move into this house and have a place of our own.” Can infer based on conversations today that client is not currently in a romantic relationship with her partner but still maintains a relationship with him as the father of her child and as part of her social group and support system.

Summary of interventions carried out/goals addressed: Saw client at new house today. Client’s partner was present for session—in other room of home painting walls. Attempted to assist client with setting up ergonomic computer workspace. Assisted with bringing in desk chair from car and beginning to set up table. (Legs of table still need carpentry work.) Educated client on correct body positioning to facilitate joint protection and minimize low back and neck strain; measured distances from knees to chair, chair to table, etc. Recommended pillows to sit on when in chair or higher chair if possible to avoid strain. Educated re: correct use of wrist and/or hand supports (which client said she was going to obtain), lighting, posture, etc. Will re-assess computer workspace when belongings are moved into new home. Client inquired about energy conservation schedule because “It’s something I read in a book from the library”—made tentative energy conservation schedule for next week. Discussed techniques for body positioning to minimize fatigue when doing home repairs and moving. Educated on hemi dressing techniques, as client reported pain with dressing d/t recent R arm injury. Client reported having difficulty opening jars and containers d/t lack of strength—will bring client non-skid liner to try when opening containers. Client denied need for OTS help with occupations being completed this morning just prior to OT session—e.g. carrying boxes, moving items, etc.

VOLITION

Personal Causation: Can infer that presence of client’s partner altered client’s communication and sense of personal causation, as if she did not want to report negative things about occupational performances around him. Per client, “He [client’s partner] is always telling me not to overdo it, and he makes sure I don’t. He always does those things for me like opening things or picking things up.” Also per client, reported that partner was living with her previously at grandmother’s house, where he “expected me to pick up after him and do his dishes and clean. But then when we’re at his place, it’s like he’s so neat and tidy and is always following me around cleaning every little thing.” Per client report, is excited about the new house; clearly is hopeful that it will increase her sense of independence and volition. Will most likely experience a definite sense of loss and decrease in volition if client is unable to move into the house soon.

Values: Perceived approval from others; Client seems to want to meet perceived expectations of OTS and her partner, to the point of not expressing true thoughts and opinions. For example, when asked about some deficits she mentioned on initial eval, client denied any difficulty currently and reported that she was doing fine with most occupations. Also can infer wanting approval from her daughter re: the new house and getting it set up and ready for her. Seems to want to provide her daughter stability but lacks the resources to.

Interests: writing, going to the library, reading, listening to music

HABITUATION

Roles: continues to strongly identify with role as a mother; clearly not as much emphasis on other roles

Habits: Per discussion and energy conservation schedule brainstorming today, client already has some good habits in place to facilitate energy conservation—e.g. regular naps, alternate occupations with daughter for nighttime, completing some chores every other day or every three days as opposed to daily, etc. When asked what the biggest concern currently was, client responded: “Really, it’s just that my body won’t cooperate. I’m doing my best to schedule everything out and stick to it, it’s just my body not following.” Client also seems to be unreliable; per RN/RD at Ryan White, client is always cancelling medical appointments or not showing up for scheduled meeting times. Client cancelled medical appointment at Ryan White this past Friday, after phone conversation about schedule with OTS—*See attempt note from 2-10-12*. Indicates further need for approval from others, as client was not direct with reasons for cancellations with either Ryan White or OTS.

***Results of MOHOST falling under VOLITION and HABITUATION:**

(Rated based on MOHOST categories and procedure: F= facilitates occupational participation, A= allows occupational participation, I= inhibits occupational participation, R= restricts occupational participation, N/S= not seen)

Motivation for Occupation:

Appraisal of Ability: F
Expectation of Success: I
Interest: I
Choices: A

Pattern of Occupation:

Routine: I
Adaptability: A
Roles: A
Responsibility: I

PERFORMANCE CAPACITY (from MOHOST)

Interpersonal/communication:

Non-verbal skills: F
Conversation: F
Vocal expression: A
Relationships: A

Motor Skills:

Posture/Mobility: F
Coordination: F

Strength and Effort: A
Energy: I

Process Skills:

Knowledge: A
Timing: A
Organization: I
Problem-solving: I

Environment:

Physical space: I
Physical resources: I
Social groups: I
Occupational demands: I

Progress Note

2-17-12, 11:00 a.m. to 12:15 p.m.

Subjective report by client: Per client, had a successful doctor's appointment this past week s/p radial fx; was okayed for light use of RUE but is not cleared for weight bearing at this time. MD recommended therapy but client declined and reported to MD, "I can just get something off the Internet to follow." Client also reported is taking her daughter to the Humane Society today to find a dog that will live with client and daughter at new house that they will be moving into. (If successful, will also apply to habits and roles.)

Summary of interventions carried out/goals addressed: Today's session took place at client's grandmother's house. Educated client re: RUE ROM exercises for recent radial fx, lifting restrictions, weight bearing restrictions, fine motor occupations encouraging R forearm supination/pronation. Facilitated play occupations with client's daughter while client performed exercises. Facilitated brainstorming occupation re: options for play when client is particularly fatigued. Brought client non-skid backing to assist with easier opening of jars and containers. Client successfully demonstrated use of backing during simple meal prep task of preparing drink for client's brother, with I.

VOLITION

Personal Causation: Client expressed, "I wish she [daughter] would spend more time with her dad. I am always so tired and she is always running around all the time. But she just wants to be with her mom." – Could infer sense of pride and personal causation from this report, as client was making strong statement about her success and efficacy in her role as a mother. Though client's daughter very clearly has a strong love and bond with her, per daughter later in the session, wanted to spend the night at "home" (child's father's house).

Values: working on new home to establish new environment—client stated to daughter, "We need to get ourselves out of there. We're moving soon."

Interests: TV shows CSI, Criminal Minds, and NCIS; vanilla flavored cupcakes

HABITUATION

Roles: Sister—client's adult brother (observed to have severe IDD) was present during entire OT session; prior to OTS arrival was coloring with client's daughter. Client's sister also present for OT session, but sleeping in the back room during entire session. Client's daughter was encouraged to be quiet throughout in order not to wake client's sister up. Client's grandmother not present for session.

Mother—client's daughter was very sweet, polite, and vocal throughout play occupations. Reported wanting to be a nurse when she grows up. Referred to client's partner's house as "home" but reported to OTS: "When I graduate from kindergarten, my mom and me are going to move into our own house."

Habits: watching TV with daughter when trying to get daughter calmed down before preparing to take an afternoon nap, making daughter a snack before taking a nap in order to help her sleep better

PERFORMANCE CAPACITY

Interpersonal/communication: Client continues to easily disclose personal information (e.g. that several family members have been incarcerated) but seems to have difficulty discussing self-deficits and asserting volition and personal causation in a problem-solving manner in order to collaborate with goal-setting and carrying out occupations. Seems to want more help from family (even after reporting these family members as unreliable) than from friends, OTS, Ryan White staff, and/or medical personnel. Continues to be a clear element of suspicion and distrust (though not directly, maliciously, or purposely)—almost as if client is thinking, “How is anyone really ever going to help me?”

Motor Skills: Per client, fatigue continues but has not become either better or worse. AROM deficits RUE s/p radial fx.

Process Skills: Some continued lack of self-awareness re: own deficits; continues to deny the need for help with occupations and to deny many of the deficits client strongly emphasized on initial eval. Continued disorganization and inconsistency with behavior.

Environment: Client’s environment continues to be inconsistent and unstable; per client, had come from client’s partner’s house the night before. During session asked daughter, “Mini-mom [nickname for daughter], do you think we should stay here [grandmother’s house] tonight?” Client’s daughter reported wanting to stay at “home” (client’s partner’s house) but client proceeded to convince daughter to stay at grandmother’s house this date.

Progress Note

3-2-12, 12:30 p.m. to 1:30 p.m.

Subjective report by client: Since last OT session, client has successfully moved all belongings except for a few clothing items into new home. Per client, will be spending the majority of time in new home with daughter when client is not visiting her grandmother. Will be sleeping at new home. Client's daughter, nephew (around age 2 to 3), and sister present for OT session today. Plumber also present for some of OT session and working on bathroom pipes in adjacent room.

Summary of interventions carried out/goals addressed: Educated again re: the importance of following WB restrictions and precautions for RUE fx, and body positioning techniques for maximal energy conservation. Provided recommendations for home organization re: maximal energy conservation. Reminded client of importance of resting and scheduling naps and rest breaks. Reviewed energy conservation schedule for new home. Assisted client's sister with moving TV from car into home. Facilitated play occupations with client's daughter while client completed fine motor occupation of screwing bolts into back of TV while seated at table with feet up, resting. Discussed goals and progress in detail.

VOLITION

Personal Causation: During discussion of goals and progress, client expressed not feeling that she has any particular goals she needs to address further, consistent with client expressing during previous OT sessions that issues brought up during initial eval were not necessarily issues any longer—said, “I’ve been dealing with this for a long time. It took me a long time to figure out that I had to just let some things go, and a long time to figure out that I needed to rest and take care of myself. I do okay. The people at UT have been really helpful and they were the ones that first told me to just let some of the things go. And now that I’m in this house and out of his [client’s child’s father’s] place, I feel like I can really get back to doing what I was doing before and just having a good routine. I’m doing okay.” Client did dishes during OT session while talking with OTS, without OTS facilitating this occupation—rated pain 2/10 and fatigue 5/10, and reported this was about normal and she did not feel that it impeded what she had to do. Client expressed that there were no things she wanted to do that she could not do—per client, is still trying to decide whether or not she wants to go back to school. (Reports that her student loans are currently in deferment/forbearance due to disability.) Declined seeking out potential contacts at area schools re: returning to school until she decides what she wants to do. “The main thing was getting into this house. And I did, and right now I just need to keep on living my life.” Client has good insight into her own habits necessary to maximize independence, and demonstrates them without prompting—e.g. has family to assist her move and carry heavy items, and client waits for family to be present to do so; knows when she needs to sit down and take a break; is able to report energy conservation techniques and reasoning for selecting specific techniques during a certain task. Client is aware when she exerts herself too much, but expresses, “Sometimes I just do it anyway. I know it’s not good, but sometimes I just have to do what I need to do to, just once in a while. And I know what will happen, but for the most part I do really well. I just let other people help me.”

Per clinical judgment, client has perhaps reached her level of maximal independence and achievement during occupational performance within the restrictions of her environment... All short-term goals met. Long-term goals related to SIGA scores still to be assessed. (Per MOHO,

achievement applies to achievement within the cultural, environmental, and social norms surrounding the client, and not any assumed to be correct by the therapist. In line with this reasoning, client has perhaps progressed to her fullest possible at this point.) Will continue to assess—will complete SIGA follow-up (and perhaps additional paperwork) next session.

Values: Client reported had the chance to go to a leadership conference with OAC (Ohio AIDS Coalition) this weekend in Columbus. Wanted to go, but decided against it because “I spent all our money for the month so far on food, so I didn’t want to waste it.” ... Client demonstrating valuing advocacy and leadership for HIV/AIDS but also placing a higher value on being financially independent and having the capacity to care for her family.

HABITUATION

Habits: Client remains in the habit of maintaining some instability in her life and being okay with it—e.g. OTS reviewed guidelines for setting up ergonomic computer station that were provided during prior OT session. Client reported that she has since decided that she will use a laptop, taking the laptop to her grandmother’s house to use the Internet and then using it at home for writing. Client does not wish to set up a stagnant computer station that will remain intact at this time and would instead like to move her laptop from place to place as she needs it. Chair that was selected for ergonomic computer workstation will also function as a dining room chair, and will also be moved around.

Client expressed today also being in the habit of setting her daughter up with the Wii video game system or with the TV when she is particularly tired at night. Expressed that client has attempted some of the play occupations designed for when she is fatigued, but that daughter tends to “get up and run around a lot anyway” and that she responds better to these other forms of entertainment (e.g. Wii & TV).

PERFORMANCE CAPACITY

Interpersonal/communication: (See comments below re: communication in “process skills” section.)

Motor Skills: Continues to display fatigue at same level as during prior sessions; some elevated fatigue recently due to moving into home, per client

Process Skills: Good insight into deficits and methods of compensation for deficits—Unknown whether client has developed improved insight into deficits or simply has improved communication skills with OTS in relation to describing such insight (perhaps as a result of having gained some trust and developed increased rapport?)

Environment: Again various family members being present caused somewhat of a distraction today; Client clearly feels that she needs to complete occupations within her home, but gets distracted by her daughter and other family members and then feels that she has to attend to them; Attempts to rest

DISCHARGE

3/9/12, 12:30 p.m. to 1:30 p.m.

Subjective report of client this date: Per client, feels like she has accomplished a lot over the last few months. “I have been cooking more, not just microwaving things out of the box, and trying to do my best to follow my schedule. Sometimes I forget to write it down like I’m supposed to, but really I’ve been doing pretty good at keeping up with everything.” Client reports that she still has low energy, but that she is learning to adjust to it and to take care of what is important.

Relevant changes discussed re: volition, habituation, and performance capacity: Per client, plans to participate in neuropathy research study over the next few weeks. Is looking forward to things again and has been trying to find more time for herself. Per client’s report on standardized assessments and via verbal report when asked specifically about progress on goals, client reports increases in volition and personal causation as well as decreases in anxiety and frustration. Organization, especially of the environment, has improved, leading to improvements with problem-solving and planning skills. “I know that things have been crazy during this but I’ve tried my best. It has helped to have someone else outside the family just to come and check up and see how we’re doing, and just to be able to talk it out. I think things are going much better now that I’ve moved in here [to the new house] and I really feel like I can get set up to do better with stuff, with my schedule and with taking care of [her daughter]. My arm is still hurting but I’m going to the doctor, so that should be good. Thanks for everything and just for all the reminders that I needed, and I hope I could help out too in return.”

Tx provided this date: Client napping when OTS arrived. Reinforced energy conservation education and HEP for RUE fx. Discussed progress with goals, especially childcare/play goals. Client demonstrated/verbalized some new play occupations she came up with over the past week to use when she is feeling fatigued. Client’s grandfather present very briefly during OT session. Reviewed recommended dimensions and set up of computer workstation. Provided client with a basic planner/mini calendar and educated re: use of planner.

Summary of Results of OSA: See OSA data summary sheet in client’s chart for full results. Overall, client’s OSA competence scores improved from initial eval to the time of D/C, indicating that client increased her sense of volition and personal causation, and indicating that the client has an improved perception of her own competence during occupations. Additionally, the client’s scores of value items significantly decreased, indicating that the client currently places less value on many of the volitional items listed on the OSA. Per clinical reasoning and client’s personal history, this is perhaps indicative that client’s level of anxiety and tendency to feel overwhelmed during daily occupations has decreased; client has perhaps since learned to prioritize her occupations in a way that is more manageable, helping her to understand what parts of her life are the most important versus feeling that all parts of life are overwhelming and/or “most important.” Specifically, examples of competence items that increased from some difficulty to well include: “handling my responsibilities,” “being involved as a student/worker/volunteer/family member,” “doing activities I like,” “working towards my goals,” “making decisions based on what I think is important,” “accomplishing what I set out to do,” and “effectively using my abilities.”

Comparison of overall scores is as follows:

Initial OSA scores: Competence: 49 (Error= 3), Value: 68 (Error= 3)

Final OSA scores: Competence: 53 (Error= 3), Value: 47 (Error= 3)

Summary of Results of SIGA: See SIGA form in client's chart for complete results of SIGA at D/C. Overall, clients SIGA scores (for both during the day and at night) on the majority of items improved from initial eval to time of D/C. Some remained the same. Examples include: Cooking during the day improved from a 4 to a 6, cleaning at night improved from a 1 to a 2, dishes at night improved from a 3 to a 5, leisure during the day improved from a 5 to a 7, leisure at night improved from a 0 to a 3. Client reported that none of the items were rated inaccurately at time of initial eval. Items "writing" and "childcare/play" were reported to be goals that the client plans to continue working on. Clients overall SIGA score for rated all items together improved from a 6 to an 8 for during the day, and from a 2 to a 4 for at night.

MOHOST:

VOLITION and HABITUATION:

(Rated based on MOHOST categories and procedure: F= facilitates occupational participation, A= allows occupational participation, I= inhibits occupational participation, R= restricts occupational participation, N/S= not seen)

Motivation for Occupation:

Appraisal of Ability: F (bolded items are scores at D/C vs. initial eval) **F**

Expectation of Success: I **A**

Interest: I **A**

Choices: A **A**

Pattern of Occupation:

Routine: I **A**

Adaptability: A **F**

Roles: A **A**

Responsibility: I **A**

PERFORMANCE CAPACITY

Interpersonal/communication:

Non-verbal skills: F **F**

Conversation: F **F**

Vocal expression: A **F**

Relationships: A **A**

Motor Skills:

Posture/Mobility: F **F**

Coordination: F **F**

Strength and Effort: A **A**

Energy: I **I**

Process Skills:

Knowledge: A **A**

Timing: A **A**

Organization: I **A**
Problem-solving: I **A**

Environment:

Physical space: I **F**
Physical resources: I **A**
Social groups: I **A**
Occupational demands: I **A**

*Environmental scores greatly improved on MOHOST after client has moved into her new home. Space much more adequately meets occupational demands and better facilitates performance, as well as facilitates improved social relationships among social group.

Recommendations: Client to continue following energy conservation schedule and energy conservation recommendations as consistently as possible, including scheduling in time for regular naps and time for writing/leisure. Client to also utilize planner to maintain attendance with medical and other appointments, such as follow-up with PCP for RUE fx. Client to also continue non-weightbearing status and ROM exercises for RUE fx as tolerable, per changes in recommendations from PCP.

Goal Status:

STG: to be met in 5 weeks

- Client will create an energy conservation schedule with VS. – **Met**
 - Client reports severe fatigue with any occupation; Edited 2-14-12, from original goal about identifying advantages and disadvantages to each of four living environments- was previously thought that client would be unable to develop or follow an energy conservation schedule when she did not have a stable or consistent living environment
- Client will complete exercise routine (5/7 days per wk during the 5th wk) re: RUE ROM and basic strengthening s/p radial fx with I, to facilitate improved occupational performance. - **Met**
 - Per client, tries to exercise about 1-2 times a week but has trouble with consistency or scheduling in when considering fatigue; would like assistance with routine and new exercise ideas
 - Edited on 2-17-12 to be directly related to exercises re: R radial fx (after being cleared for movement by MD)
- Client will complete at least two new play occupations with daughter specific to times when client feels fatigued, with VS. - **Met**
 - Client is concerned with the role of being a good mother to her daughter and strongly identifies with this role; has expressed sadness and anxiety re: feeling inadequate as a mother due to not being able to have the energy to play. Occupations designed for when client feels fatigued might help with increased sense of volition re: this role of being a mother
- Client will set up an ergonomic workspace to complete occupation of writing, with S. - **Met**

- Client very much enjoys writing but does not have a specific workspace in which to complete the occupation
- Client will demonstrate use of non-skid assistive device when opening jars and containers during meal prep and meal cleanup occupations, with VS. – **Met**
 - Added 2-13-12, after client expressed difficulty opening jars and containers (SIGA score of 6/10) and having to wait until partner or family member got home to assist her

LTG: to be met in 10-12 weeks

- Client will successfully follow an energy conservation schedule with I, during 5/7 days per wk during the 10th wk. - **Progressing**
 - See related STG above
- Client will increase SIGA scores of at least two IODLs performed at night (e.g. cooking, dishes, cleaning, laundry) by at least one point, with VS. - **Met**
 - See related STG above; potential demonstrations of increase in endurance through more consistent exercise and strength-building might be transferred to IODL tasks. Client rated performance significantly lower on SIGA when asked about performance at night versus during the day.
- Client will increase sense of volition, as demonstrated by an increase of at least one increment on at least two OSA items related to volition. - **Met**
 - Goals for this client were chosen in a broad, general way to minimize rigidity and allow the client lots of room for change. The client clearly wants to and needs to increase volition, but lacks clear organization or ability to do so without support. This goal was chosen to be general and allow for specific meaningful interventions to arise over time, after the client has established trust and rapport with OTS and is better able to identify life priorities and potential sources of volition. Increasing volition will also help client increase occupational performance in most other life areas.
- Client will successfully move her belongings into her new home, with S. - **Met**
 - Added 2-14-12 after prior tx session when client reported having found a new home to live in, adding potential stability to her environment if client is able to find support with moving

Annotated Bibliography:

Applying the Model of Human Occupation:
Three Community-based Case Studies of Individuals with HIV/AIDS

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Annotated Bibliography

Adair, P. (Producer & Director). (1991). *Absolutely positive* [Motion picture]. United States: Adair & Armstrong Productions.

This documentary, filmed by a man who himself passed away from AIDS in 1997, provides a realistic, passionate, and humanizing look at how eleven individuals of various ages (ranging from 17 to 60) struggle with initial and progressing diagnosis, challenges during daily occupations, and the psychosocial ramifications that come with coping with living with HIV/AIDS. Because this film was released in 1991, prior to many of the advancements in medications and medical care available for those with HIV/AIDS, it offers a genuine look at how HIV/AIDS affected daily life during a time when little outside support was available.

The American Occupational Therapy Association. (1989). Human immunodeficiency virus: Position paper. *The American Journal of Occupational Therapy*, 43, 803-804.

This original position paper from AOTA expresses how the association originally addressed HIV/AIDS, closer to when the epidemic began. It informs practitioners of their ethical responsibility to provide care to all individuals, including those with HIV/AIDS, and reminds them of universal infection precautions that should be taken during care. It also lists some symptom manifestations of HIV/AIDS, and warns of the psychological adjustments that are often required by these patients. It is important to know how views of AOTA, and therefore views of clinicians in the field of OT, change over time, as well as what causes these changes.

The American Occupational Therapy Association. (1996). Position paper: Providing services for persons with HIV/AIDS and their caregivers. *The American Journal of Occupational Therapy*, 50, 853-854.

This updated position paper addresses the more current overall attitude of the American Occupational Therapy Association in relation to individuals with HIV/AIDS, focusing less on education of practitioners and more on how these practitioners should ideally interact with clients, such as providing un-biased, holistic care while maintaining confidentiality and ignoring social stigmas against those with HIV/AIDS.

Anandan, N., Braveman, B., Kielhofner, G., & Forsyth, K. (2006). Impairments and perceived competence in persons living with HIV/AIDS. *Work*, 27, 255-266.

This study sought to determine impairments most commonly identified by those with HIV/AIDS, what performance areas were experienced with difficulty, and whether or not there is a relationship between self-identified impairments and perceived occupational competence. This study's underlying themes greatly overlap with the capstone case studies, as this study also used the Occupational Self Assessment (OSA) to determine participants' sense of volition, goals, and perceptions about occupational performance. Additionally, the five areas most identified as

difficult for participants in this study were: fatigue, fear/worries or anxiety, difficulty concentrating, muscle aches, and depression, all symptoms and client factors identified by capstone case study participants. Furthermore, OSA results in this study revealed that managing finances was the performance area in which most participants were challenged, perhaps due to social status and poverty (according to the authors), which overlaps with one capstone case study participant who identified this area as his major deficit as well. Overall, this study illustrates a good representation of the relationship between identified impairments and occupational competence. This study is a secondary analysis of data previously collected as part of another research project, which was currently underway at the time of publication.

Anis, A. H., Nosyk, B., Sun, H., Guh, D. P., Bansback, N., Xin, L., . . . & Brown, S. T. (2009). Quality of life of patients with advanced HIV/AIDS: Measuring the impact of both AIDS-defining events and non-AIDS serious adverse events. *Journal of Acquired Immune Deficiency Syndromes*, 51, 631-9.

Abstract: Objective: To investigate the relative magnitude and duration of impact of AIDS-defining events (ADEs) and non-AIDS serious adverse events (SAEs) on health-related quality of life (HRQoL) among patients with advanced HIV/AIDS. Methods: We use data from OPTIMA (OPTions In Management with Antiretrovirals), a multinational, randomized, open, control, clinical management trial of treatment strategies for patients with multidrug-resistant HIV and advanced immune disease. Longitudinal models were used to determine the effects of ADEs and SAEs on HRQoL across periods before, during, and after event onset. The Medical Outcomes Study HIV Health Survey (MOS-HIV) physical and mental health summary scores (MOS-PHS and MOS-MHS), EQ-5D, and the Health Utilities Index Mark 3 HRQoL measures were all assessed at regular follow-up intervals during the trial. Results: ADEs occurred much less frequently than SAEs ($n = 147$ vs. $n = 821$) in the study sample population of 368 patients, during median follow-up of 3.96 years. Although both ADEs and SAEs had significant negative impacts on HRQoL, SAEs had at least as large an impact upon HRQoL as ADEs when both were included in a multivariate linear regression model, controlling for other covariates. However, the effect of ADEs on HRQoL was more persistent, with larger magnitude of effect across all instruments in time intervals further from the onset of the event. Conclusions: Non-AIDS SAEs occurring in patients with late-stage HIV/AIDS seem to have at least as important an immediate impact on patient HRQoL as ADEs; however, the impact of ADEs seems to be more persistent. Our findings call for a greater emphasis on the detection and active prevention of non-AIDS SAEs in patients with late-stage HIV/AIDS. Key Words: AIDS-defining events, HIV/AIDS, HRQoL, non-AIDS serious adverse events

In this study about the impact of AIDS-related events, when compared with serious adverse events that were unrelated to HIV/AIDS, both created significant life stress for individuals with HIV/AIDS. However, results indicated that healthcare professionals more readily addressed AIDS-related events than non-related serious adverse events, suggesting that various psychosocial needs of patients with HIV/AIDS were left unmet because they were not directly related to the disease itself. This article, therefore, serves as an excellent example that occupational therapists, and all healthcare practitioners working with the HIV/AIDS population, should take special care to establish a holistic view of patients, including using assessments that

take all aspects of their health into consideration and continuously performing goal updates and collaborations on occupations in order to ensure that all patient needs are met. Though this study used objective selection criteria and a multivariate linear regression model, additional research is needed to provide greater emphasis on non-AIDS serious adverse events in patients with late stage HIV/AIDS.

Arling, G., Kane, R. L., Cooke, V., & Lewis, T. (2010). Targeting residents for transitions from nursing home to community. *Health Services Research, 45*, 691-711.

Abstract: Objective. To analyze nursing home utilization patterns in order to identify potential targeting criteria for transitioning residents back to the community. Data Sources. Secondary data from minimum data set (MDS) assessments for an annual cohort of first-time admissions (N524,648) to all Minnesota nursing homes (N 5 394) from July 2005 to June 2006. Study Design. We conducted a longitudinal analysis from admission to 365 days. Major MDS variables were discharge status; resident's preference and support for community discharge; gender, age, and marital status; pay source; major diagnoses; cognitive impairment or dementia; activities of daily living; and continence. Principal Findings. At 90 days the majority of residents showed a preference or support for community discharge (64 percent). Many had health and functional conditions predictive of community discharge (40 percent) or low-care requirements (20 percent). A supportive facility context, for example, emphasis on post acute care and consumer choice, increased transition rates. Conclusions. A community discharge intervention could be targeted to residents at 90 days after nursing home admission when short-stay residents are at risk of becoming long-stay residents. Key Words. Outcome, community care, consumer preference, length of stay, quality of care

This article discusses the tendency of individuals who remain in nursing homes for longer periods of time than initially expected to risk not being able to successfully transition to independent living within a community at all. For example, only 10% of nursing home residents in this study tended to remain in the facility after 90 days. Because one of the capstone case study participants was a resident of a nursing home for approximately two years before being able to transition to community living, this article directly relates to the way that occupational therapy can assist individuals in transitioning from skilled nursing facilities to home environments. The article also focuses on the importance of developing a supportive environment during this period of transition, and reveals that 32% of nursing home discharges in this study transitioned to a home environment where home health care or home rehabilitation services were provided, increasing individuals' chances of succeeding with independent living after transition. However, because only 10% of residents in this study remained at the facility after the 90 day span had elapsed, future research should focus on successful transition rates of individuals who remained in SNFs for longer than 90 days, in order to make the sample more generalizable to all individuals who transition to home.

Atchison, B. J., Beard, B. J., & Lester, L. B. (1990). Occupational therapy personnel and AIDS: Attitudes, knowledge, and fears. *The American Journal of Occupational Therapy, 44*, 212-217.

Abstract: This study explored the attitudes, knowledge, and fears of occupational therapists and certified occupational therapy assistants regarding AIDS and HIV. The 119 respondents' scores related to knowledge and fear revealed that many had significant fears about AIDS, which in turn may inhibit their willingness to care for persons with AIDS. The respondents also indicated a need for specific information about the condition, including current research data and information on infection control.

Though this article was published in 1990, a time when HIV/AIDS was less understood than it is currently, information in this article provides a reminder to occupational therapists even today of the importance of knowledge of the facts in reference to this disease and when caring for the individuals who have it. At the time, survey results of practitioners indicated that respondents felt that HIV/AIDS patients received inferior care at healthcare facilities, in addition to revealing a significant fear by practitioners of contracting the disease during care giving. The survey also explored the level of knowledge of HIV/AIDS that the practitioners filling out the survey had, as well as the most popular sources from which they obtained their information. Though today practitioners are more informed, continued exploration of knowledge and information from credible sources is needed to provide ethical, quality care to all patients. Though this article contains very beneficial information regarding the perspectives of therapists in reference to HIV/AIDS, it represents a low level of evidence in that it is qualitative survey data obtained by tallying frequencies of responses that were then calculated to obtain a "knowledge score."

Atkins, J. H., Rubenstein, S. L., Sota, T. L., Rueda, S., Fenta, H., Bacon, J., & Rourke, S. B. (2010). Impact of social support on cognitive symptom burden in HIV/AIDS. *AIDS Care*, 22, 793-802.

Abstract: As many as 50% of people living with HIV/AIDS report cognitive difficulties, which can be associated with objective neuropsychological impairments and depression. A number of studies have demonstrated an association between higher social support and lower rates of depression. Using a cross-sectional design, we examined the role social support may play in attenuating the effects of both neuropsychological status and depression on cognitive difficulties. A total of 357 participants completed a battery of neuropsychological tests, questionnaires about cognitive difficulties and depression, and an interview that included an assessment of perceived level of social support. A multivariate linear regression analysis revealed that higher levels of cognitive symptom burden were significantly associated with depression ($P < 0.05$) while lower levels of cognitive symptom burden were significantly associated with greater social support ($P < 0.01$) and higher level of education ($P < 0.05$). There was a significant interaction between neuropsychological status and depression ($P < 0.001$); the presence of neuropsychological impairment with depression was associated with higher levels of cognitive symptom burden. There was also a significant interaction between social support and depression ($P < 0.05$). Interestingly, social support was also associated with a lower cognitive symptom burden for non-depressed individuals living with HIV/AIDS. These findings have important clinical implications for promoting psychological well being in persons living with HIV/AIDS. To improve quality of life, it is important to screen for and identify individuals with HIV/AIDS who may be depressed and to intervene appropriately. Further research should examine the potential role of social

support interventions in modifying the effects of both depression and neuropsychological status on cognitive symptom burden. Keywords: social support; HIV; AIDS; neuropsychology; depression; cognitive symptoms

Because a large majority of individuals with HIV/AIDS also have depression, other psychological disorders, or depressive symptoms, screening for or discussing depression and other cognitive deficits with clients becomes crucial when caring for this population. As this study indicates, individuals with more social support also experience a decline in depressive symptoms, and even individuals with an already low “burden” of cognitive or psychosocial deficits experience relief of potential negative symptoms from increased social support. It is extremely necessary, therefore, for occupational therapists working with individuals with HIV/AIDS to address not only psychosocial goals and interventions, but also those that will increase and maintain social support and positive social group environments. Though this study used objective selection criteria and a multivariate linear regression model, additional research is needed to examine the potential role of social support interventions and their effects on depression and cognitive status in order to corroborate this study’s results.

Auerbach, J. D., Parkhurst, J. O., & Caceres, C. F. (2011). Addressing social drivers of HIV/AIDS for the long-term response: Conceptual and methodological considerations. *Global Public Health*, 6, 293-309.

As medical advances shift to allow those with HIV/AIDS to live longer and more meaningful lives, healthcare support for HIV/AIDS has also shifted to focus more on prevention. This article examines the sociology behind how medical practitioners of various backgrounds can seek to conceptualize, measure, and evaluate approaches to maintaining long-term strategies for managing HIV/AIDS, and also provides a framework with which to do so. The article explains that “social drivers,” or the underlying causes of action, for patterns of behavior within the HIV/AIDS population interact dynamically with biological, psychological, social, and behavioral factors to create actions. The article touches on gender differences, poverty, risk-taking behaviors, and environment in general, and how they might affect an individuals’ tendency to maintain a positive long-term response to living with HIV/AIDS. As many of the capstone case study participants were affected by these concepts, and because most individuals with HIV/AIDS will continue to be exposed to such factors throughout their lives, it is important for occupational therapists providing care to this population to understand the social and structural forces that drive behavior, especially when seeking to better understand clients, their behavior, their responses to therapy, and their potential for change. Though this study is thorough in regard to uncovering sociological patterns in the lives of individuals with HIV/AIDS, it is a methodological analysis versus a quantitative study yielding numerical data.

Barrett, L., Beer, D., & Kielhofner, G. (1999). The importance of volitional narrative in treatment: An ethnographic case study in a work program. *Work*, 12, 79-92.

This article is an ethnographic case study within an occupational therapy work program. Though it is not specific to HIV/AIDS, it includes some of the key themes that provide a

foundation for MOHO, as well as demonstrates the true importance of the personal narrative in utilizing MOHO with patients in occupational therapy when attempting to elicit maximum volitional progress. According to the authors, volitional narratives exemplify how an individual's life is intimately connected with the construction and maintenance of his or her world, and assists in understanding the causes and constraints of volition. Additionally, attention to a client's volitional narrative and the detailed life factors included within it will provide crucial information about the meaning and nature of change from the client's perspective. Often, the process of writing a volitional narrative can provide illumination to the client regarding allowing them to comprehend that volitional change is a process, and that progress is achieved when all life factors interact instead of in isolation. Volitional narrative was used in written form with one of the capstone case study participants, and was discussed in detail with the other two participants during various therapy sessions.

Bedell, G. (2000). Daily life for eight urban gay men with HIV/AIDS. *The American Journal of Occupational Therapy*, 54, 197-206.

Abstract: **OBJECTIVE.** The purpose of this qualitative research study was to gain an understanding of the daily life experiences of eight gay men with HIV/AIDS living alone in New York City. **METHOD.** The participants ranged in age from 25 to 50 years. Data were primarily collected using in-depth personal interviews in 1996 followed by telephone interviews 1 year later. Constant-comparison and thematic analyses were used to identify themes and subthemes. **RESULTS.** Two broad themes with related subthemes were generated from the data. "A Reasonably Stable Base" represented the emotional, physical, and environmental foundation that preexisted or was created as a consequence of living with HIV/AIDS. This theme played a particularly important role in the participants' lives, especially during periods of emotional and physical instability. "Finding and Maintaining Balance" was a second theme that illustrated strategies used for managing and readjusting daily routines, goals, and priorities, as well as how the participants experienced this readjustment process. **CONCLUSIONS.** All of the participants developed their own daily living strategies that were comparable to intervention methods provided in occupational therapy such as energy conservation and work simplification. The findings suggest that occupational therapy practitioners could potentially assist urban gay men with HIV/AIDS with finding and maintaining stability and balance in their daily lives.

This qualitative study explores what brings elements of meaning and purpose to the lives of eight individuals living with HIV/AIDS in New York City. In addition to determining that occupational therapy could benefit these clients by assisting them in establishing better solidarity with occupations of daily living (ODLs) and instrumental occupations of daily living (IODLs), priority occupations were identified and included the ability to thrive in the home environment, talking on the phone, maintaining communication and socialization with others, planning, successfully adjusting to changes in planning, and working. Overall, participants all provided insight that suggested that HIV/AIDS had changed their ideas of life meanings and purposes, indicating that occupational therapists could most benefit these individuals by first understanding their unique needs, environments, meanings, and purposes. This study does not represent a research level of evidence in that it is in the form of case studies.

Bersch, K. & DiRamio, D. (2010). The changing face of HIV/AIDS. *Medical Laboratory Observer*, 10-14.

Abstract: LEARNING OBJECTIVES- Upon completion of this article, the reader will be able to: 1. describe statistics on HIV/AIDS to include the number of people affected in various geographic regions of U.S. and in other continents; 2. list various age groups, in particular at-risk groups, which should be tested for HIV; 3. discuss the rationale for comprehensive education on HIV/AIDS; and 4. discuss different available tools of communication that can be used to raise awareness and detection of HIV/AIDS.

As many individuals within the HIV/AIDS population seek to advocate to others who have been newly diagnosed, or to the community in general, about the risk factors, methods of prevention, and general effects of the disease, it is important for practitioners working with these individuals to understand the mindset of advocacy. This article provides a helpful overview about some popular advocacy methods and efforts within the HIV/AIDS community, and might be a good resource for occupational therapists working with clients who value advocacy to better understand their perspective. In relation to MOHO, advocacy for many HIV/AIDS clients is a meaningful and purposeful method of experiencing volition and personal causation, and can often be a relevant goal to work toward in therapy.

Bowyer, P., Kielhofner, G., & Braveman, B. (2006). Interdisciplinary staff perceptions of an occupational therapy return to work program for people living with AIDS. *Work*, 27, 287-294.

This study examined staff perceptions related to the impact of a model for work and independent living, as implemented through a program for residents at supportive living facilities. Staff identified the four biggest areas of impact: utilization of a holistic and process-oriented approach, an ability to identify and work with the strengths of the clients, an emphasis on learning practical skills, and creating an environment where all aspects of services can intersect. The themes identified by this study can be applied to occupational therapy services with the HIV/AIDS population in various settings, including home healthcare, giving therapists additional information about methods of providing the most efficient interventions for clients. This study represents a lower level of evidence in that it is a qualitative study that utilized focus groups and personal interviews to obtain data.

Bozman, R. M., & Goetzman, G. (Producers), & Demme, J. (Director). (1993). *Philadelphia* [Motion picture]. United States: TriStar Pictures.

This powerful fictional movie depicts the story of a man with AIDS who is fired from a conservative law firm because of his disease. Taking place in the 1980s, when the height of social fear surrounding HIV/AIDS was occurring, Andrew Beckett, the main character, hires a lawyer struggling with homophobia to represent him as an advocate in a wrongful employment termination suit. This movie brings up various social ideas and themes that still surround HIV/AIDS today and affect individuals' daily life occupations, such as homophobia (particularly

in the workplace), gay rights, intimate and sexual relationships among individuals in the gay community, modes of HIV transmission, medical treatment of HIV/AIDS, and general social stigmas surrounding the disease.

Braveman, B., Levin, M., Kielhofner, G., & Finlayson, M. (2006). HIV/AIDS and return to work: A literature review one-decade post-introduction of combination therapy (HAART). *Work*, 27, 295-303.

This literature review, spanning a ten-year period, seeks to identify the barriers and needs of those with HIV/AIDS as related to work and utilizing other community and professional resources. Completed approximately ten years after the introduction of HAART (Highly Active Antiretroviral Therapy), when needs and barriers had changed as a result of the introduction of these new medications, the literature review found commonalities related to mental health and emotional needs, physical health needs, identity needs, training and educational needs, and financial needs. Nine articles specifically related to return-to-work, a primary area of exploration within HIV/AIDS and OT at the time. These needs included: health concerns preventing individuals from working, uncertainty of disease progression, physical and cognitive symptoms impairing work performance, interference of medications and scheduling, fear of loss of public benefits while maintaining a job, and discrimination and stigmatization. As these concepts also apply to how individuals form their sense of identity and volition, aside from return-to-work, these ideas are helpful for therapists working in various settings with the HIV/AIDS population.

Braveman, B. & Kielhofner, G. (2006). HIV/AIDS and employment: The continuing challenge. *Work*, 27, 205-207.

This article is an editorial preface explaining what was included in a special issue of the journal *Work* that was published in 2006, related to individuals with HIV/AIDS and employment. In addition to providing background information on the topic of HIV/AIDS and work, the article discusses the changes that the HIV/AIDS community has experienced since the onset of the epidemic, including pharmacological changes and social changes. Of particular interest, however, is the article's blatant mention that "the body of literature providing empirical evidence on effective vocational programs for persons living with HIV/AIDS is limited," a trend still applicable today within the literature. Six years later, a lack of quantitative articles related to HIV/AIDS and work still exists, as well as a lack of quantitative articles related to most other areas of life, especially within an occupational therapy context.

Braveman, B., Kielhofner, G., Albrecht, G., & Helfrich, C. (2006). Occupational identity, occupational competence, and occupational settings (environment): Influences on return to work in men living with HIV/AIDS. *Work*, 27, 267-276.

Individuals with HIV/AIDS often experience drastic changes in life roles secondary to diagnosis, including loss of vocation. This can result in loss of occupational identity and occupational competence, with the assumption of new roles, hobbies, jobs, and identities

providing new meaning and purpose that had previously been lost. If a participant's goal for productivity is to get a new job, for example, interventions can focus on mock interviewing, planning and organization, verbal and written communication skills, and time management. One of the capstone case study participants has a long-term goal of returning to work, though it is not the individual's primary focus during occupational therapy sessions. Articles like this one can serve as a model when providing interventions related to organization, increasing self-efficacy, and improving personal volition with individuals with HIV/AIDS in regard to work-related goals. This study represents qualitative research, as interviews were conducted and data were coded using sections of the text as the unit of analysis.

Braveman, B. & Suarez-Balcazar, Y. (2009). Social justice and resource utilization in a community-based organization: A case illustration of the role of the occupational therapist. *The American Journal of Occupational Therapy*, 63, 13-23.

Abstract: Social justice and occupational justice have received increased attention in the occupational therapy literature. This evolving discourse has focused on establishing a connection between the effects of social injustice and the resulting negative influences on occupational participation. This literature has also addressed the role of occupational therapists in responding to social injustice at the societal, population, or individual levels. We examine the two most well known theories of social justice to understand the responsibility of organizations, institutions, or governments in providing for people who have experienced difficulties in maintaining self-sufficiency. We use two case examples to illustrate how community-based organizations act as brokers of human, financial, and other resources and the challenges they face in distributing these resources in a manner consistent with social justice concepts. Finally, we suggest how an occupational therapist might assist such organizations in fairly distributing resources by applying occupational therapy paradigmatic knowledge and skills.

Though this entire article is not specific to HIV/AIDS, it does include a section providing an example of how social justice and related principles connect specifically to the HIV/AIDS community. In relation to social justice, the article discusses how the HIV/AIDS population experiences disparities in various ways, and how underserved populations such as women and ethnic minorities are increasingly growing demographics affected by the disease. Consequently, social justice, occupational justice, a person's sense of empowerment, and at times even basic human rights might suffer as a result. This article includes examples of helpful resources and non-profit programs, examples of questions therapists can ask themselves to assist in ensuring and maintaining social justice, and ways that MOHO relates to and encourages social justice when being used as a foundation for intervention in therapy. This article presents information through case examples of two individuals with HIV/AIDS.

Butters, E., Higginson, I., George, R., Smits, A., & McCarthy, M. (1992). Assessing the symptoms, anxiety, and practical needs of HIV/AIDS patients receiving palliative care. *Quality of Life Research*, 1, 47-51.

Abstract: We report the work of two community teams who care for people with AIDS/HIV

related illness, the characteristics of patients referred, and the impact of the teams on four aspects of quality of life. Data was collected on 140 patients (85 St. Mary's Home Support Team, 55 Bloomsbury Community Care Team) who were referred to and remained in the care of these teams until death. All patients were male, mean age 37.9 years, 116 were homosexual. Most referrals were from genitourinary medicine clinics (48%) or AIDS wards (41%). There was a wide range of reasons for referral. At referral 62% were in hospital and 35% at home. Mean time in care was 31 weeks 5 days. Fifty-seven per cent died in hospital, 22% at home and 21% in a hospice. The Support Team Assessment Schedule (STAS), consisting of 17 Items of care, was used by the teams to measure aspects of quality of life. Throughout care until death four STAS items: pain control, symptom control, patient anxiety and practical aid are reported in detail. Symptom control was a commonly severe problem at referral and although the teams had some success in improving this Item it remained a serious problem throughout care. Patient anxiety, also a commonly severe problem at referral, improved significantly throughout care. Pain control was less commonly severe at referral and improved significantly throughout care. Practical aid, in contrast, was rarely a severe problem at any stage of care.

This article is beneficial in establishing a better view of the types of long-term needs of individual with HIV/AIDS. According to this study, 22% of participants died at home, and 21% of participants died while in Hospice services, with bereavement follow-ups completed with family and friends. These percentages indicate that a significant portion of patients with HIV/AIDS require care from healthcare practitioners surrounding the end of life, more specifically related to developing a supportive environment for the end of life, whether in the home or through Hospice. Anxiety in general, anxiety over pain, and methods of controlling pain were all significant issues identified in this study. As such, when considering quality of life and long-term effects of HIV/AIDS, occupational therapists might play a role for these clients within palliative care settings. Furthermore, OT goals and interventions carried out long before clients are at the end of their lives or considering long-term planning might be related to anxiety and pain control, helping clients prepare for these challenging areas earlier on. This study represents evidence level III, in that it is a pretest/posttest measurement of one group. It is also part of a larger longitudinal study, which began in 1985.

Cameron, D., Tran, T., Bone, G., & Thomas, S. Occupational therapy strategies for people living with HIV/AIDS. *Occupational Therapy Now*, 9, 31-32.

This helpful handout highlights areas to focus on specific to OT for therapists working with HIV/AIDS clients, including: basic energy conservation tips, use of DME and adaptive equipment, options for transportation, use of calendars and memory aids, routines and structure, healthy coping strategies, safety, housing concerns, and return to work. Its brief and easy to understand format allows it to potentially be distributed to clients as well, perhaps to help them gain a better initial understanding of what OT is and how it can specifically help individuals with HIV/AIDS.

Carter, S. (Ed.). *Dear friend: Wise words and shared journeys of people living with HIV*. Toledo, Ohio: The University of Toledo Medical Center.

This book is a collection of memoirs from individuals with HIV/AIDS who are patients at the Ryan White Clinic at the University of Toledo Medical Center. At the time the memoirs were collected, these patients were attendees at the monthly support groups facilitated by the Ryan White Clinic. The book was made to be an anthology of letters, poems, and stories to advise and bring hope and compassion to those who have been newly diagnosed with HIV, and the book is routinely given out to new attendees of the support groups. Since the UTMC Ryan White Clinic was the site of the capstone, and since one of the capstone case study participants wrote his personal narrative within the book, this collection of personal accounts by individuals with HIV/AIDS serves as an incredibly unique and genuine look into the minds and hearts of those with HIV/AIDS, specific to the Toledo, Ohio area. Specific to MOHO, this book also provides excellent examples of the structure of personal narratives written by clients examining their pasts and presents while working toward building positive futures.

Catz, S. L., McClure, J. B., Jones, G. N., & Brantley, P. J. (1999). Predictors of outpatient medical appointment attendance among persons with HIV. *AIDS Care*, 11, 361-373.

Abstract: Non-adherence to medical regimens is a critical threat to the health of HIV-infected individuals. Patients who do not adhere to routine medical care cannot fully benefit from the increasingly efficacious treatments available to them. Consistent attendance at medical appointments plays a central role in both prolonging life and enhancing quality of life for persons living with HIV/AIDS. By identifying why many patients do not reliably attend medical services, interventions can be undertaken to improve appointment keeping. The primary purpose of the present study was to identify factors predictive of HIV-related medical appointment attendance. One-hundred-and- forty-four outpatients in a public hospital ambulatory care HIV clinic were followed for seven months. Demographic, medical care and psychosocial factors were measured in order to prospectively predict the percentage of missed clinic appointments by persons with HIV disease. Greater outpatient appointment non-attendance was associated with younger age, minority status, less severe illness and lower perceived social support. Treatment duration, provider consistency, hopelessness and religious coping did not emerge as significant predictors of outpatient appointment-keeping in this sample. Practical and theoretical implications of these findings are discussed in light of recent medical advances in HIV/AIDS care.

Medication adherence, medical appointment adherence, and general planning and organization of one's schedule are often goals addressed by occupational therapists when working with clients with HIV/AIDS. This study seeks to examine factors predictive of non-adherence specifically to medical appointments, which might also relate to non-adherence patterns with other outpatient appointments, such as those with occupational therapists. Results indicated that those who are younger, of minority status, and have more under control HIV status tend to demonstrate non-adherence, as do those with less social support. These factors are also very relevant to some of the capstone case study participants, who fall into these demographic categories and tend to exhibit some non-adherence with OT appointments. Because other factors were not significant, such as religion, treatment duration, or provider consistency, the solution to improving adherence seems to be to attempt to help clients increase social support, in addition to other methods of improving organization and scheduling. This study utilized a longitudinal

analysis of one group of individuals and a quasi-experimental design.

Center for Disease Control. (2008). *Estimates of new HIV infections in the United States*. Retrieved from <http://www.cdc.gov/hiv/default.htm>

This document of statistics related to the incidence of HIV infections in the United States demonstrates that the amount of infections has leveled off to a stable amount as of the early 1990s. Though approximately over 56,000 cases of HIV infections occur each year, this number has decreased from about 130,000 infections per year since the epidemic began in the 1980s. The document also explains common methods of transmission that result in infection. When providing services to individuals with HIV/AIDS, it is necessary to understand the larger picture of HIV/AIDS as a disease, in order to better understand its severity.

Center for Disease Control. (2008). *MMWR analysis provides new details on HIV incidence in U.S. populations*. Retrieved from <http://www.cdc.gov/hiv/default.htm>

Released one month after the previously listed CDC document, this document essentially adds to some statements made by the CDC regarding the estimation of HIV infections in the United States. Though it was previously suspected that infection rates had leveled off, newer data indicated that the epidemic was worse than previously known, highest among gay and bisexual men of all races, African Americans, and Hispanics/Latinos. Though none of this information is new, confirming that these already known trends are on the rise is important in understanding the future of HIV/AIDS care. Additionally, this analysis of data was able to break down estimates into the most detailed categories provided by the CDC thus far, separating greatest risks even further by demographics. For example, within the category of African Americans, women experience the greatest impact. Within bisexual men, impact was greatest in those ages 30 to 40.

Center for Disease Control. (2010). *HIV in the United States* [Fact sheet]. Retrieved from <http://www.cdc.gov/hiv/default.htm>

Approximately one million people in the United States are living with HIV, and an estimated 56,300 people become infected with it each year. As of 2007, more than 576,000 people have died of AIDS since the epidemic began, and it is estimated that approximately 18,000 people with AIDS still die each year. The CDC identifies that homosexuals, bisexual males, and men who have sex with men continue to be the groups at highest risk for contracting HIV/AIDS. Because occupational therapists working with HIV/AIDS patients will come across individuals of various sexual orientations, it is imperative that therapists understand their needs, sociological behavior patterns, and risk factors, especially when sexuality is often a large component of therapy provided in the form of self-care and ODL education and intervention.

Chan. S. C. C. (2004). Chronic obstructive pulmonary disease and engagement in occupation. *The American Journal of Occupational Therapy*, 58, 408-415.

Abstract: The goal of this study was to gain an understanding of participants' experiences with chronic obstructive pulmonary disease (COPD) and their perceptions of an occupational therapy intervention as it related to occupational behaviors. The researcher conducted semi-structured interviews with three participants recruited from a pulmonary rehabilitation program in Hong Kong. Using thematic analysis, five themes related to the disease experience were identified: (1) uncertainty during the course of the disease, (2) external attribution, (3) activity restriction and isolation, (4) anxiety and depression, and (5) passive fortitude. Regarding the participants' perceptions of the effects of the occupational therapy intervention on occupation engagement, four themes were identified: (1) increased knowledge of COPD, (2) taking control of the disease and reengagement in activities, (3) alleviation of mental burden, and (4) social support from peers and therapists. The study suggests a temporal framework for better understanding participants' experiences of COPD as well as for developing more appropriate occupational therapy interventions.

Many individuals experiencing significant life stressors, such as the burden of disease, tend to utilize negative coping strategies at times, with smoking being a significant example. As two of the three capstone case study participants are smokers, and as one of these two has beginning stage COPD, it was crucial for at least one occupational therapy intervention during the project to focus on smoking cessation, COPD risk factors, and COPD prevention. This article, therefore, is beneficial in developing an understanding of how COPD affects occupation, and how occupational therapy can play a role in addressing COPD side effects during goals and interventions. This study represents a lower level of evidence, in that it used a qualitative approach in which interviews were conducted to obtain data.

Corless, I. B., Bunch, E. H., Kemppainen, J. K., Holzemer, W. L., Nokes, K. M., Eller, L. S., . . . Chou, F. (2002). Self-care for fatigue patients with HIV. *Oncology Nursing Forum*, 29, 60-68.

Abstract: Purpose/Objectives: To identify when fatigue is reported as a problem by people who are HIV positive, what the perception of fatigue is, and which self-care behaviors are used and with what efficacy. Design: Multisite descriptive study. Setting: University-based AIDS clinics, community-based organizations, and homecare agencies located in cities across the United States, in Norway, and through a university Web site. Sample: Convenience sample of 422 self-identified people who are HIV positive. Main Research Variables: Symptom description, symptom relief, symptom help, and self-care strategies. Findings: The sixth most reported symptom in this study, fatigue, was treated with a variety of self-designed strategies. In only three instances was consultation with a healthcare provider (i.e., physician) or an injection (medication not defined) mentioned. The most frequently used interventions were supplements, vitamins, and nutrition followed by sleep and rest; exercise; adjusting activities, approaches, and thoughts; distraction; and complementary and alternative therapies. In addition to self-designed strategies, the media and friends and family were sources of information. Conclusions: Fatigue was reported less frequently in this study than in other HIV-, AIDS-, or cancer-related studies. This may be an artifact of the study design. The use of informal networks for assistance, let alone the prevalence of unrelieved fatigue, indicates the need for more attention to this problem among people with AIDS. Implications for Nursing: Careful assessment of the pattern of fatigue and

its onset, duration, intervention, and resolution is required if the varied types of fatigue are to be identified and treated successfully.

This article is beneficial in establishing a more in-depth understanding of the causes of HIV-related fatigue, a deficit that was present in all three of the capstone case study participants and in many others within the HIV/AIDS population. The article identifies some causal factors as being: anemia, impaired liver or thyroid function, malnutrition, wasting, AIDS dementia, HIV myopathy, immunosuppression, hormonal deficiencies, depression, lack of exercise, pain, infection or fever, nutritional deficiencies, excessive inactivity or rest, and growth hormone dysregulation. Top intervention strategies for relief of fatigue revealed by the study included: supplements, vitamins, and nutrition (n = 29, 31%); sleep or rest (n = 21, 23%); adjustments to activities, approaches, or thoughts (n = 16, 17%); and exercise (n = 14, 15%). As all of these interventions can be addressed within occupational therapy, this study offers good justification and information that might be used during goal setting and intervention planning. This study does not represent a randomized controlled trial, in that it used both descriptive and quantitative methods to organize data, aggregated by type of HIV/AIDS symptom.

Cran, W. & Barker, G. (Producers). (2006). *Frontline: The age of AIDS* [Television broadcast]. United States: The Corporation for Public Broadcasting.

This news program provides a detailed and extensive review of the history of HIV/AIDS, perhaps particularly beneficial to those who have little prior knowledge of the causes, symptoms, prevalence and incidence of HIV/AIDS. This program seems to greatly emphasize prevention, seeking information from social, political, economic, and scientific researchers and experts within the field, as well as world leaders, advocates, activists and patients themselves, regarding the complicated implications of the disease. This film is an excellent general overview of HIV/AIDS, and can remind occupational therapists of the importance of HIV/AIDS advocacy and the crucial nature of remaining knowledgeable of political and social change.

Cubie, S. H., & Kaplan, K. (1982). A case analysis method for the model of human occupation. *The American Journal of Occupational Therapy*, 36, 645-656.

Abstract: This paper introduces a method for analyzing clinical cases, which is based on ten primary questions and on criteria for OT selecting level of treatment. The questions and the criteria are derived from the model of human occupation. Four steps in the method are: gathering data in relevant categories; reviewing and analyzing data using the questions in sequence; selecting levels of treatment; and recording case studies. Three brief case studies taken from an acute care psychiatric setting are described to illustrate the use of this method.

This article includes three brief case studies using MOHO, though they are applied in a psychiatric acute care setting and are not specific to HIV/AIDS. Though published in 1982, and despite changes since then that have occurred with MOHO terminology and methods, this article is still a helpful overall example of how to utilize MOHO when completing case studies. The article includes an organized chart illustrating patients' changes in volition, personal causation,

habits, roles, etc. over the course of intervention, as well as lists of questions that therapists should ask themselves regarding how to determine methods to illicit change and progress in patients. Though each therapist may interpret MOHO differently, and though it might be applied slightly differently depending on the type of setting, this informational article with case study examples facilitates universal MOHO analysis and application to therapy, as well as guides clinical reasoning.

Davis, S. J., Mbugua, A., Koch, D. S., & Johnson, A. (2011). Recognizing suicide risk in consumers with HIV/AIDS. *Journal of Rehabilitation*, 77, 14-19.

Abstract: Mental health disorders and suicide occur in persons with HIV/AIDS at higher rates than the general population. Rehabilitation professionals need to be aware of risk factors for suicide in this population and should be prepared to manage situations involving potential suicide. For this study 71 individuals living with HIV/AIDS were interviewed using the Global Appraisal of Individual Needs (GAIN). Rates of depressive symptoms and anxiety were found to be prevalent among the participants. Depressive symptoms and low life satisfaction were significantly associated with suicide risk.

Because most individuals with HIV/AIDS experience greater life stressors than do those within the general population, a large part of occupational therapy interventions provided to this population relate to coping skills, stress management, and management of the disorganization and lack of volition often secondary to psychological disorders. Because all of the capstone case study participants had psychological disorders, varying from depression to Borderline Personality Disorder, it is critical to understand how to address the depressive symptoms and low sense of life satisfaction present within individuals among this population. Furthermore, when providing occupational therapy interventions to individuals with HIV/AIDS, increased empathy, understanding, and compassion are needed to gain trust and increase rapport, allowing increased opportunities for communication and therefore raising the probability of a therapist to potentially recognize when a person is at high risk for suicide. This study represents a lower level of evidence, in that it analyzed the results of survey data obtained by a psychosocial assessment that participants completed. However, internal consistency studies of the assessment tool (referenced in the article) show acceptable reliability ($\alpha = .63$ to $.97$). Validity results were not listed.

Denton, R. (1987). AIDS: Guidelines for occupational therapy intervention. *The American Journal of Occupational Therapy*, 41, 427-432.

Abstract: Acquired immune deficiency syndrome (AIDS) is currently considered the nation's number one health problem. More than 30,000 persons have been diagnosed with this disease to date, and 40,000 new cases are anticipated for the next 2 years. This paper reviews the current facts regarding AIDS, including its modes of transmission and clinical symptomatology. Guidelines for occupational therapy assessment and treatment are presented, including general precautions and recommended intervention strategies.

Though published in 1987, this article outlines occupational therapy intervention

guidelines at a time when HIV/AIDS care was first emerging. Because the same interventions and precautions still apply today, strategies for care should include significant elements of patient education about precautions and daily routines, standards for evaluation that take all aspects of physiological and psychosocial needs into account, and treatment that focuses on individualized goals and plans of care.

DiStefano, A. S., & Cayetano, R. T. (2011). Health care and social service providers' observations on the intersection of HIV/AIDS and violence among their clients and patients. *Qualitative Health Research*, 21, 884-899.

Abstract: Associations between HIV/AIDS and several forms of violence have been demonstrated in recent research. We conducted qualitative interviews with 30 providers who offered services related to HIV/AIDS or violence to identify specific manifestations of HIV/AIDS–violence intersections, factors that explain why HIV/AIDS and violence intersect in client/patient populations, and the theoretical salience of providers' narratives. Providers confirmed links between HIV/AIDS and violent victimization, and yielded new insights into crossover risk between HIV/AIDS and suicidality, non-suicidal self-harm, and witnessing and perpetrating violence. We also isolated 20 explanatory factors, including substance use, poor mental health, sex work/trading sex, and sexual orientation/gender identity. Narratives were consistent with syndemics theory, indicating that HIV/AIDS and violence fueled each other's occurrence and magnified the health-related burden on affected client/patient populations, often under conditions of health and social disparity. Providers contribute a novel perspective on our understanding of HIV/AIDS–violence syndemics that shows promise in informing future interventions and practice.

This article helps develop a profile of risk factors to violence within the HIV/AIDS population, as well as to facilitate analysis and thought regarding how violence and its precipitating factors impede or affect ODLs and IDOLs in the lives of individuals with HIV/AIDS. Additionally, the article demonstrates how psychosocial and cognitive deficits within this population, including depression and other psychological disorders, contribute to individuals harming themselves or others. Interestingly, however, the article reveals that violence itself tends to be a risk factor for subsequent HIV infection, versus violence being a secondary result of living with HIV/AIDS. Explanatory factors identified for violence within this population include: substance use, culture, stigma and marginalization, hopelessness, poverty, crime and incarceration, rage, having a cheating partner, intergenerational sexual relationships, poor mental health, sex work and trading sex, and confusion over sexual orientation or gender identity. Overall, the possibility of violence needs to be considered by occupational therapists when providing care to this population, as it adds to the common disorganization that can often occur within the home and social environments of individuals with HIV/AIDS, impacting the sometimes chaotic nature of the lives of these individuals and affecting daily occupations. This study represents a lower level of evidence, in that it obtained results from qualitative measures through interviews with service providers.

Evans, S., Weinberg, B. A., Spielman, L., & Fishman, B. (2003). Assessing negative thoughts in

response to pain among people with HIV. *Pain*, 105, 239-245.

Abstract: A growing body of literature suggests that negative thoughts and interpretations in response to pain can significantly increase the suffering associated with the pain experience. As part of an outcome study on a cognitive-behavioral treatment for HIV-related peripheral neuropathic pain, 85 seropositive men and women were administered the inventory of negative thoughts in response to pain (INTRP), a self-report assessment that includes three subscales: negative self-statements, negative social cognitions and self-blame. Pearson product moment correlations coefficients were calculated between INTRP scores and pain and distress ratings. A series of regression analyses were performed to determine predictors of pain and distress. Results demonstrated highly significant associations between the negative self-statements and negative social cognitions and pain intensity. Highly significant associations were also found between negative self-statements, negative social cognitions, self-blame and measures of pain interference, affective symptoms and distress. Additionally, negative cognitions significantly predicted interference in daily functional activities, overall distress and affective symptoms. Future directions for developing and testing cognitive-behavioral treatments for restructuring dysfunctional cognitions are indicated. Finally, internal scale reliability of the INTRP was shown to be moderately high and this study offers construct validity of the INTRP as a useful tool for assessing thoughts in response to pain in people with HIV.

As chronic pain tends to be a prevalent issue among individuals with HIV/AIDS, as does neuropathy, this article is a great resource for intervention ideas for goals working toward improving quality of life in the face of these deficits. All three of the capstone case study participants had pain issues, and two had neuropathy. This article offers suggestions about prioritizing the power of positive thinking, and teaching clients to more accurately assess and interpret their bodily responses. For example, this study found that those who scored higher on measures of self-blame, negative thoughts, and negative self-statements were more likely to experience pain. These pain experiences then interfered with ODLs and IDOLs, as well as caused distress. Occupational therapists, therefore, might focus on developing new strategies for self-appraisal and for managing pain, as well as strategies to minimize negative self-thoughts and increase self-esteem. This study represents a lower level of evidence because it used a self-report assessment to collect data. However, as stated in the abstract, “internal scale reliability of the INTRP was shown to be moderately high and this study offers construct validity of the INTRP as a useful tool for assessing thoughts in response to pain in people with HIV.”

Ferarri, L. F., & Levine, J. D. (2010). Alcohol consumption enhances antiretroviral painful peripheral neuropathy by mitochondrial mechanisms. *Neurosystems*, 32, 811-818.

Abstract: A major dose-limiting side effect of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) chemotherapies, such as the nucleoside reverse transcriptase inhibitors (NRTIs), is a small-fiber painful peripheral neuropathy, mediated by its mitochondrial toxicity. Co-morbid conditions may also contribute to this dose-limiting effect of HIV/AIDS treatment. Alcohol abuse, which alone also produces painful neuropathy, is one of the most important co-morbid risk factors for peripheral neuropathy in patients with HIV/AIDS. Despite the prevalence of this problem and its serious impact on the quality of life and continued

therapy in HIV/AIDS patients, the mechanisms by which alcohol abuse exacerbates highly active antiretroviral therapy (HAART)-induced neuropathic pain has not been demonstrated. In this study, performed in rats, we investigated the cellular mechanism by which consumed alcohol impacts antiretroviral-induced neuropathic pain. NRTI 2',3'-dideoxycytidine (ddC; 50 mg/kg) neuropathy was mitochondrial-dependent and PKCe-independent, and alcohol-induced painful neuropathy was PKCe-dependent and mitochondrial-independent. At low doses, ddC (5 mg/kg) and alcohol (6.5% ethanol diet for 1 week), which alone do not affect nociception, together produce profound mechanical hyperalgesia. This hyperalgesia is mitochondrial-dependent but PKCe-independent. These experiments, which provide the first model for studying the impact of co-morbidity in painful neuropathy, support the clinical impression that alcohol consumption enhances HIV/AIDS therapy neuropathy, and provide evidence for a role of mitochondrial mechanisms underlying this interaction.

This article offers new evidence that suggests that alcohol consumption increases neuropathy symptoms associated with ART (antiretroviral therapy) during treatment of HIV/AIDS. Though this article is very medically based, it provides concrete and objective evidence to support limiting alcohol intake when dealing with neuropathy and when participating in ART that can still be related to OT. Because many HIV/AIDS patients utilize alcohol as a coping strategy, this evidence is very relevant to OT interventions addressing prevention in this population. Furthermore, because two of the three capstone case study participants drank alcohol on a regular basis, one of whom was a self-reported alcoholic who also had neuropathy symptoms, research like this might be passed on to clients as proof of evidenced-based practice, helping to establish a justified, trusting therapeutic relationship and to facilitate promotion of good health habits. This study represents a high level of evidence, as it is a randomized controlled clinical trial. However, this study was performed on rats, and not with human participants.

Fisher, G. S., Emerson, L., Firpo, C., Ptak, J., Wonn, J., & Bartolacci, G. (2007). Chronic pain and occupation: An exploration of the lived experience. *The American Journal of Occupational Therapy*, 61, 290-302.

Abstract: OBJECTIVE. There is limited research on the relationship between chronic pain and occupation. This phenomenological research study explored the lived occupational experiences of people who have chronic pain. METHOD. Via demographic questionnaires, semi-structured interviews, and field notes, data were collected on 13 participants with various types of pain. RESULTS. Thematic analysis yielded one main theme: "Chronic Pain Is Life Changing." The following sub-themes also emerged: "Chronic Pain Triggers Emotional Distress"; "Chronic Pain Reveals the Strength of Relationships"; "Chronic Pain and Occupation Are Reciprocally Related Forces"; and "Chronic Pain Elicits Innovative Adaptive Responses." Study participants reported experiencing myriad troubling emotions; however, they resourcefully modified their routines and tasks and found enhanced meaning in favored occupations. CONCLUSIONS. This study illuminates the importance of therapeutic listening, the innovativeness of people who have chronic pain, and the possible therapeutic potential of occupation.

This article focuses on the potential benefits of therapeutic listening in response to chronic

pain. Though not specific to HIV/AIDS, many individuals within the HIV/AIDS population experience chronic pain and often have difficulty dealing with its effects. Themes emerging from this qualitative study indicate that individuals with chronic pain do find meaning and purpose in participating in occupation, as well as find therapeutic results from maintaining a positive client-therapist relationship when dealing with pain issues. Interventions focusing on maintaining other positive relationships within the social group, coping with emotional distress, finding new occupations and hobbies, and working on being able to positively adapt can help deal with chronic pain. In general, this article offers good support for the use of occupation with patients of various medical histories who experience chronic pain. This study represents a lower level of evidence, in that it yielded qualitative data from semi-structured interviews.

Flower, A., Naxon, E., Jones, R. E., & Mooney, V. (1981). An occupational therapy program for chronic back pain. *The American Journal of Occupational Therapy*, 35, 243-248.

Abstract: This paper describes a multidisciplinary approach to the evaluation and treatment of the patient with chronic spinal pain with particular emphasis on the cooperative roles of the physical disabilities occupational therapist and the psychosocial occupational therapist. The goal of the total program is to help patients progress from a sick role of dependent, painful behavior to a less pain-centered, more productive role-one in which they have begun to assume control over the way they feel and function. The success of the program is measured by the patient's increased activity level and improved ability to cope with the demands of home and job. A review of patient records after one year of operation showed that only 4 of 54 patients who completed both phases of the program were returning to the orthopedic back clinic as outpatients.

In addition to the previous article related to chronic pain in general, this article offers intervention suggestions specific to chronic back pain. Because one of the capstone case study participants had various deficits to occupational performance due to back and/or spinal pain, this article, though published in 1981, offers meaningful strategies for managing pain. The article outlines the phases of a program that was implemented, offering suggestions from initial evaluation through discharge and follow-up. Results indicated that progress from intervention was retained, with only 4 of 54 patients returning to the orthopedic back clinic after one year due to pain issues. In relation to the case studies, intervention methods from this program can be taught to clients for use in their homes after in-home therapy services have concluded. This article represents information disseminated in narrative form, and is not quantitative research.

Gaidhane, A. M., Zahiruddin, Q. S., Waghmare, L., Zodpey, S., Goyal, R. C., & Johrapurkar, S. J. (2008). Assessing self-care component of activities and participation domain of the international classification of functioning, disability and health (ICF) among people living with HIV/AIDS. *AIDS Care*, 20, 1098-1104.

Abstract: Disability experience of persons with HIV illness has shifted from issues related to physical well being to those concerning performance of daily life activities. This study aimed to find out the nature of self-care among people living with HIV/AIDS (PLWHA) in rural tertiary care center. The objectives were to determine reported self-care by performance qualifier of

PLWHA and to find out reported self-care by capacity qualifier of PLHIV. A cross sectional study was conducted among the 194 PLHIV in rural tertiary care hospital. The Self-Care (d5) component of Activities and Participation domain (d) of the International Classification of Functioning, Disability and Health (ICF) was used. Among the 194 PLHIV patients studied, 82% were male. The average age was 36.87 years (SD99.01) with a median of 35 years, varying from 15 to 65 years. Over 65% of the study group experienced one or more impairments. As HIV disease has become a more lifelong, unpredictable, but medically manageable condition, there is a need for more collaboration with other disability groups in order to identify commonalities in their experiences and to share collective concerns. Keywords: self-care; ICF; people living with HIV/AIDS; performance qualifier

This study found that 65% of 194 participants with HIV experienced impairments directly related to self-care. The study also revealed self-care deficit trends relevant to the nature of HIV/AIDS, such as participants having difficulty caring for teeth, skin, and nails, or difficulty with urination and defecation, typical areas of concern as the symptoms and severity of HIV/AIDS progress. Because occupational therapy interventions often apply to the category of self-care, HIV/AIDS interventions should be designed to inform participants of how to compensate for the particular deficits occurring at their stage in the disease. This study represents a cross-sectional design in which the ICF-systematic coding scheme was used to code data.

Ginsburg, D. R., Power, I. K., & Worth, M. (Producers), & Cristofer, M. (Director). (1998). *Gia* [Motion picture]. United States: HBO Pictures.

This movie tells the true story of New York City fashion model Gia Carangi, who died from AIDS in 1986 at the age of 26. During a time when HIV/AIDS was seemingly unheard of and highly misunderstood, this movie outlines Carangi's battle with heroin and cocaine addiction that directly contributed to her contracting HIV from sharing an infected needle. This movie provides history on the sociology of HIV/AIDS, allowing viewers to better appreciate how far medical interventions have come in treating the disease, as well as how far society has come in accepting and understanding individuals with HIV/AIDS.

Giordano, T. (2011). Retention in HIV Care: What the clinician needs to know. *Topics in Antiviral Medicine*, 19, 12-16.

This study, a rare look at how to improve retention in HIV care, is one of the only randomized trials examining the topic. Less retention among individuals with HIV/AIDS can result in decreased likelihood of receiving ART, higher rates of ART failure, increased HIV transmission risk behavior, increased hospitalization rates, and worse survival. According to the CDC, studies have shown that 17% to 40% of persons who knew their HIV serostatus were not in regular care, perhaps due to the associated risk factors identified by this study: being young, being female, being of racial or ethnic minority status, being of low socioeconomic status, have no usual source of healthcare, having less advanced HIV disease, having greater psychosocial needs, and having fewer non-HIV-related comorbidities. Though the national magnitude of this problem is still unknown, proposed interventions stemming from this study include: a 90-day

intensive case management program, use of ancillary services, participating in research projects, skills building sessions, and motivational interviewing. The authors suggest that treating medical appointment retention similar to how one would treat medication adherence when providing interventions might help to better conceptualize it. Additionally, reducing substance dependence, improving trust and communication among medical personnel and clients, and removing associated structural barriers such as transportation, housing, childcare, and financial needs for clients can also help improve retention.

Gonzalez, A., Zvolensky, M. J., Parent, J., Grover, K. W., & Hickey, M. (2012). HIV symptom distress and anxiety sensitivity in relation to panic, social anxiety, and depression symptoms among HIV-positive adults. *AIDS Patient Care and STDs*, 26, 1-9.

This study explores the relationship between symptom distress and exacerbation and anxiety sensitivity, specifically in relation to social anxiety, depression, and panic. Perhaps as suspected, the study found that HIV symptom distress increases when anxiety sensitivity is higher, indicating that those who are better able to deal with panic and anxiety have less prevalence of HIV symptoms. Occupational therapy contacts with individuals with HIV/AIDS, therefore, should include psychosocial evaluations screening for anxiety, panic, and depression, as well as goal-setting and methods of intervention geared toward developing positive coping strategies and promoting mental health, in addition to psychosocial well being. Though this study reported very specific, detailed statistics including main and interactive effects and results of regression analyses, data were obtained from results of participants completing a series of written assessments of which validity and reliability are unknown.

Griswold, G. A., Evans, S., Speilman, L., & Fishman, B. (2005). Coping strategies of HIV patients with peripheral neuropathy. *AIDS Care*, 17, 711-720.

Abstract: The aim of this study was to evaluate the association between coping strategies and reports of with pain and distress in patients with HIV-related peripheral neuropathy. Seventy-eight HIV seropositive subjects completed the Coping Strategies Questionnaire (CSQ), a self-report measure that assesses seven factors, the Brief Pain Inventory (BPI), the Brief Symptom Inventory (BSI) and the Beck Depression Inventory (BDI). Bivariate correlations revealed that younger patients used more Praying-Hoping ($r = .23$, $pB = .04$) and Catastrophizing ($r = .30$, $pB = .007$). t-tests demonstrated that women used more Praying-Hoping ($t(76) = 3.42$, $pB = .01$), while Hispanic and African American patients used more Praying-Hoping more than Caucasians ($F(1,77) = 22.11$, $p = .0005$). Catastrophizing significantly predicted higher scores on the BDI ($t = 2.968$, $p = .004$), the Global Severity Index (GSI) of the Brief Symptom Inventory BSI ($t = 2.400$, $p = .02$); and pain interference on the Brief Pain Inventory BPI ($t = 2.996$, $p = .004$) controlling for age, gender, and ethnic background. These results demonstrate that coping strategies may differ according to age, gender, and ethnic background in an HIV population, and that Catastrophizing predicts distress and interference with functioning in this sample.

Because many individuals with HIV/AIDS have various types of neuropathy that impact their occupational performances in daily life, identifying the coping strategies that these

individuals might use specific to HIV/AIDS can assist with developing insight into their personal experience. This study revealed that certain demographics (e.g. women, African Americans, and Hispanics) tend to place higher emphasis on spirituality, religion, and prayer than do Caucasians when coping with neuropathy-related pain. Furthermore, younger individuals with HIV/AIDS dealing with neuropathy-related deficits tend to use a more passive approach (catastrophizing) that increases their sense of depression and hopelessness and also decreases their productivity in daily life. Occupational therapists who understand current coping strategies within this population can better recommend new coping techniques for neuropathy, attempt to incorporate hands-on doing, as well as better empathize with their clients and develop a more accurate client-therapist relationship. Though this study included detailed statistics such as results of an ANOVA and of multiple regression analyses, data were obtained from results of participants completing a series of assessments with interviewers. However, “inter-rater agreement among assessors of the interviews demonstrated a high level of reliability with an intraclass correlation coefficient (ICC) of .86.”

Guterman, L. (1990). A day treatment program for persons with AIDS. *The American Journal of Occupational Therapy*, 44, 234-237.

Abstract: This paper describes the Village Nursing Home's day treatment program for persons with AIDS, with an emphasis on the role of occupational therapy and the outcomes of occupational therapy interventions. The clients' demographics are included, and a general program philosophy of clients' empowerment is discussed. The health promotion framework and the use of holistic modalities address the spiritual aspect of the individual and how occupational therapy and spirituality might interconnect.

Though this article was published in 1990, interventions used are still relevant today, such as food shopping, meal prep, nutrition education, pain management, interventions related to strength and coordination, cognitive interventions, time management skills, hobbies and leisure, substance abuse management, and vocational skills. Clients who participated in the program of more severe HIV/AIDS status reported that when they were not at the program they were at medical appointments or spending time in waiting rooms, making time spent on meaningful and purposeful occupations through the program absolutely crucial. This finding suggests that occupational therapists in general should consider the importance of prioritizing the most meaningful occupations for clients to complete, as clients' time might be divided in various ways in order to manage their care, some of which are stressful or difficult. For OT to create the most potential benefits for clients, the process should place hands-on doing and occupation at the foundation. This article represents information presented in narrative form.

Hall, H. I., Song, R., Rhodes, P., Prejean, J., An, Q., Lee, L. M., . . . Janssen, R. S. (2008). Estimation of HIV incidence in the United States. *Journal of the American Medical Association*, 300, 520-529.

Abstract: Context Incidence of human immunodeficiency virus (HIV) in the United States has not been directly measured. New assays that differentiate recent vs. long-standing HIV infections

allow improved estimation of HIV incidence. Objective To estimate HIV incidence in the United States. Design, Setting, and Patients Remnant diagnostic serum specimens from patients 13 years or older and newly diagnosed with HIV during 2006 in 22 states were tested with the BED HIV-1 capture enzyme immunoassay to classify infections as recent or long-standing. Information on HIV cases was reported to the Centers for Disease Control and Prevention through June 2007. Incidence of HIV in the 22 states during 2006 was estimated using a statistical approach with adjustment for testing frequency and extrapolated to the United States. Results were corroborated with back-calculation of HIV incidence for 1977-2006 based on HIV diagnoses from 40 states and AIDS incidence from 50 states and the District of Columbia. Main Outcome Measure Estimated HIV incidence. Results: An estimated 39 400 persons were diagnosed with HIV in 2006 in the 22 states. Of 6864 diagnostic specimens tested using the BED assay, 2133 (31%) were classified as recent infections. Based on extrapolations from these data, the estimated number of new infections for the United States in 2006 was 56 300 (95% confidence interval [CI], 48 200-64 500); the estimated incidence rate was 22.8 per 100 000 population (95% CI, 19.5-26.1). Forty-five percent of infections were among black individuals and 53% among men who have sex with men. The back-calculation ($n = 1.230$ million HIV/AIDS cases reported by the end of 2006) yielded an estimate of 55 400 (95% CI, 50 000-60 800) new infections per year for 2003-2006 and indicated that HIV incidence increased in the mid-1990s, then slightly declined after 1999 and has been stable thereafter. Conclusions: This study provides the first direct estimates of HIV incidence in the United States using laboratory technologies previously implemented only in clinic-based settings. New HIV infections in the United States remain concentrated among men who have sex with men and among black individuals.

This article provides reliable and objective recent statistics related to the prevalence and incidence of HIV/AIDS in the United States, as reported by the American Medical Association. This study also provides the first direct estimate of HIV incidence in the U.S. utilizing laboratory technologies. This study represents an epidemiological study, specifically a cohort study.

Hansen, R. A. (1990). The ethics of caring for patients with HIV or AIDS. *The American Journal of Occupational Therapy*, 44, 239-244.

Abstract: Health care professionals encounter many ethical issues in the care of persons who are HIV positive or who have been diagnosed as having AIDS. Such issues include the allocation of scarce resources for research and health care; the use of various methods of disease control, including mandatory testing, forced isolation, informing of sexual partners, and education; and the determination of the responsibility to treat infected patients. These issues are presented as a stimulus to readers to examine their own attitudes regarding HIV and AIDS. The usefulness and limitations of occupational therapy's professional code in resolving ethical dilemmas are discussed, followed by the description of a process that can be used to analyze and solve these dilemmas.

Though this article, published in 1990, is not the most recent view of OT ethics when caring for HIV/AIDS patients, it is one of the only ethics references available in the OT literature. The article also brings up the very relevant point, as it was in 1990, that AOTA's code of ethics did not specify methods for the resolution of ethical dilemmas. The article, therefore,

suggests that therapists consider: the “players” in the dilemmas, what other facts and information are needed, actions that might be taken, potential consequences (ethical, medical, and/or legal), and actions or combinations of actions that therapists might recommend that can be defended and justified. These methods of resolution might apply in situations where therapists are attempting to allocate resources and funding, cope with the potential stigmatization that often affects HIV/AIDS patients, and provide education about sensitive topics, such as sexual relationships and substance use. This article represents a critical analysis, and not a quantitative study.

Higgins, C. A. (1997). Outcome measurement in home health. *The American Journal of Occupational Therapy*, 51, 458-460.

This article outlines how outcomes are measured in home health OT, providing therapists with more objective methods for assessing changes in patients. The author divides measuring change into three levels—organ level impairments, disability, and limitations. Within these three types of measurements are specific strategies for identifying factors that influence progress, as well as methods to determine treatment strategies and goals and monitor overall effectiveness of outcomes. The author also discusses that outcome measurements should be completed in a systematic, quantitative manner across particular points in time, and how outcome monitoring and the use of repeated measurement outcome indicators over time can yield accurate results. Articles like these, especially when specific to OT, can help practitioners develop evidence-based practice while delivering effective therapy. This article represents a critical analysis, and not a quantitative study.

Hogarth, L. (Producer & Director). (2002). *The gift: Does anyone die of AIDS anymore?* [Motion picture]. United States.

This unique documentary explores a rare pattern among homosexual men in some communities within the United States who actively seek to contract or transmit HIV to fulfill a need for belonging within a culture, social group, or community. Exploring the moral, ethical, and sociological complications related to this practice, the documentary also explores larger themes related to social environments, habits, roles, and perceptions of volition and personal causation as they might exist for these individuals. Overall, this film might serve as a reminder of the often subjective nature of providing healthcare services, and that to truly understand and observe a person’s environment in a clinical manner, practitioners must first understand what the client considers “normal” or routine, even if it goes against the personal beliefs of the clinician.

Hooley, L. (1997). Circumventing burnout in AIDS care. *The American Journal of Occupational Therapy*, 51, 759-766.

Abstract: Previous studies have determined that health care providers who specialize in AIDS care are particularly susceptible to work-related stress and resulting burnout. This qualitative study derived themes from interviews with three occupational therapists in order to examine these findings. Ultimately, stress and burnout were not dominant themes in the interviews.

Instead, the prominent themes were loss; death and dying; boundaries, connecting, and empathy; education; and coping strategies. An accepting attitude toward diversity coupled with the use of both individual and institutional stress management techniques modulated stress and prevented burnout among the study participants.

Though this article is specific to AIDS care, which involves care for patients whose illness has progressed past the often controlled nature of HIV status, emerging qualitative themes described here are relevant to occupational therapists working with HIV/AIDS patients at any stage of disease progression, as well as for therapists working with populations of any sort that are made up of individuals with difficult, serious, or long-term illnesses. This article describes beneficial coping strategies from the perspective of therapists who have been in specific difficult situations or have experienced burnout, allowing readers to gain knowledge from their experiences. Implementing their suggested strategies, even when working with the HIV/AIDS population over a brief period of time, is helpful in maintaining a professional, healthy mentality in order to deliver the best quality of care. This study represents a lower level of evidence, as it used phenomenological methods and qualitative approaches to obtain information from in-depth interviews.

Hughes, A. (2004). Symptom management in HIV-infected patients. *Journal of the Association of Nurses in AIDS Care*, 15, 7S-13S.

Abstract: Symptom management has always been a focus of nursing care. Assessing and managing symptoms is an important component of HIV nursing practice. When effective, interventions to relieve symptoms may improve quality of life (QoL), potentially increase adherence to highly active antiretroviral therapy, and improve other outcomes such as functional status. Common underrecognized and/or undertreated symptoms that may influence the QoL of persons living with HIV include fatigue, pain, anxiety/depression, and sleep disturbances. These symptoms may also contribute to the difficulty of adhering to HAART. When evaluating a patient's symptoms, the nurse attempts to understand the symptom experience from the patient's perspective because symptoms are subjective experiences. Together, the nurse and patient work to determine feasible interventions. Symptom management plans are evaluated frequently. Fundamentally, symptom management aims to decrease the frequency, intensity, and distress of symptoms, with the ultimate goal of improving QoL. Key words: symptoms, HIV, intervention, quality of life

According to this article, fatigue is the most common symptom associated with HIV, and healthcare providers do not always see treating it as a priority. Other symptoms, such as sleep disturbances, can occur as additional side effects to fatigue. Because lack of energy impacts all areas of a person's life, interventions related to decreasing fatigue and managing HIV/AIDS symptoms might improve participant vitality. To manage fatigue, assistive devices can be introduced to improve the ease with which occupations are completed, such as reachers, grabbers, sock-aids, and grab bars. Additionally, the home environment can be rearranged to conserve energy, and participants might make schedules of daily routines to help organize occupations and expend energy according to priority. All three of the capstone case study participants have severe to chronic fatigue, making this article particularly relevant to planning

and implementing occupational therapy services. This article represents a critical analysis, and not a quantitative study.

Kielhofner, G., & Barrett, L. (1998). Meaning and misunderstanding in occupational forms: A study of therapeutic goal setting. *The American Journal of Occupational Therapy*, 52, 345-353.

This article presents a case study that used MOHO as a base, as part of a larger program focused on developing and following through on individual client goals. Clients participated in weekly groups in which they engaged in goal setting. However, this article is specific to the results of OT with one woman named Barbara, and analyzes the potential reasons that the therapy did not result in the expected or intended results. By examining the relationship between meaning and misunderstanding, as well as how social processes and environments play into how clients use their occupational forms, the authors argue that clients themselves must make the effort to “get inside the worldview” of occupations and their respective forms, allowing them to create meaning and make way for volitional changes. “This work is substantial and does not always succeed,” often despite the best efforts of therapists. Overall, this article is an extremely beneficial analysis of why therapy is unpredictable, suggesting that when truly completing client-centered therapy, occupational therapists take the risk of not being able to facilitate progress. Even so, strong statements about volition, personal causation, habits, roles, and environment will still emerge.

Kielhofner, G. (2002). Motives, patterns, and performance of occupation: Basic concepts. In *Model of human occupation* (3rd ed.) (13-27). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter outlines the MOHO concepts of volition (including personal causation, values, and interests), habituation (including internalized roles), and performance capacity that embody what individuals do, and how they in turn experience such doing. According to MOHO, occupation can only be understood by taking into account each of these concepts, how they interact with each other, how they interact with the environment, and how they can be addressed during therapy through evaluation, goals, and interventions to help clients improve their quality of life.

Kielhofner, G. (2002). Dynamics of human occupation. In *Model of human occupation* (3rd ed.) (28-43). Philadelphia, PA: Lippincott, Williams, & Wilkins.

By examining a dynamic perspective on key MOHO ideas such as volition, habituation, and performance capacity, this chapter outlines how mechanistic views of human thinking are limited and promotes further understanding of dynamic thought in the formation human occupation. According to Kielhofner, dynamic ways of thinking, including the concepts of heterarchy and emergence, demonstrate how human beings are creatures of constant change. Occupational therapists, therefore, can help clients better understand the ever-changing nature of

their lives through further analysis of thoughts, feelings, and actions as well as how they are organized and maintained.

Kielhofner, G. (2002). Volition. In *Model of human occupation* (3rd ed.) (44-62). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter explains how an individual's sense of volition, including his or her sense of personal causation, values, and interests, are anticipated, interpreted, chosen, and experienced in ways that dictate how the individual interacts with his or her world. Volition also relates to self-efficacy and self-control, or one's sense of effectiveness in using personal abilities to achieve desired outcomes. Volition is also a process, during which individuals make choices and change according to their experiences. Occupational therapy focuses on increasing volition in clients to help them gain self-efficacy and improve their sense of identity, also improving occupational performance.

Kielhofner, G. (2002). Habituation: Patterns of daily occupation. In *Model of human occupation* (3rd ed.) (63-80). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter explains the patterns and routines that shape human occupation on a daily basis, and which go on to form habits and internalized roles. Kielhofner explains how habituation allows individuals to develop meaning and purpose by crafting their own sort of "territory" in everyday life, as well as the potential negative outcomes when habits and roles are disrupted by environmental change.

Kielhofner, G., Tham, K., Baz, T., & Hutson, J. (2002). Performance capacity and the lived body. In *Model of human occupation* (3rd ed.) (81-98). Philadelphia, PA: Lippincott, Williams, & Wilkins.

Overall, this chapter explains according to MOHO the connection that individuals often make between their physical bodies and occupational performances, as well as how they are helped or hindered by such physical capacity. Kielhofner also discusses how performance capacity is closely connected to habituation and volition, as would be the case for individuals with disabilities who might feel a sort of disconnect between performance capacity, sense of volition, and actual occupational performance. In general, performance capacity is defined as the ability for doing things via the interaction between the objective physical experience and the corresponding subjective experience, emphasizing how one's body is connected to one's mind.

Kielhofner, G. (2002). The environment and occupation. In *Model of human occupation* (3rd ed.) (99-113). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter outlines how an individual's environment is made up of his or her culture and social groups as well as his or her physical environment and the objects in this environment.

According to MOHO, the environment provides an environmental impact, or physical opportunities or restrictions to occupational performance, as well as occupational settings, which allow individuals to form a contextual meaning based on the physical spaces and people in the environment that promote occupational performance. Because occupational therapy often plays a key role in setting up “just right” environments for clients, it is crucial to understand the significant impact that environment can have on people, both positively and negatively, and how helping clients to change their environments can facilitate increased performance and better quality of life.

Kielhofner, G. (2002). Dimensions of doing. In *Model of human occupation* (3rd ed.) (114-123). Philadelphia, PA: Lippincott, Williams, & Wilkins.

In this chapter, MOHO concepts of occupational participation, occupational performance, and occupational skill are explained, listed from most broad to most specific. Through successful therapeutic and client-centered interventions, clients should grow to utilize communication and interaction skills, as well as motor and process skills, to achieve occupational adaptation by interacting with their environments. Based on the quality of these adaptations, clients should achieve a certain degree of occupational competence within their environments, as well as increase their occupational participation and gain skills, or goal-directed actions. Overall, these changes within clients add to their sense of occupational identity, or the composite sense of who a person is based on their personal history, their environment, and their patterns of occupational performances.

Kielhofner, G. (2002). Doing and becoming: Occupational change and development. In *Model of human occupation* (3rd ed.) (145-158). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter identifies how change occurs within clients, whether positive or negative, and how it impacts all aspects of clients' lives. Kielhofner describes normal, developmental changes, as well as incremental changes that occur more gradually and catastrophic changes that require entire reorganization of a person's life structure. This chapter explores how change affects every aspect of occupational identity, including volition, habituation, and performance capacity, and how stages of change are required as clients respond and adjust to change. For example, exploration occurs when clients seek out new preferences, values, and environments. As clients begin to adjust to change and solidify new patterns of doing, competency occurs.

Kielhofner, G., & Forsyth, K. (2002). Thinking with theory: A framework for therapeutic reasoning. In *Model of human occupation* (3rd ed.) (162-178). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter might benefit occupational therapists in that it serves as a reminder of the importance of clinical reasoning when utilizing MOHO with clients. It reminds therapists that they must engage in the phases of the therapeutic reasoning process, including gathering

information, having a comprehensive knowledge of strategies and information-gathering tools, and being able to apply these strategies successfully while collaborating with clients in a way that supports rapport and allows the most potential for client change. Especially with the HIV/AIDS population, being prepared and having the correct tools and strategies becomes most crucial when entering the sometimes disorganized and chaotic environments in clients' lives.

Kielhofner, G. (2002). Gathering client information. In *Model of human occupation* (3rd ed.) (179-190). Philadelphia, PA: Lippincott, Williams, & Wilkins.

In line with the previous chapter, Chapter 12 specifically emphasizes the potentially negative outcomes that might arise if therapists do not take adequate time to prepare and gather information relevant to their clients, as they risk doing harm during the therapeutic process. The chapter uses case examples to illustrate basic clinical principles, such as remembering time constraints, prioritizing questions, gathering client's past history information prior to first meeting to develop maximal understanding, and beginning with information-gathering at its broadest level while become more specific as additional trust is gained. As the HIV/AIDS population is often sensitive and concerned about confidentiality issues, these tips are excellent reminders for clinicians working with this population.

Kielhofner, G., Forsyth, K., Federico, J., Henry, A., Keponen, R., Oakley, F., & Woan Pan, A. (2002). Self-report assessments. In *Model of human occupation* (3rd ed.) (213-236). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter provides beneficial information related to the self-report assessments that are often paired with MOHO in practice, including the Occupational Self Assessment (OSA), which was used during the capstone case studies. By emphasizing how the OSA can be used to support client-therapist collaboration, this chapter offers good tips for clinicians about how the OSA should be introduced, as well as how it might be used to create the most useful and meaningful goals and therapy priorities with clients.

Kielhofner, G., & Forsyth, K. (2002). The process of change in therapy. In *Model of human occupation* (3rd ed.) (296-308). Philadelphia, PA: Lippincott, Williams, & Wilkins.

In this chapter Kielhofner provides significant statements about how clinicians should view the process of change as they assist clients in navigating the therapy process. For example, all occupational therapy targets some form of change, though only clients can accomplish their own change. The process of change is complex, requiring clients to make choices and decisions, commit themselves to undertaking goals and potential accomplishments, and explore new occupational forms in order to evoke change. Furthermore, clients must then begin to identify new information and alternatives for taking action, including new attitudes, feelings, and thoughts that come along with any changes. Clients might be required to negotiate with others to develop these new perspectives, create plans or agendas that will make change most possible for longer lasting results, and practice these plans and actions, usually with an occupational therapist

in an environment that promotes change. Finally, clients must re-examine their previous beliefs, attitudes, actions, feelings, habits, and roles, with the ultimate goal of being able to sustain the changes they have made to facilitate the best occupational performances.

Kielhofner, G., & Forsyth, K. (2002). Therapeutic strategies for enabling change. In *Model of human occupation* (3rd ed.) (309-324). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter, paired with the previous chapter, offers suggestions for occupational therapists when helping clients facilitate and sustain change. Kielhofner advises clinicians to advise clients by reminding them of goals and strategies, to coach them using instructions, prompting and guidance, to encourage them with emotional support and reassurance, to give feedback by sharing overall conceptualizations and observations regarding ongoing actions that clients might not be aware of, and finally to provide physical support, structure, and validation to clients by assisting them with problem-solving but not completing hands-on doing for them, conveying respect for the clients' experiences and perspectives.

Kielhofner, G., & Forsyth, K. (2002). Putting theory into practice. In *Model of human occupation* (3rd ed.) (325-345). Philadelphia, PA: Lippincott, Williams, & Wilkins.

This chapter is helpful for clinicians when they themselves are attempting to conceptualize MOHO terms and ideas, whether during clinical reasoning and analysis, documentation, or when explaining MOHO theories and ideas put into practice to clients, families, and/or co-workers. For occupational therapists who truly wish to exemplify MOHO correctly during interventions with clients and during their entire careers, this chapter offers excellent strategies for consistency as well as quality of use, allowing practitioners to implement MOHO to the best of their abilities.

Kielhofner, G., Bryze, K., Goldbaum, L., Last, D., Rey, D., & Rockwell-Dylla, L. (2002). Facilitating participation through community-based interventions. In *Model of human occupation* (3rd ed.) (404-428). Philadelphia, PA: Lippincott, Williams, & Wilkins.

Finally, this chapter uses four case examples with MOHO to illustrate the dynamic nature of community-based occupational therapy, and how MOHO might be used from the time of initial evaluation, through goal-setting and intervention, to the time of discharge to develop the highest potential for client change and to ensure the best client-centered practice. The HIV/AIDS capstone case studies are a clear example of community-based care, and this chapter offers advice to clinicians using four MOHO case examples that closely parallel the environments of work, play, home, school, community, and spaces of daily living that were encountered during the HIV/AIDS capstone case studies. Because of the fluctuating nature of community-based OT, circumstances are often unpredictable and present challenges to maintaining consistency. Any clinical examples, therefore, become valuable resources in learning how to provide the best OT to clients as possible.

Kielhofner, G., Braveman, B., Finlayson, M., Paul-Ward, A., Goldbaum, L., & Goldstein, K. (2004). Outcomes of a vocational program for persons with HIV/AIDS. *The American Journal of Occupational Therapy*, 58, 64-72.

Abstract: Advances in medical treatment combined with changes in the demographics of persons who are becoming infected with autoimmune deficiency syndrome (AIDS) have transformed this illness from a rapidly progressing to a chronically disabling condition in a short period of time. This paper describes the development, implementation, and outcomes of a program of vocational services for persons with AIDS. This program was studied using a single group design, in which participatory action research strategies were used to investigate and improve the program as it unfolded. In addition to examining the overall outcomes of services, the study aimed to discover which components were most helpful to participants and which participants were most likely to benefit from the program. Of 129 participants of who initially enrolled, 39 dropped out before finishing the program. Sixty of the 90 participants who completed the program achieved employment, returned to school, or began a volunteer position or internship. Consequently, the overall success rate was 46.5% and the success rate for program completers was 66.7%. The occupational narrative, which participants told in their initial assessment interview, was closely associated with both program completion and successful outcomes. This association adds support to the importance of narrative for understanding participants and predicting future behavior, as well as for the therapy process.

Specific to vocational needs, this article offers implications for occupational therapy and individuals with HIV/AIDS who wish to maintain or obtain employment as part of life roles, an area of particular challenge and meaning to this population. Commonly identified challenges in relation to working include the impact of health status on working, concerns about coping, absence of a functional routine, role disruption, lack of social support and peer networking, and limited communication skills. Evidence suggests that with compliance to vocational programs, occupational therapy can play a definite role in assisting individuals with HIV/AIDS with succeeding in the workplace. This study represents evidence level IV, or a single group design.

Kielhofner, G., Braveman, B., Fogg, L., & Levin, M. (2008). A controlled study of services to enhance productive participation among people with HIV/AIDS. *The American Journal of Occupational Therapy*, 62, 36-45.

Abstract: **OBJECTIVE.** This study assessed the effectiveness of a model program designed to increase productive participation among people living with HIV/AIDS within supportive-living facilities. **METHODS.** Using a nonrandomized, two-group design, 65 study participants were assigned to either the model program or standard care. Data on productive participation were collected at 3, 6, and 9 months after completion of the model or standard program. Outcomes were compared at each time point. **RESULTS.** Forty-six participants completed the study. Participants in the two programs did not differ significantly on baseline demographic variables. Model program participants showed significantly higher levels of productive participation at all three time points ($p < .05$). Odds ratios were all > 3 , reflecting that participants attending the

model program were at least twice as likely to be productively engaged at all three time points. CONCLUSION. Results support the effectiveness of the model program in achieving sustained productive participation in persons living with HIV/AIDS.

This study provides a specific model of a program designed to improve productivity with community participation in individuals with HIV/AIDS, when compared with only standard care services. Results support methods of using MOHO with individuals with HIV/AIDS to enhance occupational performance, volition, and habituation, and to reduce environmental barriers. This study represents evidence level II, or a non-randomized two-group design.

Kielhofner, G. (2009). *Conceptual foundations of occupational therapy practice* (4th ed.). Philadelphia: FA Davis Company.

Chapter 11 of Kielhofner's book on various models of practice specifically outlines his Model of Human Occupation, the model of practice being used for the capstone case studies, providing a basic review of the underlying theories, ideas, and guidelines of this model that assist occupational therapists in evaluating, providing interventions to, and ultimately discharging their clients. Kielhofner discusses main ideas such as volition, personal causation, values, interests, habituation, roles, performance capacity, the environment, and occupational participation, performance, identity, competence, and adaptation. He also touches on the process of therapeutic reasoning, involving generating questions, utilizing information, making observations, and implementing and monitoring therapy in a collaborative way. The chapter also provides a brief overview of the MOHO assessments and what they are designed to screen, as well as various case examples with clients participating in therapy. This chapter serves as a good foundation for a review of MOHO, to be supplemented by a larger textbook about MOHO also included in this annotated bibliography.

Landsburg, A. (Producer), & Herzfeld, J. (Director). (1989). *The Ryan White story* [Motion picture]. United States: The Landsburg Company.

This movie depicts the story of Ryan White, a young boy with hemophilia who contracted HIV during a tainted blood transfusion. Diagnosed with HIV/AIDS in 1984, at a time when the disease was very misunderstood and little was known about modes of transmission, Ryan White was ostracized from attending public school in his town of Kokomo, Indiana, forcing he and his family to seek legal action. Though he later died at the age of 18, the story of his life serves as one of the first examples of HIV/AIDS in the public eye, as well as the sociology and strong negative stigmas surrounding the disease at the time. Today, federal funding is provided to Ryan White clinics around the country, allowing free or discounted care to those with HIV/AIDS in local communities.

Lee, S. W., Taylor, R., Kielhofner, G., & Fisher, G. (2008). Theory use in practice: A national survey of therapists who use the model of human occupation. *The American Journal of Occupational Therapy*, 62, 106-117.

Abstract: OBJECTIVE. This study describes how occupational therapists who reported using the Model of Human Occupation (MOHO) actually use the concepts and tools of this model in everyday practice as well as identifies supports and barriers to its use.

METHOD. A systematic random sample of 1,000 occupational therapists was surveyed as to what theories they used in their practice. Those using MOHO (430) were sent a detailed questionnaire; 259 therapists (60.2%) responded to the survey questionnaire.

RESULTS. More than 80% of respondents indicated that they used MOHO in their practice at least some of the time. Therapists reported that MOHO supports holistic, occupation-focused, client-centered, and evidence-based practice. They reported finding MOHO concepts useful for treatment planning and intervention. Most saw the major barrier to using MOHO as their own lack of knowledge.

CONCLUSION. Making resources more readily available and accessible to therapists might enhance the extent to which they use conceptual models such as MOHO.

This study sought to determine if therapists differ in their understanding and use of MOHO by experience, education, client population and practice setting, how occupational therapists characterize their understanding and perception of the usefulness of MOHO concepts, how therapists report using MOHO tools in practice, and what therapists report as beneficial and/or challenging with using MOHO. Results indicated that therapists, in general, either somewhat or clearly understood the four main MOHO concepts (volition, habituation, performance capacity, environment), but did not consistently or correctly utilize MOHO assessments in practice. More than half (over 52%) reported using MOHO concepts or ideas to better understand interactions with clients, and over 88% reported that MOHO provides a strong base for generating treatment goals. Overall, challenges and barriers included insufficient knowledge of MOHO, and lack of resources. This study provides a good foundation for determining areas to improve upon when seeking to use MOHO correctly and consistently, as well as validates the use of MOHO as an objective and effective model of practice with clients. A significant limitation of this study, however, is that therapists surveyed were all members of AOTA, and might not accurately represent the entire population of therapists within the field of OT.

Lerdel, A., Gay, C. L., Aouizerat, B. E., Portillo, C. J., & Lee, K. A. (2011). Patterns of morning and evening fatigue among adults with HIV/AIDS. *Journal of Clinical Nursing*, 20, 2204-2216.

Abstract: Aims and objectives. Describe patterns of morning and evening fatigue in adults with HIV and examine their relationship to demographic and clinical factors and other symptoms. Background. Most studies of HIV-related fatigue assess average levels of fatigue and do not address its diurnal fluctuations. Patterns of fatigue over the course of the day may have important implications for assessment and treatment. Design. A cross-sectional, correlational design was used with six repeated measures over 72 hours. Method. A convenience sample of 318 HIV-infected adults was recruited in San Francisco. Socio-demographic, clinical and symptom data were collected with questionnaires. CD4+ T-cell count and viral load were obtained from medical records. Participants completed a four-item version of the Lee Fatigue Scale each

morning and evening for three consecutive days. Participants were grouped based on their diurnal pattern of fatigue (high evening only, high morning only, high morning and evening and low morning and evening). Group comparisons and logistic regression were used to determine the unique predictors of each fatigue pattern. Results. The high evening fatigue pattern was associated with anxiety and the high morning pattern was associated with anxiety and depression. The morning fatigue pattern showed very little fluctuation between morning and evening, the evening pattern showed the largest fluctuation. The high morning and evening pattern was associated with anxiety, depression and sleep disturbance and this group reported the most fatigue-related distress and interference in functioning. Conclusions. These results provide initial evidence for the importance of assessing the patient's daily pattern of fatigue fluctuation, as different patterns were associated with different symptom experiences and perhaps different etiologies. Relevance to clinical practice. Different fatigue patterns may benefit from tailored intervention strategies. Management of depressive symptoms could be tested in patients who experience high levels of morning fatigue.

As all of the capstone case study participants had moderate to severe fatigue that impeded their occupational performances during daily life, this article is very relevant to guiding goal setting and interventions. Additionally, because many individuals with HIV/AIDS suffer from fatigue, it is crucial to separate their types of fatigue, as this article demonstrates, based on the time of day and/or circumstances during which the fatigue is the worst and most affects occupations. For one of the capstone case study participants in particular, an energy conservation schedule was created that focused on differentiating between fatigue levels in the morning versus at night. This individual in particular, who also had depression, might have been placed into the high morning and high evening category within this study, also associated with the highest distress. Overall, this article illustrates the importance of tailoring occupations for fatigue to the needs of individual clients, resulting in most efficient occupational performance and independent functioning. This study utilized a cross-sectional, correlational design with six repeated measures over 72 hours to obtain data through fatigue scales.

Levin, M., Kielhofner, G., Braveman, B., & Fogg, L. (2007). Narrative slope as a predictor of work and other occupational participation. *Scandinavian Journal of Occupational Therapy*, 14, 258-264.

Abstract: This study aims to determine the utility of the narrative slope in predicting the vocational/productive outcomes of participants. For 65 participants living in supportive facilities for adults with HIV/AIDS in the United States, narrative slopes, based on the Occupational Performance History Interview II, were constructed and classified as progressive, stable, or regressive. Information regarding participants' productive activities was collected at discharge from intervention programming, and at 3-month intervals, up to 9 months. Data were analyzed to examine the relationship between narrative slope and engagement in employment and other productive activity post-intervention. Demographic variables were also analyzed. None of the demographic factors significantly correlated to outcomes. It was found that a more positive narrative slope was predictive of a higher likelihood of being employed or engaged in other productive activity.

In MOHO, narrative slope is a visual representation of a client's volitional narrative, as determined by a MOHO assessment (the OPHI-II) when a person's major life events are plotted on a timeline, placing them above or below a neutral line to indicate the extent that they are perceived as "bad" or "good" points in time. Results of this qualitative predictive study were obtained through interviews with MOHO-trained occupational therapists, with follow-up at three, six, and nine months post-intervention. Results of the study demonstrate that a positive narrative slope was correlated with a higher likelihood of being employed or otherwise productive in the community, suggesting that the personal narrative and how clients perceive life events, environments, and changes are more relevant than personal traits in predicting productivity. This study was completed with individuals with HIV/AIDS, and can therefore be applied by therapists who might administer the OPHI-II to clients in this population when attempting to understand how they form meaning.

Levine, R. E. (1984). The cultural aspects of home care delivery. *The American Journal of Occupational Therapy*, 38, 734-738.

Abstract: This paper uses a patient example to demonstrate the pervasive influence of culture on an individual's values, goals, interests, roles, habits, and performance. Culture is filter through which patients determine the direction and degree of their involvement in self-care, work, and leisure activities. Every occupational therapist intervention depends on an exchange of values. The constraints of home care practice accentuate the therapist's need to create a therapeutic environment that is understood and valued immediately. As a guest in the patient's home, the home care occupational therapist must quickly incorporate the patient's needs into the therapeutic program.

Though not specific to HIV/AIDS, this article offers suggestions for therapists when considering culture and client factors in delivering therapy services. The article outlines parts of home healthcare that are different than other therapy settings, including: "a) participating in a working team that is frequently led by a nurse; b) working independently without day-to-day supervision; c) delivering services in a home environment; d) working with minimal supplies and equipment; e) making decisions that must be consistent with the patient's and caretaker's value systems; f) changing one's therapeutic milieu with every patient; g) offering uninterrupted one-to-one therapy to the patient and the caretaker; h) interacting with the patient's social groups; and i) using documentation to justify retroactive payment for services." The author relates culture to MOHO as well, indicating that culture shapes values, which in turn affect a client's volition, participation in OT, and development of rapport with the occupational therapist. This article is valuable in developing methods of observing and analyzing cultural effects on clients, as well as integrating them with MOHO goals and interventions. This article represents a critical analysis, and not a quantitative study.

McArthur, J. C. (2004). HIV dementia: An evolving disease. *Journal of Neuroimmunology*, 157, 3-10.

Abstract: Several advances have led to improvements in the care and prognosis of HIV+

individuals. The first is an understanding of the direct relationship between HIV replication and subsequent immunological and clinical progression, reinforcing the need to completely suppress HIV replication to control disease progression. The second is the wider availability of HAART, which can provide effective suppression of HIV. The third major change is the ability to monitor HAART through the reliable and widespread measurement of plasma HIV RNA levels, which has become a routine part of clinical care. Since the introduction of highly active antiretroviral therapy (HAART) in the 1990s, there have been significant declines in the incidence rates of opportunistic infections in developed countries. HAART has clearly improved survival for individuals with HIV/AIDS, and has reduced the incidence of HIV-associated dementia (HIV-D) by 40–50% (Brodt et al., 1997; Sacktor et al., 2001a,b). The prevalence of sensory neuropathies in advanced HIV/AIDS now exceeds 20% (Schifitto et al., 2002), and may rise further with prolonged exposure to neurotoxic HAART. HIV-D and HIV-related sensory neuropathies (HIV-SN) have a combined prevalence of about 30–50% in advanced HIV disease, suggesting that HAART does not provide complete protection against neurological damage (Bouwman et al., 1998). HIV-associated dementia (HIV-D) remains a common cause of dementia worldwide, and with HIV-related sensory neuropathies (HIV-SN) represents the commonest neurological disorders associated with AIDS. Furthermore, the temporal progression of HIV-D appears to have been altered by HAART, with most patients now showing an attenuated form of dementia, which with treatment is slowly progressive or static (Dougherty et al., 2002). This overview will review some of the outstanding questions relating to HIV-dementia, including: (a) are there differing phenotypes or temporal patterns of progression in HIV-dementia? (b) what determines these temporal patterns? and (c), what has been the impact of therapy on HIV dementia?

This article provides an overview of the neurological implications caused by HIV, and more specifically by HAART (Highly Active Anti-retroviral Therapy) provided as treatment to patients with HIV/AIDS. Outlining the rates and changing trends of the most prevalent deficits—sensory neuropathies and HIV-related dementia—review of the literature reveals that HAART does not provide complete protection against neurological damage. Though there are many different kinds of medications prescribed as part of HAART, it is important for occupational therapists working with patients to understand the overall effects that medications have on the physical body as well as psychosocially in order to best arrange adequate care. Furthermore, because sensory neuropathies and dementia are both issues that OT addresses, it is crucial to promote understanding of their possible origins within the HIV/AIDS population. This article represents a literature review, and is not a randomized controlled trial.

McGuire, M. J. (1997). Documenting progress in home care. *The American Journal of Occupational Therapy*, 51, 436-445.

Abstract: The home is an ideal environment for the practice of occupational therapy. However the tumultuous health care environment of the Late 1990s requires practitioners to take special care not only in delivering effective services, but also in documenting the delivery of skilled care. Documentation is the bridge between the delivery of occupational therapy services in the home and the approval for reimbursement of services by third-party payers. This article presents principles for writing reimbursable progress notes for home care that are based on Medicare documents related to occupational therapy. Application of these principles can improve

efficiency and excellence in practitioners' documentation skills.

Though this article contains suggestions for therapists regarding documentation in home health care mainly to comply with standards that promote reimbursement, it also contains beneficial information that is relevant to the ideal method, according to the author, of how home health documentation should be completed. Though the capstone case studies were not eligible for reimbursement, consistent and objective documentation was still crucial in being able to analyze and report progress of clients in a manner that could be understandable to all those within the field of occupational therapy. This article, though published in 1997, is still applicable today, and includes examples of both effective and ineffective progress notes from home health care. This article represents a critical analysis, and not a quantitative study.

Mello, V. A., Segurado, A. A., & Malbergier, A. (2010). Depression in women living with HIV: Clinical and psychosocial correlates. *Archives of Women's Mental Health*, 13, 193-199.

Abstract: The number of Brazilian women living with HIV has increased significantly in past years, rendering studies of their particular care demands including psychiatric issues. This study measures the prevalence of major depression, using the Structured Clinical Interview for DSM-IV Axis I Disorders, in a sample of 120 women living with HIV in treatment at a reference centre in São Paulo. Socio-demographic variables, HIV-related clinical and laboratory data, including CD4+ cell counts and HIV plasma viral loads, as well as psychosocial features (intimate relationships, disclosure of HIV serostatus, partner's serostatus and patient's emotional and financial support) were investigated as factors potentially associated with depression. The prevalence of major depression at the time of evaluation was 25.8% (95% CI 18.2–33.4%). Clinical status ($p = 0.002$), lack of emotional support ($p = 0.02$), use of antidepressants ($p = 0.028$) and length of time since HIV diagnosis ($p = 0.05$) were associated with major depression in univariate analysis. In multivariate multiple- regression model, HIV clinical status, lack of emotional support and higher plasma viral loads were associated with depression. Sixty per cent of the women have a major depression diagnosis during lifetime. We conclude that major depression is highly prevalent among women living with HIV, but it is still underdiagnosed and undertreated.

Corroborating prior studies about depression incidence in the HIV population, this study is specific to rates of depression in women. Though results of this study match most data from other studies in revealing that depression rates are elevated among the HIV/AIDS population, as well as that depression rates are patterned with life stressors for individuals with HIV/AIDS, this study expands upon other data forms, providing information about trends revealing how women with HIV specifically handle these stressors. Interestingly, for example, in women who were depressed before learning of their HIV diagnosis, only 22.4% had a major depressive episode prior to learning about their HIV status. Though this study was not completed in the United States, results might be generalized to women in the U.S., providing insight to therapists working with women with both HIV/AIDS and depression. This study represents a lower level of research, as it obtained data through a survey implemented through 45 to 60 minute face-to-face interviews. Limitations include a small sample size, and potential interference of temporal associations between study variables.

Millett, G. A., Crowley, J. S., Koh, H., Valdiserri, R. O., Frieden, T., Dieffenbach, C. W., . . . & Fauci, A. S. (2010). A way forward: The national HIV/AIDS strategy and reducing HIV incidence in the United States. *Journal of Acquired Immune Deficiency Syndromes*, 55, S144-47.

Abstract: In July 2010, the Obama Administration released a National HIV/AIDS Strategy for the United States to refocus national attention on responding to the domestic HIV epidemic. The goals of the strategy are to reduce HIV incidence; to increase access to care and optimize health outcomes among people living with HIV; and to reduce HIV-related disparities. The strategy identifies a small number of action steps that will align efforts across federal, state, local, and tribal levels of government, and maximally impact the domestic HIV epidemic. In this article, we outline key programmatic and research issues that must be addressed to accomplish the prevention goals of the National HIV/AIDS Strategy.

In order to better provide quality therapy to individuals with HIV/AIDS, it is important to comprehend the underlying legal and political issues that drive access to healthcare, including financial assistance programs, disclosure laws, state medication programs, and available federal grants. Because a significant part of occupational therapy for this population is helping with developing a routine, assisting with general organization, and encouraging better and more consistent navigation of the healthcare system, it is crucial for therapists to understand current laws, programs, and expected outcomes surrounding access and barriers to the healthcare system.

Milloy, M. J., Marshall, B., Kerr, T., Buxton, J., Rhodes, T., Montaner, J., & Wood, E. (2012). Social and structural factors associated with HIV disease progression among illicit drug users: A systematic review. *AIDS*, 00, 1-14.

This article is a systematic review of 2,668 studies, of which 58 met inclusion criteria and were part of the analysis. Aiming to identify factors associated with how HIV/AIDS progresses among illicit drug users, results indicate, perhaps as expected, that environmental influences play a significant role in relation of drug use and HIV/AIDS exacerbation. Literature suggests that in addition to HIV status potentially being caused by drug use, characteristics of drug users as well as their environments tend to promote both continued drug use and HIV/AIDS progression over time. Future research is needed to explore the various significant social, physical, economic, and policy-level exposures that this study identified in the literature that promote drug use and HIV/AIDS progression. This article represents a meta-analysis of peer-reviewed English language studies.

Murphy, N., Messina, W., Getter, E., Gutterman, L., Martin, T., Rincon, P., et al. (1999). The village AIDS day treatment program: A model of interdisciplinary and interdependent care. *The American Journal of Occupational Therapy*, 53, 561-565.

Abstract: This article describes the Village AIDS Day Treatment Program, a program for people

living with HIV/AIDS that provides health care by using a full range of interdependent services. Opened in 1988, this program was the first of its kind in the country. It has provided leadership in developing a model of care that addresses the full spectrum of health care—promotion, prevention, maintenance, and treatment. Along with describing the program and its services, this article includes the program's history and its influencing philosophies.

This article illustrates the advantages of interdisciplinary services provided during an AIDS treatment program, including rehabilitation services, social services and substance abuse counseling, recreational and art therapies, psychiatry and counseling, and nutrition services. This program's example can be transferred to other programs or forms of OT services for this population, reminding practitioners of the importance of health promotion, prevention, maintenance and treatment across all disciplines. This study represents evidence level IV, a single subject design.

Nevins, S. (Producer), & Kennedy, R. (Director). (2003). *Pandemic: Facing AIDS* [Motion picture]. United States: HBO.

This documentary provides a worldly view on HIV/AIDS, including footage from over 50 countries to demonstrate the personal nature of the effects of the disease around the world. This film provides an interesting statement related to the similarities and differences of how individuals cope with diagnosis around the world, as well as how society views these individuals. This film is a most humanizing look at HIV/AIDS, allowing viewers to truly empathize with patients of all ages, ethnicities, and cultural backgrounds.

Nicholas, P. K., Kemppainen, J. K., Canaval, G. E., Corliss, I. B., Sefcik, E. F., Nokes, K. M., . . . Gallagher, D. M. (2007). Symptom management and self-care for peripheral neuropathy in HIV/AIDS. *AIDS Care*, 19, 179-189.

Abstract: As part of a larger randomized controlled trial examining the efficacy of an HIV/AIDS symptom management manual (n = 775), this study examined the prevalence of peripheral neuropathy in HIV-infected individuals at 12 sites in the USA, Puerto Rico, and Africa. Neuropathy was reported by 44% of the sample; however, only 29.4% reported initiating self-care behaviors to address the neuropathy symptoms. Antiretroviral therapy was found to increase the frequency of neuropathy symptoms, with an increased mean intensity of 28%. A principal axis factor analysis with Promax rotation was used to assess the relationships in the frequency of use of the 18 self-care activities for neuropathy, revealing three distinct factors: (i) an interactive self-care factor; (ii) a complementary medicine factor; and (iii) a third factor consisting of the negative health items of smoking, alcohol, and street drugs. The study's results suggest that peripheral neuropathy is a common symptom and the presence of neuropathy is associated with self-care behaviors to ameliorate HIV symptoms. The implications for nursing practice include the assessment and evaluation of nursing interventions related to management strategies for neuropathy.

This article demonstrates the need for occupational therapy to focus on ODLs with the

HIV/AIDS population, specifically in regard to management of neuropathy symptoms related to the disease and during daily occupations. For example, only 14.6% of participants in the study reported initiating self-care behaviors to combat their neuropathy symptoms, indicating a high need for external services to facilitate personal causation over healthcare needs and related deficits. Results were similar for those individuals taking ART and those not taking ART, in that both experienced high levels of neuropathy that affected their daily lives and independence. The article also offers intervention and educational ideas for OT, including strategies that worked to relieve symptoms for individuals in the study, such as: taking a hot bath, resting, elevating the feet, walking, using analgesics and anti-epileptic agents, taking vitamin B and/or calcium supplements, massage, acupuncture, and meditation. This article represents one of the few randomized, controlled trials present in the HIV/AIDS literature, though this particular article is only one part of a larger randomized controlled trial.

Nicholas, P. K., Voss, J., Wantland, D., Lindgren, T., Huang, E., Holzemer, W. L., . . . Bain, C. A. (2010). Prevalence, self-care behaviors, and self-care activities for peripheral neuropathy symptoms of HIV/AIDS. *Nursing and Health Sciences*, 12, 119-126

Abstract: Peripheral neuropathy is the most common neurological complication in HIV and is often associated with antiretroviral therapy. As part of a larger study on self-care for symptoms in HIV disease, this study analyzed the prevalence and characteristics of peripheral neuropathy in HIV disease, sociodemographic and disease-related correlates and self-care strategies. A convenience sample of 1,217 respondents was recruited from data collection sites in several US cities, Puerto Rico, Colombia and Taiwan. Results of the study indicated that respondents with peripheral neuropathy (n = 450) identified 20 self-care behaviors including complementary therapies, use of medications, exercise and rest and/or elevation of extremities. Ratings of frequency and effectiveness were also included. An activities checklist summarized into five categories of self-care behaviors including activities/thoughts, exercise, medications, complementary therapies and substance was used to determine self-care behaviors. Taking a hot bath was the most frequent strategy used by those with peripheral neuropathy (n = 292) and received the highest overall rating of effectiveness of any self-management strategies included in this study at 8.1 (scale 1-10). Other self-care strategies to manage this symptom included: staying off the feet (n = 258), rubbing the feet with cream (n = 177), elevating the feet (n = 236), walking (n = 262), prescribed anti-epileptic agent (n = 80), prescribed analgesics (n = 84), over-the-counter medications (n = 123), vitamin B (n = 122), calcium supplements (n = 72), magnesium (n = 48), massage (n = 156), acupuncture (n = 43), reflexology (n = 23) and meditation (n = 80). Several behaviors that are often deemed unhealthy were included among the strategies reported to alleviate peripheral neuropathy including use of marijuana (n = 67), cigarette smoking (n = 139), drinking alcohol (n = 81) and street drugs (n = 30).

Expanding on some aspects of the previously annotated article, this article breaks down potential neuropathy intervention strategies by frequency of use by patients, as well as by a rating of perceived effectiveness on a scale of 1 to 10. Previously listed intervention strategies are included, as well as patterns of substance abuse coping strategies (e.g. use of alcohol, cigarettes, marijuana, and street drugs) and additional medication/nutritional interventions not included in the last study. Overall, all strategies were rated within the range of 5.87 to 7.53, with

the exception of substance abuse strategies, which were rated within the range of 4.60 to 5.04. Techniques were also stratified by race/ethnicity and gender, demonstrating patterns in coping and self-care among different demographics. Drug use as a coping strategy for neuropathy was lowest among Asians, and highest among African Americans. Frequency and effectiveness of all interventions was also compared and contrasted among four other countries in addition to the United States, allowing this study and its recommended interventions to take on a more global perspective. This descriptive, cross-sectional study was again part of a larger ongoing study.

Ohio Department of Health HIV/AIDS Surveillance Program. (2010). *Summary of HIV infection among blacks in Ohio* [Graph illustrations]. Retrieved from http://www.odh.ohio.gov/healthStats/disease/hivdata/hiv_hl.aspx

These statistics from the state of Ohio illustrate the clear disparity among African Americans versus other ethnicities related to the incidence of HIV/AIDS. For example, only 12% of Ohio's population is African American, yet 47% of Ohio HIV/AIDS diagnoses are of African Americans. When providing occupational therapy to individuals within the African American community who are HIV positive, it is important to understand the prevalence of the disease among this ethnicity in order to better understand how to recommend interventions related to prevention of transmission and general health promotion.

Ohio Department of Health HIV/AIDS Surveillance Program. (2010). *Summary of HIV infection among women and girls in Ohio* [Graph illustrations]. Retrieved from http://www.odh.ohio.gov/healthStats/disease/hivdata/hiv_hl.aspx

Similar to the disparity that exists within the African American population, the HIV/AIDS rate among women and girls continues to grow. These Ohio Health Department statistics illustrate a greater trend that has occurred in recent years nationwide. For example, from 2004 to 2008, the incidence of HIV/AIDS increased among females aged 45 and older by 45%, among females aged 25 to 44 by 24%, and among females aged 13 to 24 by 18%. It is important for occupational therapists to understand how HIV/AIDS affects women differently than men, especially when dealing with prevention education. As 47% of infections in women and girls occur from heterosexual contact with an HIV positive male, women should be encouraged to understand health prevention as part of occupations of daily living and sexuality.

Opacich, K. J. (2008). Human immunodeficiency virus. In M. V. Radomski & C. A. T. Latham (Eds.), *Occupational Therapy for Physical Dysfunction* (6th ed., 1345-57). Baltimore, MD: Lippincott Williams & Wilkins.

This brief chapter provides good background information on the epidemiology of HIV/AIDS in the United States, the mechanism of the disease, its symptoms, common medical interventions, and disease prognosis. Because this chapter was written within an occupational therapy text, it provides additional information related to occupational therapy's role with this disease in addition to with special populations, such as women, individuals who abuse drugs and

alcohol, and gay men, while also examining the sociopolitical context of the disease and the neurobiological and psychosocial changes that often affect occupations. The chapter also provides basic guidelines for practitioners about how to preserve, restore, and facilitate adaptation related to meaningful doing through occupation, and is a great example of a general overview of the role of OT in the field of HIV/AIDS care.

O'Rourke, G. C. (1990). The HIV-positive intravenous drug abuser. *The American Journal of Occupational Therapy*, 44, 280-283.

Because very few case studies exist with individuals with HIV/AIDS participating in occupational therapy services, this article provides a good example of how to establish and implement a meaningful, holistic, individualized case study with this population. The article provides detailed suggestions for evaluation, assessment, treatment, and discharge, including how to consider all aspects of the individual when formulating goals.

Parks, R. A., Oakley, F., & Fonseca, M. (1998). Play development in children with HIV-infection: A pilot study. *The American Journal of Occupational Therapy*, 52, 672-675.

Researchers in this study administered the Revised Play History Interview to caregivers of children infected with HIV during routine play visits, with results indicating that overall, children with HIV did not achieve the same developmental milestones as their peers and attempted to compensate during play for their physical deficits. Some were unable to relate to their peers during play due to prior insufficient opportunities for play with others. Because many individuals with HIV/AIDS have children, it is crucial for occupational therapists to understand how HIV infection affects children and young adults. Even though many individuals with HIV/AIDS have healthy children who are HIV negative, it is still important to emphasize education related to prevention of transmission during care giving. This study represents a lower level of evidence, in that it obtained data through qualitative semi-structured assessments of a convenience sample.

Parruti, G., Manzoli, L., Giansante, A., D'Eramo, C., Re, V., Graziani, R. V., & D'Amico, G. (2007). Occupational therapy for advanced HIV patients at a home care facility: a pilot study. *AIDS Care*, 19, 467-470.

Abstract: Occupational therapy holds promise to increase quality of life and social functioning in patients with HIV infection. Since 2000 through 2005, we experimented a complex structured intervention including directly administered HAART, psychiatric support and occupational therapy for 14 patients with advanced HIV infection and multiple disabilities, cared for at an Italian home care facility. Social and occupational abilities were evaluated using the Axis V of DMS-IV, as assessed by the Global Assessment of Functioning Scale. Patients' abilities in coping with stressful situations were examined using the Social Dysfunction Rating Scale. Both outcomes were evaluated in interviews at study entrance and yearly thereafter. As compared to baseline, social function mean score significantly increased by 42% after one year of follow-up,

and social stress mean score was significantly reduced by 11%. Both outcomes continued to improve constantly during the entire follow-up. Acceptance of the intervention was high, and three patients got outdoor job positions. The findings from this pilot study suggest that occupational therapy could be integrated with success in the treatment of severely disabled patients with advanced HIV infection. Confirmation from further research is required.

This Italian study provides a great example of the positive outcomes that OT can create in individuals with HIV/AIDS, as results of this study showed participant improvement throughout the duration of the interventions, and results were maintained at one-year follow-up. Specific improvements of participants included increased social function and reduced social stress. This article also demonstrates the benefit of utilizing a team approach to providing OT, as individuals in the study participated in psychiatric support and medical/pharmacological interventions as well as occupational therapy. Because few studies have been completed regarding the effects of OT on occupational performance outside of the realm of OT for vocational needs and work, this study is a much-needed example in the literature of how OT can impact the HIV/AIDS population. This study represents level IV of evidence, or a single subject design.

Paul-Ward, A., Kielhofner, G., Braveman, B., & Levin, M. (2005). Resident and staff perceptions of barriers to independence and employment in supportive living settings for persons with AIDS. *The American Journal of Occupational Therapy*, 59, 540-545.

Abstract: The purpose of this study was to identify perceived barriers to independent community living and employment among clients and staff members in a transitional living facility for persons with AIDS. This qualitative study used focus groups to collect these perceptions from staff members (N = 21) and clients (N = 16). Whereas staff identified both systemic and personal barriers, clients only identified systemic barriers. These findings suggest that both clients and staff recognize the types of environmental barriers to participation that have been identified by disability scholars. The findings also underscore a consequential gap between clients' exclusive emphasis on environmental barriers and staff emphasis on clients' personal barriers that impact upon participation.

This article explores research that identifies environmental barriers to participation encountered by individuals with HIV/AIDS, suggesting that theoretical models centered on disability studies and/or rehabilitation, such as the Model of Human Occupation, can provide solutions to overcoming such barriers. Barriers explored include those related to employment and independent living, occurring at both the systemic and personal levels. This study represents qualitative research with focus groups.

Phillips, I. (2002). Occupational therapy students explore an area for future practice in HIV/AIDS community wellness. *AIDS Patient Care and STDs*, 16, 147-149.

Abstract: Participating in community wellness projects is one way occupational therapy students at Winston-Salem State University (WSSU), Occupational Therapy Program in North Carolina are learning to expand occupational therapy into the community. In a fieldwork

experience, 13 juniors are assigned to a community HIV/AIDS project to increase community awareness and prevention of the spread of HIV/AIDS. The project is implemented in conjunction with HOPE (HIV Outreach Programs and Education), STEP ONE, and the Samaritan Ministries. The students' efforts culminate in an HIV/AIDS Rally. Student learning is grouped into categories of planning, implementation, and follow up. This experience resulted in students working as volunteers for HOPE; students collaborating together on a research project to determine the extent University students understand how to prevent the spread of HIV; and students considering a WSSU campus-based HIV/AIDS awareness activity during October 2001 AIDS Awareness Month.

Though HIV/AIDS community-based care is not a common area of practice in occupational therapy, caring for this population is definitely within occupational therapy scope of practice. This article outlines the Level I fieldwork experience of occupational therapy students and implications for the field, offering a new perspective about the potential for occupational therapy to impact this population. This article represents information presented in narrative form.

Pizzi, M. (1990). The model of human occupation and adults with HIV infection and AIDS. *The American Journal of Occupational Therapy*, 44, 257-264.

Abstract: HIV infection affects all aspects of a person's occupational functioning. This article examines the application of the Model of Human Occupation (Kielhofner & Burke, 1980) to adults with HIV. An occupational therapy assessment battery based on the model is introduced. Given the physical, psychosocial, and environmental needs of persons with HIV, the assessment must be comprehensive to fully evaluate the effect of HIV on occupational behaviors. Goal planning and treatment follow the assessment process. A case example illustrates the integration of the Model of Human Occupation with clinical practice.

Because the course of HIV/AIDS changes with time and progression of the disease, plans of care need to be adjusted according to the changing needs of individual clients. In this article, the Model of Human Occupation is used as a basis to assess changes in goals, interventions, and outcomes, including an example of this process utilized with a specific client, and the use of relevant, helpful assessments such as the Role Checklist Summary Sheet. This article represents information presented in narrative form.

Pizzi, M. (1990). The transformation of HIV infection and AIDS in occupational therapy: Beginning the conversation. *The American Journal of Occupational Therapy*, 44, 199-203.

This article was published in 1990 by a leader of HIV/AIDS advocacy within the field of OT, who sought to reduce the fear and stigma surrounding the disease at the time. Seeking to "begin the conversation" regarding the way HIV/AIDS was perceived, this article is a thoughtful and hopeful account of one individual's perspective on what occupational therapy's role could and should be for this population. Pizzi writes, "Occupational therapy can become the role model

for the creation of safe and secure environments in which persons with HIV can live, work, and function. We need only to believe in the abilities and inherent power of people to change, in the power of occupation, and in the power of ourselves as the catalyst for transformation.” Though this article was written at a time when medical professionals still believed that a vaccine and even possibly a cure might be found for HIV/AIDS, it provides a unique view of OT’s potential role with intervention. Today, over two decades later, many of Pizzi’s ideas and goals for occupational therapy’s role in HIV/AIDS care have not been achieved, clearly warranting further exploration, interaction, and research.

Pizzi, M. (1992). Women, HIV infection, and AIDS: Tapestries of life, death, and empowerment. *The American Journal of Occupational Therapy*, 46, 1021-1027.

Abstract: Women, the minority population in the human immunodeficiency virus (HIV) pandemic, are becoming one of the highest subgroups to be infected and affected by the disease. In the United States, most of these women are black or Hispanic, poor and urban dwellers, and addicted to drugs. This paper discusses the physical, psychological, and social manifestations of the disease in women, such as diminished activity tolerance, neurologic or cognitive changes, occupational and social role imbalance, and stigma and discrimination, and describes the sociocultural aspects of women's lives for assessment and treatment of women with HIV. Health promotion, education, and NDS prevention and wellness programming are emphasized as strategies toward/facilitation of self empowerment for women with HIV disease. These health promotion and wellness strategies include learning of new and adaptation of current roles, learning strategies for self care that include care for one's physical, psychosocial, spiritual, and sexual health, and learning and developing action plans toward healthy living and self empowerment.

Though published in 1992, this article represents what was, especially at the time, a unique look at women, who were a minority group of those affected with HIV/AIDS. Though women with HIV/AIDS are still a minority, they are one of the fastest growing populations affected within the HIV/AIDS community. In relation to OT and MOHO, when specifically considering the unique needs of women in regard to occupations, roles, habits, and volition, it is important for therapists to consider the unique perspectives women may have. “Women with HIV share four unique characteristics: (1) a shorter life span than other groups, which leaves less time for planning their own lives and lives and custody of their children; (2) diagnosis-precipitated emotional chaos and shock, which may overwhelm the patient and her family; (3) presence of dependent minor children for whom crucial decisions must be made quickly; and (4) the nature and patterns of nontraditional but culturally specific familial relationships (e.g., large extended families)... (Kassel, 1991, pp. 227-228).” These aspects of life and how they affect occupational performance still apply today, and therapists should seek to take an individualized view of each patient based on his or her environment, history, and special needs.

Pizzi, M. (2006). HIV infection and AIDS. In H. M. Pendleton & W. Schultz-Krohn (Eds.), *Pedretti's occupational therapy practice skills for physical dysfunction* (6th ed., 1193-1203). St. Louis, MO: Mosby, Inc.

This chapter offers quantified, detailed demographic statistics related to the incidence and prevalence of HIV/AIDS by race and ethnicity, age, and gender, while relating these demographic trends to the role of OT within this population. It outlines typical symptoms of HIV/AIDS as they most relate to effects on ODLs and IODLs, provides information for therapists related to pharmacology, and discusses the different levels of prevention that can be addressed in therapy. Finally, the chapter includes a holistic assessment written by Pizzi, which takes into account the client's perspective on various aspects of life, including ODLs, play and leisure, sleep, physical function, cognition, work, time and organization, body image and self-image, stressors, coping, and goals. Though this assessment was not used for the capstone case studies, it does facilitate creativity and problem solving related to clinical reasoning, rapport building, and client-therapist collaboration when providing OT interventions to those with HIV/AIDS.

Rhodes, S. D., Malow, R. M., & Jolly, C. (2010). Community-based participatory research: A new and not-so-new approach to HIV/AIDS prevention, care, and treatment. *AIDS Education and Prevention*, 22, 173-183.

This article outlines the need for and the process of how communities might engage in collaborative research, designed to team together organizational representatives, academic researchers, and community health specialists in a manner to increase well being and quality of life and to better understand the social processes that create need for community services. Specific to HIV/AIDS, this article is relevant for occupational therapists who seek to advocate for the field within the setting of community-based care, as well as to promote increased understanding in practitioners about the methods of obtaining, encouraging, and utilizing community resources when working with the HIV/AIDS population. Because OT is present and involved in community-based care only minimally, this article facilitates increased understanding of the need for more research as well as additional involvement in this setting if true outcomes are to be gained. This article represents a critical analysis, and not a quantitative study.

Samson, A., Lavigne, R. M., & MacPherson, P. (2009). Self-fulfillment despite barriers: volunteer work of people living with HIV. *AIDS Care*, 21, 1425-1431.

Abstract: With the decline in the morbidity and mortality associated with HIV infection, the majority of people living with HIV (PWHIV) experience a higher quality of life and longer life expectancy. Since this diagnosis no longer prevents an active lifestyle, many PWHIV are re-integrating into the workplace or are contemplating this possibility. Despite the multiple advantages associated with a return to work, research has identified barriers related to work and HIV infection. These barriers could prevent an important minority of PWHIV who wish to return to work from re-integrating into this environment. In this context, volunteering could be an alternate way to regain an active lifestyle. This research found that volunteer work allowed participants to enrich their social lives, to regain a sense of psychological well being, and to apply their abilities to the benefit of others. However, participants are restricted by their

preference to volunteer for HIV-related organizations in order to avoid social stigma and rejection.

Because occupational therapy seeks to help patients find meaning and purpose within their lives, volunteering emerges as a relevant source of productivity and occupation for many individuals with HIV/AIDS, especially those who remain outside of the workforce. Because all of the capstone case study participants volunteered or participated in advocacy work at one time or another after being diagnosed with HIV/AIDS, and because one participant expressed high ratings of meaning and value placed on advocacy work during initial MOHO assessments, occupational therapists should seek to facilitate volunteering as a beneficial source of personal causation for many individuals. This study represents a lower level of research, as it used phenomenological methods to organize results of participant testimonies into various themes.

Sankar, A., Neufeld, S., Berry, R., & Luborsky, M. (2011). Cultural rationales guiding medication adherence among African Americans with HIV/AIDS. *AIDS Patient Care and STDs*, 25, 547-555.

Abstract: To date, only modest gains have been achieved in explaining adherence to medical regimens, limiting effective interventions. This is a particularly important issue for African Americans who are disproportionately affected by the HIV epidemic. Few studies have focused on intragroup variation among African Americans in adherence to ART. The aim of this study was to identify and describe the cultural rationales guiding African American patients' formulation and evaluation of adherence. Rationales are key features of purposeful human action. In-depth interviews with 80 seropositive African Americans were tape recorded, transcribed, and analyzed. Participant CD4, viral load and medical histories were collected at each data point. Analysis of four waves of panel data identified three types of adherence rationales: Authoritative Knowledge Rationale (AKR; n = 29, 36.3%), Following Doctors' Orders Rationale (DOR; n=24, 30.0%) and Individualized Adherence Rationale (IAR; n=27, 33.8%). Differences in mean reported adherence between the rationale groups did not achieve statistical significance. However, the fraction reporting low adherence (<70%), although not different by rationale group at the first interview (T1), was significantly higher for the IAR group by the fourth interview (T4). Objective clinical markers (CD4 and viral load) improved over time (from T1 to T4) for AKR and DOR groups, but remained unchanged for the IAR group, yet self-reported adherence declined for all groups over the course of the four interviews.

This article provides patient views of rationales behind medication adherence or non-adherence. Because regularly taking HIV/AIDS medications is so crucial to controlling the disease, occupational therapists often work with individuals on interventions for maintaining regular schedules of medication adherence and strategies for remembering to take medications. Information in this article might give OTs an inside perspective of why patients may or may not be adhering to their medications, allowing therapists to gain empathy into the reasoning patients may have when displaying deficits with medication adherence. This study represents a lower level of research, as it used phenomenological methods to organize results of participant testimonies into various themes.

Schindler, V. J. (1988). Psychosocial occupational therapy intervention with AIDS patients. *The American Journal of Occupational Therapy*, 42, 507-512.

Abstract: The role of psychosocial occupational therapy with AIDS patients is explored. The clinical picture is defined, information regarding the transmission, incidence, diagnosis, and treatment is presented, and the impact of the illness on the developmental cycle is described. The occupational behavior framework is used to guide evaluation and intervention and case examples are provided. Finally, fears and issues affecting therapists working with these patients are explored.

Because HIV/AIDS care is very closely tied with the psychosocial needs of this population, recommendations for how to apply psychosocial interventions in occupational therapy are very useful when designing goals and intervention plans. Though this article is somewhat outdated, its principles are still very relevant and applicable today, outlining how psychosocial deficits impact life roles and tasks, as well as occupational behavior. This article represents a critical analysis, and not a quantitative study.

Schindler, V. P., & Ferguson, S. (1995). An education program on acquired immunodeficiency syndrome for patients with mental illness. *The American Journal of Occupational Therapy*, 49, 359-361.

Though this article is also somewhat outdated, it emphasizes the need for consistent education in relation to the prevention of HIV/AIDS. Specific to individuals with mental illness, this article outlines methods for teaching prevention strategies and other aspects of HIV/AIDS health education to those who are HIV positive and who also have impairments due to psychological illness. Because many patients in the HIV/AIDS population, including those who participated in the capstone case studies, are affected by mental illness, understanding how to incorporate HIV/AIDS education into occupational therapy (if only to reinforce prior education given) is a key part of providing intervention to this population. This study represents a single subject design.

Sharpe, T. T., Voute, C., Rose, M. A., Cleveland, J., Dean, H. D., & Fenton, K. (2012). Social determinants of HIV/AIDS and sexually transmitted diseases among black women: Implications for health equity. *Journal of Women's Health*, 21, 1-7.

As part of health promotion and prevention, OTs might cover education about prevention of sexually transmitted infections, as well as further transmission of HIV to others as part of therapy interventions. It is very relevant, therefore, for therapists to understand the disparity that exists among African American women with HIV/AIDS in regard to risk of further infections and contracting other diseases, as well as the factors that contribute to such risks. According to the article, possible factors include: socially determined poorer health outcomes, higher poverty rates, higher incidences of single-parent homes of which women are the heads of households, decline in marriage rates among African American women, lower education retention, and higher exposure to drugs and other substances. This article contains information provided in the form of

an epidemiological report and is not an experimental study.

Siegel, K., Brown-Bradley, C. J., & Lekas, H. M. (2004). Strategies for coping with fatigue among HIV-positive individuals fifty years and older. *AIDS Patient Care and STDs*, 18, 275-288.

Abstract: Fatigue, a common symptom among persons living with HIV/AIDS, is often underreported and undertreated. However, given fatigue's pervasive effects on well-being and functioning, the identification of its physiologic and psychological causes and strategies to alleviate it are important to patients' quality of life. As part of a study to understand better how HIV-positive middle-aged and older adults (501) manage common symptoms, 49 participants discussed in depth their experience with fatigue. Most engaged in both self-care activities and sought the assistance of a health care professional. Frequent strategies included dietary changes, vitamins, modification of routines, rest, exercise, and prescribed medications for anemia, Vitamin B12 deficiency, or testosterone deficiency. Complementary and alternative medicine (e.g., acupuncture, massage, herbal remedies, special juices) was also commonly used. Participants often used multiple strategies to alleviate their fatigue, possibly because of their tendency to attribute it to multiple causes. These HIV-positive older adults were also apt to view fatigue as an indirect indicator of their overall health status and immune functioning. This may explain why many of the coping strategies they used could be considered approaches to improving their overall health status as a means to increasing their energy levels. Health care professionals can play an important role in helping HIV-positive individuals manage their fatigue. The majority of participants tried to implement the coping suggestions offered by health care professionals, as well as those from family, friends, and support group members.

Corroborating information from previously annotated fatigue studies, methods of intervention commonly used by individuals with fatigue range from exercise to alternative medicine methods to nutritional adjustments. However, new information included in this study reveals that few individuals with HIV/AIDS seek medical care solely for their fatigue, instead taking a "wait and see" approach and raising the issue of fatigue with their doctors only when already attending medical appointments for other reasons. Additionally, a majority of study participants took the advice provided to them by healthcare professionals, valuing their opinions and input. Occupational therapists, therefore, should continue to emphasize education for fatigue interventions, as well as maintain interdisciplinary communication to ensure that all practitioners caring for patients are aware of fatigue patterns. This study represents a lower level of research, as it used phenomenological methods to organize results of participant testimonies into various themes.

Taylor, R. R., Braveman, B., & Hammel, J. (2004). Developing and evaluating community-based services through participatory action research: Two case examples. *The American Journal of Occupational Therapy*, 58, 73-82.

Abstract: Occupational therapy has a strong history of embracing concepts of client empowerment. However there is limited literature in the field on how to achieve empowerment,

or on how to extend empowerment to the level of the community and social groups and services within it. This article discusses how concepts and strategies of participatory action research, an extension of empowerment theory, can be used to inform service development and evaluation in occupational therapy. The participatory action research approach is illustrated using two case examples of participatory action research programs for persons with chronic fatigue syndrome and individuals with autoimmune deficiency syndrome (AIDS). A critical analysis of the application of this approach to research and practice is provided. Finally, the paper identifies key principles of participatory action research that can be used to guide occupational therapy services and empower both individuals and communities.

This article is a beneficial reminder of both the rarity of community-based care and the need for continued assessment of the efficacy of this type of care through research and outcomes studies. Including outcomes of participatory action research with individuals with HIV/AIDS and occupational therapy return to work programs, this article outlines strategies and methods that were effective, methods that could improve with change, and any internal and/or socioenvironmental barriers. Outcomes of the participatory action research in regard to return to work revealed that participants gained meaning and purpose as well as quality of life, even if they did not actually attain jobs. For example, many gained volunteering or advocacy experiences, but found this to be just as meaningful as employment. In general, occupational therapists should continuously seek to validate their interventions with research, and perhaps go even further and explore the methods that provide justification for finding meaning in such research. This article represents a critical analysis, and not a quantitative study.

Taylor, R. R. (2004). Quality of life and symptom severity for individuals with chronic fatigue syndrome: Findings from a randomized clinical trial. *The American Journal of Occupational Therapy*, 58, 35-43.

Abstract: OBJECTIVE. Chronic fatigue syndrome is a profoundly disabling condition characterized by severe, unrelenting fatigue and a number of other physical and cognitive symptoms. Currently, there is no cure or widely accepted treatment for chronic fatigue syndrome, and few rehabilitation programs exist to address quality of life issues in chronic fatigue syndrome. In the present randomized clinical trial, the effects of an integrative, consumer-driven rehabilitation program on quality of life and symptom severity for individuals with chronic fatigue syndrome were examined.

METHOD. Forty-seven participants were randomly assigned to either an immediate program group ($n = 23$) or a delayed program control group ($n = 24$) and assessed with the Chronic Fatigue Syndrome Symptom Rating Scale and the Quality of Life Index before the program, after program participants completed the group phase, and after program participants completed the one-on-one phase. It was hypothesized that the program would lead to improvements in quality of life and an overall reduction in symptom severity.

RESULTS. Linear growth models were estimated comparing program and control conditions over time using random-effects regression analyses. Significant condition by time interactions were observed for the main outcomes of symptom severity and overall quality of life. Effect sizes for these interactions involving symptom severity (Cohen's $d = 0.71$) and overall quality of life (Cohen's $d = .66$) were moderate.

CONCLUSIONS. Findings indicate that consumer driven programs such as this one can have a positive impact on symptom severity and quality of life over time for individuals with chronic fatigue syndrome.

Though this study is not specific to HIV/AIDS, it explored the outcomes of a program to provide interventions to those with chronic fatigue, a very significant problem for many in the HIV/AIDS population. Results indicated that after the chronic fatigue program, participants' symptom severity decreased, quality of life ratings increased significantly, and quality of life in regard to family functioning also increased, revealing that rehabilitative fatigue interventions in general can definitely impact level of functioning and quality of life. Occupational therapists addressing fatigue in HIV/AIDS patients, therefore, should perhaps assess outcomes related to these factors, as well as addressing goal progress. This study represents a randomized controlled clinical trial, or the highest evidence level.

Taylor, R. (2008). *The intentional relationship: Occupational therapy and use of self*. Philadelphia: F.A. Davis.

The Intentional Relationship Model of Practice (IRM) is compatible with the Model of Human Occupation, in that it compliments its underlying theoretical ideas while not contradicting them. Though MOHO is the primary model being used for the capstone case studies, input from other compatible models is encouraged to fully ensure client-centeredness. IRM defines the communication skills, values, reasoning processes, and interpersonal behaviors required to form a unique and effective relationship between client and therapist. It identifies six modes of communication between client and therapist: advocating, collaborating, empathizing, encouraging, instructing, and problem solving. The overall goal of this model of practice is to change the communication style of the therapist based on the type of client being treated in order to maximize therapy results and the focus on the meaning and purpose behind the therapeutic occupations being facilitated.

U.S. Department of Health and Human Services. (2010). *Healthy People 2020: HIV*. Retrieved from <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=22>

This document outlines objectives to be met by the year 2020 in relation to HIV/AIDS, including reducing the incidence among both adolescents and adults, among the homosexual community, and among those who acquire HIV perinatally. Other goals include increasing the amount of HIV diagnoses before progression reaches AIDS status and reducing overall death rates from HIV/AIDS. These objectives from the U.S. Department of Health and Human Services demonstrate a view of HIV/AIDS on a national level, and it is imperative for anyone providing services of any type to those with HIV/AIDS to understand such objectives in order to better facilitate common goals and ideals among healthcare providers and patients by allowing room for common ground, hope, and encouragement.

Wagner, G. J., Goggin, K., Remien, R. H., Rosen, M. I., Simoni, J., Bangsberg, D. R., & Liu, H. (2011). A closer look at depression and its relationship to HIV antiretroviral adherence. *Annual Behavioral Medicine*, 42, 352-360.

Abstract: Background: Depression consistently predicts non-adherence to human immunodeficiency virus antiretroviral therapy, but which aspects of depression are most influential are unknown. Such knowledge could inform assessments of adherence readiness and the type of depression treatment to utilize. Purpose: We examined how depression severity, symptom type, and change over time relate to adherence.

Methods: Microelectronic adherence and self-reported depression data from 1,374 participants across merged studies were examined with cross-sectional and longitudinal analyses. Depression variables included a continuous measure, categorical measure of severity, cognitive and vegetative subscales, and individual symptoms.

Results: At baseline, mean adherence was 69%, and 25% had mild/moderate and 18% had severe depression. In cross-sectional multivariate analyses, continuous depression, cognitive depressive symptoms, and severe depression were associated with lower adherence. In longitudinal analysis, reductions in both continuous and categorical depression predicted increased adherence.

Conclusions: The relationship between global continuous depression and non-adherence was statistically significant, but relatively weak compared to that of cognitive depressive symptoms and severe depression, which appear to pose strong challenges to adherence and call for the need for early detection and treatment of depression.

This study revealed a significant positive correlation, though weak, of depression in individuals with HIV/AIDS with demonstration of low adherence to medication regimens. Furthermore, “good adherence” was associated with lower levels of almost every separately identified depression symptom included in the study. This study provides beneficial information for occupational therapists when seeking to understand the relationship of depression in those with HIV/AIDS to their many other deficits, both physically and psychosocially. Because depression occurs at high rates among this population, and because medication adherence is so crucial, therapists who can form a connection between the two while providing intervention might see maximum progress and change. This study obtained data from the Multi-site Adherence Collaboration on HIV (MACH14), which is a project of pooled data from 16 longitudinal studies using electronically monitored adherence across 14 U.S. research sites. Data were both continuous and categorical.

Wantland, D. J., Mullan, J. P., Holzemer, W. L., Portillo, C. J., Bakken, S., & McGhee, E. M. (2011). Additive effects of numbness and muscle aches on fatigue occurrence in individuals with HIV/AIDS who are taking antiretroviral therapy. *Journal of Pain and Symptom Management*, 41, 469-477.

Abstract: Context. Muscle aches, numbness in the feet/toes (neuropathy), and fatigue are often reported concurrently and are among the symptoms most frequently reported by individuals with HIV/AIDS, whether or not they are taking antiretroviral therapy (ART).

Objectives. This study used a longitudinal analytical methodology to analyze these symptoms together to determine whether symptom clusters are maintained over time and to determine

whether there is a temporal relationship between fatigue and reports of neuropathic pain and muscle aches.

Methods. This was a secondary analysis of a subset of data from a six-month, longitudinal, randomized, controlled trial of 243 HIV-positive individuals taking ART. Self-reported symptom frequency and intensity were recorded using the Revised Sign and Symptom Checklist for Persons with HIV disease at baseline (Month 0), one, three, and six months. Multilevel, logistic regression models were used to analyze time-lagged effects of muscle aches, numbness of the feet/toes, and fatigue to estimate any predictive and interactive effects that the symptoms have upon one another.

Results. A significant relationship between muscle aches and fatigue intercepts was noted (odds ratio [OR] 1/4 1.80, $P \leq 0.05$). Significant relationships between numbness and fatigue also were noted for the entire measurement period (OR 1/4 2.70, $P \leq 0.05$). Time-lagged models showed persons reporting neuropathic-related numbness in one period were nearly twice as likely to report fatigue in subsequent periods (OR 1/4 1.89, $P \leq 0.05$). The final model revealed that the addition of muscle aches and numbness explained 28% of the random variance in the occurrence of fatigue. Between-person descriptive variables including years living with HIV, age, having an AIDS diagnosis, ethnicity, and nucleoside reverse transcriptase inhibitor treatment regimens with stavudine, zalcitabine, or didanosine did not significantly explain any additional model variation. **Conclusion.** These findings are consistent with physiological research and provide evidence that analyzing multiple symptom change over time can provide a more accurate representation of an individual's symptom experience. When evaluating patients with muscle aches or numbness, particularly when both symptoms are present, an evaluation of fatigue should be considered. Similarly, if fatigue is reported, underlying physiological assessments for neuropathic symptoms and muscle aches may be considered.

As summarized in this study's abstract, results of this study suggest that when assessing fatigue in HIV/AIDS patients taking ART, muscle aches and numbness should be considered, and when assessing muscle aches and numbness, fatigue should be considered. Because there appears to be some sort of relationship between fatigue and muscle aches and numbness, occupational therapy interventions should take both problem areas into account, considering how they exist separately as well as how they might impact each other during daily function. Because these two issues are significant problems for the HIV/AIDS population, considering them together might most benefit patients in improving quality of life and learning compensatory strategies. This study represents a randomized trial using two assessment tools to screen participants for symptoms and information, with follow-ups at one month, three months, and six months.
