A holistic treatment approach for individuals experiencing phantom phenomena: an occupational therapy approach

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A HOLISTIC TREATMENT APPROACH FOR INDIVIDUALS EXPERIENCING PHANTOM

PHENOMENA: AN OCCUPATIONAL THERAPY APPROACH

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A Scholarly Project
Submitted to the Occupational Therapy Department
of the
University of North Dakota
In partial fulfillment of the requirements
for the degree of
Master’s of Occupational Therapy

Grand Forks, North Dakota

May 2010
This Scholarly Project Paper, submitted by Jenna Akkanen and Laura Olauson in partial fulfillment of the requirements for the degree of Master’s of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and hereby approved.

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The authors would like to thank Dr. Jan Stube for her dedication and guidance throughout this project's completion. Her support and continued encouragement promoted our learning, enthusiasm and commitment to this work.
ABSTRACT

The prevalence of individuals who have had an amputation and experience adverse types of sensory input from the missing limb is very high (Hunter, Katz, & Davis, 2005). According to the literature, sensory input can be divided into non-painful sensations or painful sensations in the amputated limb often called “phantom sensations.” These pains and sensations can have many negative implications upon an individual’s occupational performance, and consequently directly implicate the need for occupational therapy. A large number of persons post-amputation experience pain and different sensations from their affected limb even after the healing process has finalized; the etiology behind why or how this occurs is unclear (Hunter, Katz, & Davis, 2005).

Wilder-Smith, Hill and Laurent (2005) noted that painful sensations after an individual has gone through an amputation is common, however it is difficult to treat and there are very few studies regarding treatment trials. Because limb pain and sensations can have a negative impact on individuals and cause impairment in their daily functioning, further information is needed regarding occupation based treatment interventions to decrease the impact of these sensations within the context of occupational therapy settings.
CHAPTER I

INTRODUCTION

The authors of this scholarly project initially became interested in phantom limb phenomena as it is an intriguing occurrence within healthcare. There is an overall lack of general knowledge regarding its origin, impact on the individual and best practice for occupational therapy (OT) intervention methods. During an OT fieldwork experience, observation was made regarding the lack of purposeful and occupation-based intervention methods for individuals who were experiencing hypersensitivity of an amputated limb and the impact it had on the individual’s motivation to engage in therapy. The authors wished to create a product in which holistic intervention methods were outlined that provided meaningful tasks for the individual to engage in.

The authors developed this product for individuals with upper extremity amputations who are experiencing phantom limb phenomena as well as a means to enable the occupational therapists to provide the best quality client care. The authors have developed an educational manual for occupational therapist which outlines general knowledge of the condition, psychosocial and physical aspects. Additional focus is also placed on client and family education as well as a sample home treatment program and outcomes measurement to guide the client’s continued progress.
The contexts in which this product may be applicable include physical disability settings in which occupational therapists work with a wide range of persons with disabilities. These settings may include outpatient facilities, rehabilitation centers, Veteran Affairs hospitals, as well as hand therapy clinics. Despite its recommended use within the physical disability settings, psychosocial factors may have an impact on the progress of therapy and therefore are taken into consideration in the therapy process and within this product.

The Model of Human Occupation (MOHO) has been utilized as the theory base for this manual due to its focus on volition, habits, roles and routines of each individual client (Kielhofner, 2009). This is important as the manual places focus on providing holistic care and encompasses what the client wants and wishes regarding treatment. MOHO also provides a wide range of assessment tools which may be utilized in regards to treating both psychosocial and physical impairments.

Key terms utilized within this product consist of residual limb pain, phantom sensations and phantom limb pain. These terms are further described in both the extensive literature review as well as the educational manual for occupational therapists. Within the next chapters you will find a review of the literature, specific methodology that was used in the development of the product, the product itself and a summary of the purpose of the product, as well as recommendations for future application.
CHAPTER II

REVIEW OF LITERATURE

Individuals who experience an amputation are more common than one may imagine. As of 2005, it was estimated that 1.6 million individuals are currently living with the loss of one or more limbs (Ziegler-Graham, MacKenzie, Ephraim, Travison & Brookmeyer, 2008). This is an integral piece of information for healthcare clinicians in regards to preparing and planning for treatment with individuals with amputations. Due to the traumatic nature in which these injuries are often acquired, it is necessary to take a holistic approach with each individual client to ensure that maximum independence is restored. It is integral for healthcare professionals to become aware of the etiology behind amputations as that may have implications as to whether or not subsequent challenges may arise. When professionals begin care and/or provide therapy with a client who has had a recent amputation, it is critical that the person is treated holistically physically and mentally, as both the body and mind are impacted when a limb is lost.

According to a study completed by Datta, Selvarajah, and Davey (2004), the researchers investigated the functional capacity of persons with an upper extremity amputation relative to returning to gainful employment. For the purposes of this study, it was critical to identify the most common causes of amputations. These causes
included trauma at 71%, malignancy, vascular disease, diabetes mellitus, infection, and brachial plexus injuries at approximately 19%, and congenital diseases at 10%. Of these individuals who had acquired an amputation, many experienced not only a change in their functional capacity, but reported neurological and psychological implications as well.

**Sensory Implications Post-Amputation**

One such classification is phantom limb sensations. Phantom limb sensations are described as non-painful tactile or kinesthetic perceptions after the amputation, including but not limited to cramping, tingling, tickling, itching, wetness, cold, pressure, movement, electric sensations, and paraesthesia (Finnoff, 2001, Flor, 2002; Keenan & Glover, 2006). Phantom limb sensations may impede function within everyday tasks among individuals with amputations, as it causes distractions and is a constant or intermittent reminder of the limb that is missing.

Phantom limb sensations occur more frequently in the body parts with the highest brain cortical representation, such as, the distal end of the affected limb which limits optimal performance of the hands and feet (Finnoff, 2001; Manchikanti & Singh, 2004; Wilder-Smith, Hill & Laurent, 2005). The incidence of phantom limb sensations within the first three weeks of an amputation is 85% to 98% and will commonly subside within two to three years if left untreated (Manchikanti & Singh, 2004). These sensations may reach peak prevalence within six months post surgery (Hunter, Katz, & Davis, 2005). However, if the sensations evolve into pain, a negative impact on daily
Another sensation that may be experienced by individuals with amputations is phantom limb pain. Phantom limb pain is described as an uncomfortable stimulus originating from the amputated limb of the individual (Mayo Clinic Staff, 2009). The incidence of individuals that experience this pain is difficult to accurately determine due to overall current lack of research, however previous estimates determine that phantom limb pain occurs in 50% to 80% of persons with an amputation (Datta, Selvarajah, & Davey, 2004; Ephraim, Wegener, MacKenzie, Dillingham, & Pezzin, 2005; Wilder-Smith, Hill, & Laurent, 2005; Ziegler-Graham et al., 2008). Some common predictors to phantom limb pain include pre-amputation pain (meaning pain felt in amputated portion of body part prior to surgery) and persistent residual limb pain (Perkins & Kehlet, 2000). A study conducted by Jensen, Krebs, Nielsen and Rasmussen (1985) showed that this high prevalence of phantom pain does not correlate to the person’s age or the etiology behind the amputation. These findings highlight the need to address pain in all patients without discrimination of demographics to ensure the best treatment practices.

Depending on the individual, phantom limb pain has been described as shocking, burning, shooting, cramping, stabbing, squeezing and unnatural positioning of the missing limb. These sensations vary in frequency, intensity and duration as many persons with an amputation report constant pain but, more so, pain that presents in intermittent periods (Manchikanti & Singh, 2004). Most often, persons with an
amputation describe daily or weekly episodes of painful sensations, with monthly or yearly experiences being quite rare (Manchikanti & Singh, 2004). Symptoms may be amplified by emotional stress, change in temperature or weather conditions, chronic problems with prosthesis, fatigue, sexual activity, smoking, and defecation (Finnoff, 2001; Sherman, Sherman & Parker, 1984).

In a study completed by Jensen, Krebs, Nielsem, and Rasmussen (1985), they sought to determine the changes in immediate and long-term phantom limb pain in persons with an amputation. Their findings suggest that immediately following the amputation, pain is felt throughout the entire limb and more proximately to the body through sensations such as knifelike or sticking. The researchers also found that, with time, persons with an amputation reported the pain having moved into more distal locations from the body with sensations that are interpreted as burning or squeezing (Jensen, Krebs, Nielsem, & Rasmussen, 1985). These findings serve as a baseline for treatment when determining best practices.

Debate has risen regarding the causes and interpretation of phantom limb pain, as well as the frequency of discussing pain with physicians, which will be further described in the following paragraph. The impact these variables have on the reported incidence could be significant. Some researchers have also hypothesized that the feelings of pain may be memories of the limb prior to amputation surgery (Flor, 2002). Another area of concern is in regards to the person’s perception of their sensations. Since there is no concrete method to compare a person’s pain threshold with another’s, Sherman, Sherman, and Parker (1984) questioned if, in fact, some of the
individuals reporting phantom pain have a lower pain tolerance. Or, in comparison, those not reporting phantom pain are less responsive and sensitive.

Sherman, Sherman, and Parker (1984) also investigated the probability of persons with an amputation reporting phantom pain to their physicians. Their findings showed only 54% of persons with an amputation who experienced phantom limb pain reported it to their physicians due to their fear of losing good standing with their physician. The literature described another previous misconceived theory in which phantom limb pain was believed to be a result of grief over the amputated limb or "just being in the head" of the person with an amputation (Flor, 2002). This misconception is due to the elusive nature of phantom limb pain, as well as the negative response other persons with an amputation have received when seeking help for pain management (Flor, 2002; Sherman, Sherman & Parker, 1984). Other literature has shown similar findings of approximately fifty percent reporting rate with a strong correlation to those persons with an amputation who experience the most severe pain for the longest amount of time and in frequent time frames (Wartan, Hamann, Wedley, & McColl, 1997).

A third sensation that is frequently associated with amputations is residual limb pain, commonly referred to as 'stump pain,' which has been described as pain originating in the remaining portion of the amputated limb (Woodhouse, 2005). Current studies suggest that residual limb pain incidence ranges from 56% to exceeding 60% (Sherman et al., 1984; Wartan, Hamann, Wedley, & McColl, 1997). There are several identified causes of residual limb pain such as: a poor fitting prosthesis,
formation of neuromas, discomfort in the joints, nerve implications, and abnormal stump tissue being the most commonly reported (Davis, 1993). Residual limb pain has been described as feeling like, pressing, throbbbing, burning or squeezing in the distal portion of the limb that has been amputated (Jensen, Krebs, Nielsen, & Rasmussen, 1985). Other accounts have indicated spontaneous painful and/or non-painful movements of the stump, resulting in hardly noticeable to severe muscle contractions that remain for days (Manchikanti & Singh, 2004).

Similarities have been highlighted between residual limb pain and phantom limb pain due to the difficulty of accurately identifying the exact origin of pain, as well as a high correlation in dual reporting of residual limb pain and phantom pain together (Jensen, Krebs, Nielsen, & Rasmussen, 1985; Sherman, Sherman, & Parker, 1984). According to Sherman, Sherman, and Parker (1984), “Sixty six percent of those reporting phantom pain also reported stump pain; whereas, only half of those not reporting phantom pain reported stump pain.” These findings suggest that the high incidence of residual limb pain is solely contributed to the prevalence of phantom limb pain. However, according to Wartan, Hamann, Wedley, and McColl (1997), phantom limb pain was ranked second in intensity when compared to sensations contributed to residual limb pain, demonstrating the true importance of addressing all sensations resulting from the amputation of a limb.

**Psychosocial Implications Post-Amputation**

As previously discussed, to fully treat a person with an amputation, it is important that healthcare professionals take a holistic viewpoint to ensure the best care
is provided. Often, when a person presents with an amputation, the focus is placed on physical ailments or deficits whereas psychological support and family education is deficient. The outcome of this lack of care results in a significant increase in depressive symptoms experienced by persons with an amputation (Darnall et al., 2005; Sherman, Sherman, & Parker, 1984; Wartan, Hamann, Wedley, & McColl, 1997). Some of the most commonly seen psychological concerns with the amputee population is a fear of the unknown, lowered self esteem, lowered self-confidence, emotional disturbances, fear of rejection by others, coupled with a loss of occupational roles (Melzack, 1971; Smurr, Gulick, Yancosek, & Ganz, 2008). Melzack (1971) conducted research to examine the implications for treatment of phantom limb pain, in which he concluded that emotional and psychiatric issues indisputably contributed to a person’s perception of pain, however were not the primary source.

According to a national survey conducted by Darnall et al. (2005) in which they sought out to determine the prevalence of depressive symptoms, risk factors and use of mental health services among persons with an amputation, researchers found that over 28% of those with a limb loss experienced significant depressive symptoms. Similar literature supports their findings and indicated that those who have experienced pain after an amputation are more likely to have depressive symptoms than similar peers who do not report pain (Ephraim et al., 2005).

Further investigation was also conducted to determine the risk factors that may indicate a need for further screening for depressive symptoms among persons with an amputation (Darnall et al., 2005). Darnall et al. (2005) identified the three highest risk
factors for depressive symptoms were: having less than twelve years of education, low socioeconomic status, and the presence of chronic, severe phantom pain. Darnall et al. (2005) speculated the explanations behind these risk factors as being those individuals with more than twelve years of education may increase the person’s likelihood of utilizing available resources and those with higher socioeconomic statuses report a more unified support group. An additional factor that further contributes to the likelihood of reporting depressive symptoms is the presence of co-morbid diagnoses (Bosmans et al., 2007; Darnall et al., 2005). As researched by Breakey (1997) a noteworthy correlation was found between a person with an amputation’s perception of body image and their experience of self-esteem, anxiety and depressive symptoms.

The prevalence of phantom limb pain shows a strong correlation to depressive symptoms across all generations and age groups, indicating the need for a complete pain assessment with each and every client (Breakey, 1997; Darnall et al., 2005). However, residual limb pain was reported less in the elderly population leading the researchers to hypothesize that with increasing age, the ability to cope with pain increases as well (Darnall et al., 2005). It is important to note that a complete medical history and physical examination is necessary by a multidisciplinary team to determine the distinction between phantom sensations, phantom pain and residual limb pain to ensure client centered and quality care for each individual.

*Neuropathology of Phantom Limb Pain*

The etiology behind phantom limb sensations and pain has not been securely identified and a pattern of uncertainty has developed throughout the literature.
Phantom limb pain is considered a type of neuropathic pain that is caused by pathology in the central or peripheral neural pathways (Flor & Birbaumer, 2000; Flor, 2002). It has been noted, however, that the etiology behind phantom limb pain arises from a multitude of both internal and external factors and may be unique to each individual who has experienced an amputation (Finnoff, 2001). There have been several theories in which the causes of phantom limb pain range from neurological hypersensitivity to persistent and chronic pain before the amputation to emotional and psychological factors that enhance these sensations (Finnoff, 2001; Flor & Birbaumer, 2000; Flor, Nikolajsen & Jensen, 2006). The most important conclusion to note, however, is that more research is needed to accurately determine what causes phantom limb sensations.

Neurological implications are strongly suggested in the literature when etiology is attempted to be determined. When an individual acquires an amputation, all of the nerve endings within the residual limb that are cut can develop a knobby tissue at the distal end of the dissection. This knobby tissue or swelling commonly becomes hypersensitive and is called a neuroma. (Finnoff, 2001; Flor, Nikolajsen & Jensen, 2006). The painful sensations derived from these neuromas have been described as sharp and shooting when stimulated (Finnoff, 2001). Chemical stimulation of the neuroma as well as external stimulation, such as tapping the distal end of the residual limb at or near the location of a neuroma, can cause pain not only in the residual limb, but pain in the phantom limb as well (Flor, 2001). This is due to spontaneous and abnormal activity of the injured neuron within the residual limb sending afferent information to the brain.
and spinal cord, consequently manifesting these signals into different variations of phantom sensations (Schley et al., 2008).

Another neurological implication to individuals who have experienced an amputation is residual limb hyperesthesia which, according to Keenan and Glover, (2006) is an “overly sensitive limb,” especially to stimulation. The occurrence then of phantom pain is in regards to peripheral or distal changes of the nerves within the amputated limb. Post amputation nerve implications, including sensitivity to external stimulation or nerve injury, may develop into the Tinel’s sign. This is when pain is felt directly where stimulation to the injured nerve occurs or in the region of the stimulation (Flor, Nikolajsen, & Jensen, 2006). Therefore, the Tinel’s sign can indicate phantom limb pain as well as residual limb pain (Flor, Nikolajsen, & Jensen, 2006). The loss of accurate sensory feedback to each individual from their residual limb, whether the sensation is diminished or is hypersensitive, can be problematic in regards to function and safety awareness. This is especially important in relation to upper extremity amputations as hand function is critical to daily activities (Keenan & Glover, 2006).

Along with the presence of neuromas within a residual limb, there are also dorsal root ganglion cells which send somatosensory information from afferent neurons to the Central Nervous System (Flor, Nikolajsen, & Jensen, 2006). When spontaneous and stimulated sensations occur within both the neuromas and at the level of the dorsal root ganglion, a process called cross-excitation occurs in which the signals are amplified and can account for increased phantom limb pain (Flor et al., 2006).
Implications for Healthcare Professionals

In reviewing the literature, it was discovered that most treatment options for phantom limb pain are ineffective at completely alleviating this sensation over long periods of time if the condition is chronic, and do not take into account the etiology behind phantom limb pain (Flor, 2002; Sherman, Gall, & Gormly, 1979; Sherman, Sherman, & Gall, 1980). It was noted that if phantom limb pain reached a chronic state in which it had not been alleviated after one year, then it was very difficult to treat successfully (Sherman, Gall, & Gormly, 1979). Sherman, Sherman, and Gall (1980) discovered that “there is no one specific therapeutic approach which is well accepted as being effective,” (p.86). In the past three decades there have been over 40 identified possible treatment options, both conservative and surgical methods, for phantom limb pain in which the results of their effectiveness have been inconsistent; consequently further research is necessary (Sherman, Gall, & Gormly, 1979; Sherman, Sherman, & Gall, 1980). “It is quite clear that the great majority of patients can be helped by non-surgical procedures and that many conservative methods should be attempted before referral to a pain treatment center” is attempted (Sherman, Sherman, & Gall, 1980, p.97).

One treatment method that has been used to decrease phantom limb pain is mirror therapy. In such interventions, the individual with an amputated limb utilizes a mirror to reflect the image of their intact limb. This technique provides visual feedback for the individual by creating the illusion that two intact limbs are in fact present.
(Darnall, 2008). This intervention strategy involves the individual making symmetrical movements with both the intact limb and the phantom limb while observing, through the mirror, an illusion that the phantom limb is intact. This, consequently, sends messages to the brain of the individual with the amputation that both of their limbs are intact (Ramachandran & Ramachandran, 2000). Mirror therapy is more commonly utilized with individuals who have experienced an upper extremity amputation versus a lower extremity amputation. According to the literature, this is due to increased success with diminishing phantom pain in upper extremities of individuals with amputations and was hypothesized to be a result of cortical restructuring from the upper extremity to the brain (Ramachandran & Ramachandran, 2000).

Another treatment method identified as a possibility in diminishing phantom limb pain was in a study conducted by Ulger, Topuz, Bayramlar, Sener, and Erbahceci (2009) in which phantom limb pain was significantly reduced after four weeks of phantom limb exercises. These exercises provided the participants with relief in both the frequency and intensity of their phantom limb pain (Ulger, Topuz, Bayramlar, Sener, & Erbahceci, 2009). Participants of the study completed a general exercise regime of stretching, strengthening, and isometric exercises depending on the level of their amputation. Other participants completed phantom exercises in which they placed both limbs in the same position that the amputated limb experienced phantom sensations in, and moved both limbs in opposite directions until the phantom pain subsided (Ulger et al., 2009). This treatment continued for four weeks after which a home program was dispersed among the participants. A follow-up was conducted two months after
treatment and participants of the study reported that the frequency of phantom limb pain had diminished and that phantom exercises were effective (Ulger et al., 2009). Due to this information originating in a pilot study, it was noted that further research is required in order to confirm the effectiveness of phantom limb exercises to decrease pain sensations (Ulger et al., 2009).

Different types of medications have been utilized in an effort to treat phantom limb pain. Two medications in which their effectiveness was analyzed were Amitriptyline and Tramadol. Amitriptyline is an anti-depressant that is used for treatment of a variety of symptoms including chronic pain and Tramadol which is an analgesic medication used for inhibiting pain symptoms. In a study conducted by Wilder-Smith, Hill, and Laurent (2005), it was determined that the medications Amitriptyline and Tramadol were effective treatment methods for diminishing phantom limb and residual limb pain in up to eighty-three percent of participants completing the study. It was reported that negative side effects were mild in most cases and did not lead to study discontinuation from any participant (Wilder-Smith, Hill, & Laurent, 2005).

In a survey conducted by Sherman, Sherman, and Gall (1980), it was reported that non-surgical conservative treatment methods for phantom limb pain were more successful than surgical interventions. Some of the non-surgical or conservative treatment methods that were determined to have a higher success rate than failure rate included heat application, normal function, phantom exercises, relaxation training, desensitization of the stump, ultrasound, biofeedback, and wrapping the stump (Sherman, Sherman & Gall, 1980). Results of the survey determined that there are no
conclusively successful treatment methods indicated for phantom limb pain (Sherman, Sherman & Gall, 1980). According to the article however, it is important to begin treatment with a conversation with the patient to discuss “normal phantom sensations, the relationship between pain, tension, anxiety, and stress” at it may intensify these sensations (Sherman, Sherman & Gall, 1980). If a patient is in need of pain management from phantom limb sensations, a multidisciplinary treatment team may be the best source for assistance (Sherman, Sherman & Gall, 1980).

Morgenstern (1964) conducted a study in which he analyzed the cumulative effects of sensory distraction and directing attention to a task on phantom limb sensations after an amputation. Participants of the study were asked to engage in tasks which required a great deal of attention and were simultaneously exposed to a wide variety of sensory distractions in which they learned to ignore to complete the task (Morgenstern, 1964). The author argued that generalization of other sensations, such as phantom limb sensations, could be ignored if an individual was engaged in a task which required large amounts of attention (Morgenstern, 1964). It was noted that in order to be effective with decreasing phantom limb sensations and pain however, that concentration had to be combined with distraction and that neither one individually was effective. Effects were also demonstrated to be more successful if the distractions were repetitive and constant in nature (Morgenstern, 1964).

Because of the relationship found between anxiety reduction, muscular relaxation and decreased phantom limb pain, Sherman, Gall, and Gormly, (1979), continued research in a study which determined that progressive muscle relaxation
done from a tape recording within the home two times per day throughout the course of treatment was effective in relieving anxiety and decreasing phantom limb pain. The exercise allowed for individuals to identify when their muscles were tense as well as how to relax them when necessary (Sherman, Gall & Gormly, 1979). It was reported that progressive muscle relaxation did not alleviate the cause of phantom limb pain; but instead interrupted the course of the "pain-tension-anxiety" cycle (Sherman, Gall & Gormly, 1979). It was suggested that relaxation training should be given prior to or simultaneously with other treatment methods to completely eliminate the source of phantom limb pain (Sherman, Gall & Gormly, 1979).

Desensitization of the amputated limb is a common treatment that typically involves the use of a transcutaneous electrical nerve stimulation (TENS) unit, which is a device that sends electrical impulses to parts of the body to block pain signals (Eustice & Eustice, 2009). In a study by Wartan et al. (1997), TENS units were a successful treatment method in 42% of persons with an amputee who experienced phantom limb pain. These same individuals with an amputation had not previously felt any sense of pain relief with any other treatment methods (Wartan et al., 1997).

Other methods for desensitization can include compression techniques, massage, tapping, sensory re-education, and the use of texture bins for immersion (Schwartz, 2006; Smurr et al., 2008). According to Smurr et al. (2008), common treatment protocol for desensitization consists of 20-30 minute sessions up to three times per day depending on the person’s skin sensitivity. Family and caregiver education is important during this stage as is critical not to hyper-sensitize the amputated limb.
when attempting to increase tolerance (Smurr et al., 2008). When the residual is over stimulated with non-harmful sensations, the central nervous system will interpret these sensations as non-painful (Keenan & Glover, 2006). When re-educating the injured limb, patients are encouraged to integrate all senses to assist. Depending on the level of amputation, bilateral hand use is encouraged to examine an object, both physically and visually, before vision is occluded to relay the message between the person’s limb and brain (Schwartz, 2006).

*Occupational Therapy Implications*

Occupational Therapist’s have the opportunity to impact the lives of those individuals who have had an amputation through the use of several treatment options. Some common treatment methods which are performed by occupational therapists include desensitization techniques, mirror therapy, progressive muscle relaxation and functional retraining in several areas of occupation. Areas of occupation affected by amputation include activities of daily living (ADLs), instrumental activities of daily living (IADLs), work, play, leisure, social participation and sleep (AOTA, 2008; Keenan & Glover, 2006).

ADLs that may be impacted include bathing, dressing, functional mobility, personal device care, personal hygiene and grooming, sexual activity and toilet hygiene (AOTA, 2008). IADL’s that are important to address include, community mobility, home establishment and management, meal preparation and cleanup and shopping (AOTA, 2008). Since some individuals who have had an amputation were employed prior to their surgery, it is also necessary to consider the impact it may have on vocation and
their job performance in which adaptations could be made to promote success (AOTA, 2008). Play and leisure are important areas of occupation to both adults and children as they are methods of interaction and personal exploration, therefore attention should be focused on the affects it may have on engagement in activity. Lastly, social participation can be hindered if the person with an amputation is self conscious about his or her body, which may result in social isolation due to their amputation (AOTA, 2008).

**Summary**

Upon review of the literature, it was concluded that there is lack of updated researched and effective treatment methods for individuals with chronic phantom limb pain. Interventions which indicated a decrease in phantom limb pain included: consultation with a multidisciplinary team, patient and family education, mirror therapy, phantom limb exercises, medications, heat application, normal function through ADLs, relaxation training, desentization, ultrasound, biofeedback, TENS unit, and wrapping the residual limb.
CHAPTER III
METHODOLOGY

This product is an education-based manual for occupational therapists to be used with individuals who have an upper extremity amputation and are experiencing phantom phenomena. An extensive literature review was conducted and it was determined that there is an overall lack of research regarding phantom phenomena, onset and progression, and effective intervention options that are applicable to occupational therapy. Due to a lack of research it is consequently noted that there is a need for further intervention options in terms of both psychosocial and physical concerns to provide best evidence-based practice. Throughout the literature review, scholarly articles were retrieved and analyzed dating as far back as 1979. These articles were the foundation of research which has not been extensively investigated further since that time.

Scholarly articles were found through The University of North Dakota School of Medicine and Health Sciences, Harley E. French Library as well as education search engines that include ODIN, PubMed, CINAHAL, and Google Scholar. Journal articles were gathered primarily from The American Journal of Occupational Therapy, Journal of Hand Therapy, Journal of Prosthetics and Orthotics, and the Archives of Physical Medicine and Rehabilitation.
The product was developed after the review of literature was completed and the authors created an outline for which to base the product. The outlined consisted of the most effective treatment options as well as concerns noted in the research regarding psychosocial factors. The product was created through knowledge gained within the past three years in the occupational therapy program at The University of North Dakota in combination with the results found in the literature. The product was then outlined into five modules. The first module is an overview of phantom limb phenomena as well as the importance of client and family education. The second module is an overview of the occupational therapy intervention process guided by MOHO. The third module addressed psychosocial concerns resulting from the loss of a limb and the impact phantom limb phenomenon has on the person’s functional independence. A variety of assessment options are presented within the third module in which therapists may choose the one most applicable to the client’s needs. The fourth module outlines a variety intervention methods and how to incorporate these into occupation-based activities. The fifth and final module is a sample home program for therapists to offer to their clients as well as means to provide tracking and measuring of progress once discharged from inpatient care. It may also serve as a means to facilitate discussion in an outpatient occupational therapy rehabilitative service.
CHAPTER IV
PRODUCT

The purpose of this manual is to provide general education to occupational therapy practitioners in integrating client-centered and occupation-based interventions for their clients with an upper limb amputation who are experiencing phantom limb phenomena. The assessment and intervention methods featured in this manual are in congruence with evidence-based methods currently available. This manual is presented in a series of five modules, which outline the course of intervention that may be provided to persons with an amputation who are experiencing phantom phenomena.

Assessment and intervention methods presented here are integrated from a comprehensive review of the literature combined with the occupational therapy practice framework and the Model of Human Occupation to enable clients to gain maximum functional independence (AOTA, 2009; Kielhofner, 2009). Intervention methods were identified to inform occupational therapists of the best evidence-based means to incorporate into their occupation-based practice. The authors’ objective regarding this manual is that its use will facilitate a holistic treatment approach to improve quality of care and overall client satisfaction for individuals who are experiencing phantom phenomena. This goal will be reached through providing a foundation of knowledge regarding general information on phantom phenomena, client
and family education, pertinent assessments, treatment methods and a sample home treatment program and outcome measurements that may provide effective solutions for each individual.
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Module One: Overview of the Phantom Phenomena
Who is this product designed for?

This product is designed for occupational therapists working with individuals who are experiencing phantom phenomena due to an upper extremity amputation. For the purposes of this manual, the authors describe phantom phenomena as a combination of phantom limb pain, phantom sensations, and residual limb pain.

Phantom Sensations

Client Reports: Non-painful tactile or kinesthetic perceptions after the amputation which may include:

- Cramping
- Tingling
- Tickling
- Itching
- Wetness
- Cold
- Pressure
- Movement
- Electric sensations
- Paraesthesia

(Keenan & Glover, 2006; Finnoff, 2001; Flor, 2002)

Incidence: The incidence of phantom limb sensations within the first three weeks of an amputation is 85% to 98% and will commonly subside within two to three years if left untreated (Manchikanti & Singh, 2004).

Additional Factors to Consider:
Phantom limb sensations occur more frequently in the body parts with the highest brain cortical representation, such as, the distal end of the affected limb which limits optimal performance of the hands and feet (Finnoff, 2001; Manchikanti & Singh, 2004; Wilder-Smith, Hill & Laurent, 2005).

Phantom Limb Pain

Client Reports: Phantom limb pain has been described as:

- Shocking
- Burning
- Shooting
- Cramping
- Stabbing
- Squeezing
- Unnatural positioning of the missing limb

(Manchikanti & Singh, 2004)

Incidence: The incidence of individuals who experience this pain is difficult to accurately determine due to overall current lack of research, however previous estimates determined that phantom limb pain occurs in 50% to 80% of persons with an amputation (Datta, Selvarajah, & Davey, 2004; Ephraim, Wegener, MacKenzie, Dillingham, & Pezzin, 2005; Wilder-Smith, Hill, & Laurent, 2005; Ziegler-Graham et al., 2008).

Additional factors to consider:
Symptoms may be amplified by
emotional stress, change in temperature or weather conditions, chronic problems with a prosthesis, fatigue, sexual activity, smoking, and defecation (Finnoff, 2001; Sherman, Sherman, & Parker, 1984).

These sensations vary in frequency, intensity and duration; as many persons with an amputation report constant pain but, more so, pain that presents in intermittent periods (Manchikanti & Singh, 2004).

**Residual Limb Pain**

**Client Reports:** Residual limb pain has been described as feeling like:

- Pressing
- Throbbing
- Burning
- Squeezing in the distal portion of the amputated residual limb (Jensen, Krebs, Nielsen, & Rasmussen, 1985)

**Incidence:** Current studies suggest that residual limb pain incidence ranges from 56% to exceeding 60% (Sherman et al., 1984; Wartan, Hamann, Wedley, & McColl, 1997).

**Additional factors to consider:** There are several identified causes of residual limb pain. A poor fitting prosthesis, formation of neuromas, discomfort in the joints, nerve implications, and abnormal stump tissue are the most commonly reported (Davis, 1993). Other accounts have indicated spontaneous painful and/or non-painful movements of the residual limb, resulting in hardly noticeable to severe muscle contractions that remain for days (Manchikanti & Singh, 2004).

**Prevalent causes of amputation**

After a review of the literature, the most common causes of an upper extremity amputation included trauma at 71%; malignancy, vascular disease, diabetes mellitus, infection, and brachial plexus injuries at approximately 19%; and congenital diseases at 10% (Datta, Selvarajah & Davey, 2004).

**Predictors of phantom limb pain:** These may include pre-amputation pain (meaning pain felt in amputated portion of body part prior to surgery) and persistent residual limb pain (Perkins & Kehlet, 2000). A study conducted by Jensen, Krebs, Nielsen and Rasmussen (1985) showed that this high prevalence of phantom pain does not correlate to the person’s age or the etiology behind the amputation. These findings highlight the need to address pain in all clients without discrimination of demographics to ensure the best treatment practices.
Module Two: The Occupational Therapy Process Applied
Therapeutic Reasoning throughout the Occupational Therapy Intervention Process:

For the purposes of this manual, as well as to achieve highest quality of client care, the Model of Human Occupation (MOHO) guidelines are suggested to outline the therapy process. Therapeutic reasoning is a major concept within the Model of Human Occupation theory; it strives to integrate the clients’ needs and wants with the therapist’s goals in returning the client back to optimal performance and independence. (Kielhofner, 2009).

Optional assessments to assist with the occupational therapy initial evaluation include:
- Model of Human Occupation Screening Tool (MOHOST)
- Occupational Self-Assessment (OSA)
- Occupational Performance History Interview (OPI)
- Occupational Circumstances Assessment Interview and Grading Scale (OCAIRS)

For further description of these assessments and applicable use, please see Module Three.

Prior to initial client contact:

Locate and review the referral form; note the reason for referral and possible implications associated with the treatment process. Make note of the level of the amputation, as well as the cause of the amputation and possible functional limitations that may be involved. Create a series of questions for the client to guide the initial occupational therapy interview. This step is also integral for establishing background knowledge on the client to determine similarities between chart information and what the client reports.

Initial Evaluation of the client:

When first meeting and evaluating the client, it is recommended by the authors that a complete occupational profile and medical history is established. Depending on the facility or context, an occupational profile can be developed through whichever means are pre-determined by the occupational therapist. Collaborate with the client to determine previous level of functioning and the impact of the amputation thus far.

The occupational therapist and the client will continue to collaborate to establish problem areas, goals and concerns regarding occupational performance. These things may include, everyday occupations of daily activities including interests, values and needs (AOTA, 2008). Discuss implications of phantom limb sensations and the length of time that pain has been present.

Within this step, the occupational therapists observes the client within a context to determine environmental and client factors that obstruct or enhance performance. Areas such as performance skills, patterns, activity demands and context are all considered while developing specific goals (AOTA, 2008).
Creating the Intervention Plan:

Engage the client in discussion regarding their volition levels, prior habits and roles, as well as their goals to re-gain their previous level of functioning. Work with the client to establish priorities of treatment interventions and tentative sequencing of these goal areas while developing a specific plan to achieve these goals. Notify the client that the treatment process will begin with purposeful and preparatory activities such as phantom limb exercises that will transition into occupation-based interventions. These may include for example, washing dishes which will facilitate prolonged volition to participate in therapy as it provides meaning within their context. In correlation with MOHO, it is important to remind the client that the more they invest in therapy, the more benefits they will receive upon completion.

Therapy Process:

Engage the client in meaningful treatment interventions that were mutually determined. Adapt/modify any intervention techniques as needed in working with the client. For example, client factors such as increased sensitivity could facilitate modification of the intervention process as the therapist would change the intervention to a tolerable activity and grade it appropriately. Evidence-based intervention methods that are in current use and have been reported as having an impact on phantom limb sensations are described in Modules Three and Four. These intervention techniques describe holistic treatment approaches in that both the body and mind are impacted when a person experiences an amputation.

Measuring Outcomes of Therapy:

It is recommended that the Functional Independence Measure (FIM) be utilized to measure the effectiveness of the therapy treatment in regards to the client’s physical performance (Brain Injury Resource Foundation, 2009; Granger, Hamilton, Linacre, Heinemann, & Wright, 1993). Other suggested assessment tools in measuring functionality of the upper extremity after an amputation would be the Disabilities of the Arm, Shoulder and Hand (DASH). The general purpose of this evaluation is to determine the functionality of an upper extremity after an individual has acquired a deficit in performance capacity. This evaluation can be used over a span of time to determine gains achieved (Veaton, Katz, Fossel, Wright, Tarasuk, & Bombardier, 2001). Some of the assessment measures include the ability to complete activities of daily living, pain assessment, performing leisure activities and vocational activities (Veaton et al., 2001). In combination with measuring physical performance, it is recommended that clinicians measure psychosocial implications as well. Example psychosocial assessments can be found in Module Three. These assessments are recommended to be utilized both pre and post treatment process to allow a baseline measurement and follow up with the measure of progress prior to discharge of the client.
Client and Family Education:

According to an article written by Sherman, Sherman and Gall (1980), it is important to begin treatment with an individual who has experienced an amputation by discussing what can be considered as normal to that individual in regards to phantom limb sensations. Additional considerations that need to be addressed include the correlation between painful sensations and a heightened emotional state. It is important to consider the psychosocial impact of an amputation and assist the client with developing coping strategies to ease the loss of their limb. Client education is also important in regards to what phantom limb sensations are and the necessity of reporting these phenomena before they negatively impact functional performance.

It is important to integrate family into the intervention process as positive support systems are beneficial in the journey to regain maximum independence. Families and other support systems can facilitate motivation and assist the client to resume their previous roles within the family, work and community. It is beneficial to provide the family members additional education materials to inform them of the therapy process, what to expect and ways they can be the most beneficial in the client's progress.

Multidisciplinary Team:

It is important to note that a complete medical history and physical examination is necessary by a multidisciplinary team to determine the distinction between phantom sensations, phantom pain and residual limb pain to ensure client-centered and quality care for each individual. If a client is in need of pain management from phantom limb sensations, a multidisciplinary treatment team may be the best source for assistance (Sherman, Sherman & Gall, 1980). A typical multidisciplinary team may be lead by a physician. Other members may consist of occupational therapists, physical therapists, nursing staff, social workers, and a prosthetist.
Module Three: Occupational Therapy Assessments- Psychosocial
An overview of utilizing a psychosocial approach:

A Holistic Viewpoint

To fully treat a person with an amputation, it is critical that healthcare professionals take a holistic viewpoint to ensure that the best care is provided. Often, when a person presents with an amputation, the focus is regularly placed on physical ailments or deficits whereas psychological support, patient and family education is deficient.

The outcome of this lack of care results in a significant increase in depressive symptoms experienced by persons with an amputation (Darnall, Ephraim, Wegener, Dillingham, & Pezzin, 2005; Sherman, Sherman, & Parker, 1984; Wartan, Hamann, Wedley, & McColl, 1997). Additional factors to consider include the co-morbidity of depressive symptoms with the experience of pain.

Co-morbidity of Psychosocial Diagnosis

It is reported that only 54% of individuals who experienced phantom limb pain reported it to their physicians due to a fear of losing good standing (Flor, 2002; Sherman, Sherman & Parker, 1984). The literature described another previous misconceived theory in which phantom limb pain was believed to be a result of grief over the amputated limb or “just being in the head” of the person with an amputation (Flor, 2002).

Some of the most commonly seen psychological concerns with the population post-amputation is a fear of the unknown, lowered self esteem, lowered self-confidence, emotional disturbances, fear of rejection by others, coupled with a loss of occupational roles (Melzack, 1971; Smurr, Gulick, Yancosek, & Ganz, 2008). Research was conducted to examine the implications of disregarding psychosocial concerns in clients with phantom limb sensations. The research concluded that emotional and psychiatric issues indisputably contributed to a person’s perception of pain; however this was not the primary source (Melzack, 1971). The prevalence of phantom limb pain shows a strong correlation to depressive symptoms across all generations and age groups, indicating the need for a complete pain assessment and depression screening with each and every client (Breakey, 1997; Darnall et al., 2005).

Psychosocial Assessments

I. Occupational Therapy Assessments

There are a variety of occupational therapy assessments that can be used when treating a client with an amputation who is experiencing psychosocial implications. Outlined
below are assessments that may be beneficial to the therapist when working with the client to determine areas of challenge, supports, and treatment goals. They can also be utilized as a means to initiate discussion regarding how a client's life has been impacted post amputation. The occupational therapist should determine which assessment is appropriate for their client based on the clinical presentation of the client.

i. **The Model of Human Occupation Screening Tool (MOHOST)**

The Model of Human Occupation Screening Tool (MOHOST) is an occupational therapy assessment which integrates concepts related to The Model of Human Occupation such as volition, habituation, skills and environment. This assessment provides the therapist with an overview of the client's occupational functioning. Therapists find the MOHOST quick to administer and useful for summarizing what was learned about a client (Parkinson, Chester, Cratchley, & Rowbottom, 2008). According to Parkinson, Chester, Cratchley and Rowbottom (2008), therapists have noted that the MOHOST analyzes every area of a person's daily engagement in activities. Therapists can use a variety of information from observation, interview, and chart review to complete the MOHOST (Forsyth & Kielhofner, 2003). The MOHOST was designed to be used to document progress towards occupational therapy intervention goals as well as to screen for occupational therapy services (The Model of Human Occupation Clearinghouse, 2010).

**Application to occupational therapy**

The MOHOST assessment is designed to aid therapists in treating client's according to the occupational therapy scope of practice. Due to its orientation towards client's habits, roles and routines, it provides a means for directing treatment towards areas that are important to the client.

**Applicable populations**

Recommended for use with adults (Forsyth & Kielhofner, 2003).

**For further information and product ordering**

Located on-line through the MOHO Clearinghouse at http://www.moho.uic.eduj.

ii. **Occupational Self Assessment (OSA)**

The Occupational Self Assessment (OSA) is designed to capture clients' perceptions of their own abilities as well as their perceptions of how they are able to adapt to performance
challenges (The Model of Human Occupation Clearinghouse, 2010). Clients are provided with a list of 21 everyday occupations and assess their level of ability when participating in the occupation. The rating for each occupation is based on a four-point scale (Kramer, Kielhofner, & Forsyth, 2008).

**Application to occupational therapy**

This assessment is designed to promote client-centered practice by promoting clients involvement within the therapy process. The data collected by the OSA is the best representation of the clients' wants and needs in regards to therapy.

**Applicable populations**

Recommended for use with adults (Forsyth & Kielhofner, 2003).

**For further information and product ordering**

Located on-line through the MOHO Clearinghouse at http://www.moho.uic.edu/.

**iii. Occupational Performance History Interview (OPI)**

The Occupational Performance History Interview 2nd version (OPI-II) is designed to provide a broad and detailed view of a client's life history, the impact their disability has had upon their life, and the direction that the client would like their life to go (The Model of Human Occupation Clearinghouse, 2010). According to an article by Ennals and Fossey (2007), “consumers find benefit in telling their stories and want to talk about the full range of their experiences and emotions, including fears, failures, hopes and dreams, along with their illnesses and day to day lives” (p. 19). The assessment consists of a semi-structured interview with three rating scales and a life history narrative (Forsyth & Kielhofner, 2003).

According to Forsyth and Kielhofner (2003), the OPI-II provides a measure of:

- Occupational competence
- Occupational identity
- Occupational behavior settings
- It also provides a format for interpreting the life history narrative and its implications for the client’s adaption.

**Application to occupational therapy**

As occupational therapists, it is important to incorporate the client into designing their treatment plan and determining the activities that are important to them, both past and present. Due to the interview structure of the OPI-II, occupational therapists are able to engage their clients in a discussion that connects the client's life experiences and occupational roles, which can then be
implemented into therapy. Occupational therapists have the training to interpret what their client is saying and identify possible barriers to their success.

**Applicable populations**

According to The Model of Human Occupation Clearinghouse (2010), “The OPHI-II is designed for use with an occupational therapy client who is capable of responding to a life history interview.” It can be used in both physical disability as well as psychiatric settings and has been determined to be applicable to those aged 15 and older.

**For further information and product ordering**

Located on-line through the MOHO Clearinghouse at http://www.moho.uic.edu/.

**iv. The Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS)**

The Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS) gathers information on a client’s values, goals, person causation, interests, habits, roles, skills, environmental, participation, long and short term goals, and adaptation necessary to be successful (Kielhofner, Forsyth, Clay, Ekbladh, Haglund, Hemmingsson, Keponen, & Olson, 2008). Assessment consists of a semi-structured interview followed by a rating scale. The rating scale then describes the client’s strengths and weaknesses regarding occupational performance (Kielhofner et al., 2008).

**Application to occupational therapy**

This can be a valuable tool to screen for occupational therapy services. Occupational therapists have the training to complete the interview process in a means that will provide the most applicable information. This assessment easily identifies the strengths and weaknesses of the client and can be used as a guide for therapy.

**Applicable populations**

The OCAIRS can be used with adolescents and adults. Clients must have the ability to engage in the interview without assistance (The Model of Human Occupation Clearinghouse, 2010).

**For further information and product ordering**

Located on-line through the MOHO Clearinghouse at http://www.moho.uic.edu/.

**II. Additional assessments for psychosocial dysfunction**
i. Beck Depression Inventory Scale

The Beck Depression Inventory Scale is a 21-item self-report instrument intended to assess the existence and severity of symptoms of depression as listed in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Research Centers for Minority Aging Research, 2006). These 21-items are intended to index symptoms of severe depression, which may indicate a need for hospitalization.

Items are to determine any increases or decreases in:
- Sleep and appetite
- Body image
- Work difficulty
- Weight loss
- Agitation
- Concentration difficulty
- Loss of energy
- (Research Centers for Minority Aging Research, 2006)

Application to Occupational Therapy

The Beck Depression Inventory Scale is a quick five minute standardized assessment that can accurately identify indicators associated with depression. The Beck Depression Inventory Scale can be used as an indicator for further psychosocial interventions. There is no additional training required to administer The Beck Depression Inventory Scale making it accessible to all therapists.

Applicable populations

It has shown to be valid among all populations providing it with a wide area of use (Research Centers for Minority Aging Research, 2006).

Evidenced based research supporting use of The Beck Depression Inventory Scale

"BDI has been used for 35 years to identify and assess depressive symptoms, it has a high depressed from non-depressed clients," (Research Centers for Minority Aging Research, 2006).

For further information and product ordering

Pearson distributing company is available for product purchasing and can be located at http://psychcorp.pearsonassessments.com/pal/ca/cahome.htm.

ii. Dallas Pain Scale

The Dallas Pain Scale is a 16 question rating scale which client's complete in order to identify how their pain has affected their lives. Items are rated on a percentage between 0-100%; the
client identifies how much of their day they experience pain (Lawlis, Cuencas, Selby, & McCoy, 1989).

**Application to Occupational Therapy**

This tool is an easy to use, accessible tool which can be used to initiate the discussion regarding the impact pain has had on the client’s life. As previously noted, often times client’s experience difficulty verbalizing their pain to physicians and therapists due to the illusive nature of the pain, this tool can aid in beginning the conversation. This tool cannot be the sole method of assessment but can, instead, give both the occupational therapist and the client goal areas.

**Applicable Populations**

Primarily used with clients who are experiencing lower back pain but has been used with other populations as well. In regards to occupational therapy treatment, it may be used with clients who are experiencing any kind of physical pain.

**For Further Information and Product ordering**

Assessments can be found online at: http://www.oarsi.org/pdfs/pain_indexes/Dallas_Pain_Questionnaire.pdf.
Module Four: Occupational Therapy Interventions - Physical and Occupation-Based Approach
An overview of utilizing a physical restoration and occupation-based approach:

In providing interventions to individuals with upper extremity amputations, there are several methods that may be employed to achieve the maximum functional performance for each individual. In correlation with the occupational therapy practice framework these intervention methods consist of preparatory, purposeful and occupation-based activities (AOTA, 2008).

The American Occupational Therapy Association (2008) describes the purpose of preparatory intervention methods as utilizing and selecting activities which will provide individuals with foundational skills. These skills are required to complete necessary tasks that will transition to, or be used in conjunction with, purposeful and occupation-based activities.

Examples of preparatory intervention methods for the purpose of this manual include phantom limb exercises, physical agent modalities, relaxation training, etc.

Once foundational skills are addressed and restored, purposeful activities may be implemented within the intervention process. The American Occupational Therapy Association (2008) describes the intention of purposeful activities is to allow the client to improve their occupational performance through graded tasks that facilitate success towards the end result of completing the occupation.

Examples of purposeful activities for the purpose of this manual include writing letters in a mirror box, exposure to various tactile stimuli within the client's environment; applying skills learned with adaptive equipment to simulated ADL scenarios, etc. It should be noted again that purposeful and preparatory intervention activities may be used simultaneously depending on the client's preferences.

The main goal of the intervention process is for the client to demonstrate the ability to engage in occupation-based activities with the highest degree of independence. This is achieved through completing tasks which are necessary for engagement in their prior habits, roles and routines within their natural context. (AOTA, 2008).

Examples of occupation-based activities for the purpose of this manual include washing dishes, folding laundry, dressing and bathing. Occupation-based activities promote independence and are the most applicable in getting the client back to their previous levels of functioning.
These intervention methods are integrated into the following activities.
Mirror Therapy:

What is it?

Within this intervention strategy for an individual with an upper extremity amputation, the individual utilizes a mirror box where the mirror is down the midline, and the individual places their unaffected limb into it to reflect that image where the amputated limb would in fact be. When the limb is viewed off center, it creates the illusion through visual feedback that both limbs are intact and present (Darnall, 2008; Hanling, Wallace, Hollenbeck, Benlap, & Tulis, 2010).

The strategy involved with this intervention involves the individual making symmetrical movements with both the intact limb and the phantom limb while observing the intact limb in the mirror, thus creating the illusion that the phantom limb is intact. This, consequently, sends messages to the brain of the individual that both limbs are intact and theoretically reduces pain (Ramachandran & Ramachandran, 2000).

Evidence Supporting:

- There have been other studies indicating that mirror therapy may be effective in minimizing, preventing or alleviating phantom limb pain. One such study, completed by Hanling et al., 2010, indicated that mirror therapy can be utilized in the prevention of phantom limb pain. Mirror therapy is thought to reverse cortical remapping within the brain and therefore alleviate phantom limb pain.

Within the study, four participants completed mirror therapy on a daily basis for 30 minutes for two consecutive weeks. These clients had previously experienced chronic pain from 4-17 months prior to elective amputation of the affected limb (which increased the likelihood of experiencing phantom limb pain). Results of the study indicated that the participants either experienced no phantom limb pain or mild episodes after a one month follow up. It was noted in the study that small improvements in the ability to prevent phantom limb pain can have a dramatic impact on the long-term prognosis of individuals with amputations.

Benefits Proposed Within the Evidence:
- Decrease in phantom limb pain
- Alleviate phantom limb pain
- Increase functional performance in rehabilitation process
- Increase in quality of life

Risks:
- No effect on alleviating or decreasing phantom limb pain
- Do not complete if other medical implications would interfere with health or safety of the client

Certification or Licensure Required:
- No certification or licensure required
- Recommended to be completed by a trained occupational therapist
Occupation-Based Application
Ideas:

It is recommended that prior to mirror therapy intervention, discussion with the client is completed to ensure client-centered practices are followed and that the client is motivated to participate in treatment. Within completion of mirror therapy, it is important to note that client may engage in occupation-based activities such as writing a letter or playing a small keyboard, to increase satisfaction and functional performance.
Phantom Limb Exercises:

What is it?

Phantom limb exercises are exercises in which the individual with an upper extremity amputation completes a general regime of stretching, strengthening and isometric exercises with both the unaffected limb, and the limb that is missing. These exercises will differ based on the level of the amputation. Basic upper extremity stretching activities can be utilized when completing this treatment method.

Evidence supporting:

Phantom limb pain can be significantly reduced in both the frequency and intensity after four weeks of completing phantom limb exercises (Ulger, Topuz, Bayramlar, Sener, & Erbahceci, 2009). Individuals completing phantom limb exercises also participated in placing both the unaffected and affected limb in the same position that the affected limb experienced phantom sensations, and moved both limbs in opposite directions until the phantom pain diminished (Ulger et al., 2009).

Home programs have been documented within this intervention method to be beneficial to clients experiencing phantom limb pain. Further research on phantom limb exercises is needed for increased evidence on the effectiveness of this intervention method.

Benefits Proposed Within the Evidence:

- Decrease in phantom limb pain
- Alleviate phantom limb pain
- Increase strength and range of motion in upper extremities
- Increase functional performance in daily activities
- Increase in quality of life

Risks:

- No effect on alleviating or decreasing phantom limb pain
- Do not complete if other medical implications would impede the health or safety of the client

Certification or Licensure:

- No certification or licensure required. Interventions recommended to be completed by occupational therapist or certified occupational therapy assistant.

Occupation-Based Application Ideas:

It is recommended that prior to completing phantom limb exercises, discussion with the client is completed to ensure client-centered practices are taken and that the client is motivated to participate in treatment.

After completion of phantom limb exercises, it is recommended that the client engage in occupation-based activities, such as washing windows, and putting dishes or laundry away. The unaffected limb may complete the task, however it important to promote the simultaneous isometric movement
of the affected limb as well to increase client satisfaction and functional performance.
Occupation-Based Approach to Coincide with Physical Agent Modalities:

What is it?

Occupation-based approaches that coincide with physical agent modalities (PAMs) include normal daily tasks which a person takes part in where modalities such as heat, vibration, massage, and wrapping of the stump, could be incorporated. This concept takes into account what the client finds meaningful as well as what their goals are in relation to function and their role within society.

Evidence Supporting:

Within the literature it was noted that non-surgical preparatory treatment methods for individuals experiencing phantom limb pain were more successful at alleviating the pain. Some of these methods that were determined to have higher success rates than failure rates included heat application, normal function, vibration, massage and wrapping the stump (Sherman, Sherman & Gall, 1980).

In another study, participants were asked to engage in tasks which required a great deal of attention and were simultaneously exposed to a wide variety of sensory distractions in which they learned to ignore to complete the task (Morgenstern, 1964). The author argued that generalization of other sensations, such as phantom limb sensations, could be ignored if an individual was engaged in a task which required large amounts of attention (Morgenstern, 1964). It was noted that in order to be effective with decreasing phantom limb sensations and pain however, that concentration had to be combined with distraction and that neither one individually was effective. Effects were also demonstrated to be more successful if the distractions were repetitive and constant in nature (Morgenstern, 1964).

Benefits Proposed Within the Evidence:

- Decrease in phantom limb pain
- Alleviate phantom limb pain
- Increase functional performance in daily activities
- Increase in quality of life

Risks:

- No effect on alleviating or decreasing phantom limb pain
- Do not complete intervention if other medical implications impede the health or safety of the client

Certification or Licensure:

- No certification or licensure is required to complete this intervention. It is recommended that intervention be completed by occupational therapist.
- If physical agent modalities (PAMs) are used by the Occupational Therapist as preparatory to the occupations, additional training in PAMs is necessary as well as compliance with state occupational therapy licensure laws.
Occupation-Based Application Ideas:
It is recommended that prior to completing occupation-based interventions, that a discussion with the client is completed to ensure client-centered practices are taken and that the client is motivated to participate in treatment. It is necessary to note that the listed intervention ideas are all dependent upon the level of amputation for each individual. Possible occupation-based interventions which incorporate heat modalities include washing dishes with both the affected and unaffected limb submerged in water, taking clothes out of the dryer soon after they are completely dried, and taking a warm bath or shower. Occupation-based intervention ideas that incorporate vibration or massage include driving or pushing a cart through a store, kneading bread dough with the affected limb, vacuuming, riding a bicycle, and putting on lotion. These activities will promote an increase in client satisfaction and overall functional performance in everyday tasks.
Progressive Muscle Relaxation:

What is it?

Progressive Muscle relaxation is an intervention method that utilizes relaxation of muscle groups throughout the body to decrease phantom limb pain (Sherman, Gall, & Gormly, 1979). Calm music can be played while a recording or facilitator/occupational therapist explains the process of relaxing muscles beginning with the head and face and continuing down the body all the way to the toes. These relaxation procedures can be described by asking participants to contract specific muscles, hold for five seconds, and relax those same muscles. The process should continue in a slow and calm manner until all of the muscles in the body have been implicated.

Evidence to Support:

Research has shown that there is a relationship between anxiety reduction, muscular relaxation and a decrease in phantom limb pain (Sherman, Gall, & Gormly, 1979). It was also noted that progressive muscle relaxation can be done from a tape recording within the home environment two times per day throughout the treatment process to relieve anxiety and decreasing phantom limb pain. This intervention allowed individuals to identify when their muscles were tense as well as how to relax them when necessary (Sherman, Gall, & Gormly, 1979).

It was reported that progressive muscle relaxation did not alleviate the cause of phantom limb pain, but instead interrupted the course of the “pain-tension-anxiety” cycle (Sherman, Gall & Gormly, 1979). It was suggested that relaxation training be given prior to or simultaneously with other treatment methods to completely eliminate the source of phantom limb pain (Sherman, Gall & Gormly, 1979).

Benefits Proposed Within the Evidence:

- Decrease in phantom limb pain
- Alleviate phantom limb pain
- Decrease anxiety and increase relaxation
- Increase functional performance in daily activities
- Increase in quality of life

Risks:

- No effect on decreasing or alleviating phantom limb pain

Certification or Licensure:

- There are no certification licensure requirements to completing progressive muscle relaxation. It is recommended to be completed by occupational therapists or certified occupational therapy assistants.

- After educating clients on proper techniques of progressive muscle relaxation, clients can continue this intervention within their home environment.

Occupation-Based Application Ideas:

It is recommended that prior to completing progressive muscle relaxation, that a discussion with the client is completed to ensure client-
centered practices are taken and that the client is motivated to participate in treatment. When facilitating progressive muscle relaxation with clients, the individuals sit or lie down in a comfortable position, away from distractions. Continue progressive muscle relaxation throughout the entire body making sure to contract muscle groups for five seconds and then release the tension for another five seconds. This intervention technique, done in conjunction with other treatment methods of phantom limb pain, will increase client satisfaction and overall functional performance in daily tasks.
Desensitization:

What is it?

When a residual limb of an individual who experienced an upper limb amputation is hypersensitive, desensitization intervention methods are utilized to decrease the hypersensitive areas of the residual limb. There are different methods of desensitization which include: transcutaneous electrical nerve stimulation (TENS), compression techniques, massage, tapping, sensory re-education, and/or the use of texture bins for immersion (Schwartz, 2006; Smurr et al., 2008).

Evidence to Support:

In a study by Wartan et al. (1997), TENS units were a successful treatment method in 42% of persons with an upper limb amputation who experienced phantom limb pain. These same individuals had not previously felt any sense of pain relief with any other treatment methods (Wartan et al., 1997).

Common treatment protocols for desensitization consist of 20-30 minute sessions up to three times per day depending on the individual’s skin sensitivity. Family and caregiver education is important during this process as it is critical not to hypersensitize the amputated limb when attempting to increase tolerance of external sensations (Smurr et al., 2008). When re-educating the injured limb, clients are encouraged to integrate all senses to assist. For example, depending on the level of amputation, bilateral hand use is encouraged to examine an object, both physically and visually, before vision is occluded to relay the message between the person’s limb and brain (Schwartz, 2006).

In evaluating an individual’s level of residual limb sensitivity to a variety of sensations, the authors of this manual recommend that a Desensitization Evaluation be completed. This tool will assist clinicians and clients in identifying specific tolerance levels of the residual limb to external stimuli. This will facilitate an individual treatment program of desensitization techniques to be incorporated into the therapy process.

Typical or usual desensitization protocols assist clinicians and client’s to establish a base line tolerance for pain using a variety of tactical sensory stimuli which may include cotton, denim, sandpaper, beans or wood (Daniel & Strickland, 1992).

Benefits Proposed Within the Literature:

- Decrease phantom limb pain
- Alleviate phantom limb pain
- Decrease hyper-sensitivity in residual limb
- Increase functional performance in daily tasks
- Increase in quality of life

Risks:

- No effect on decreasing or alleviating phantom limb pain
- Additional training or certification is needed for use of TENS.
  - NOTE contraindications of TENS units prior to use; do not use if client
has a pacemaker or heart disease
- Be aware of any other medical implications of the client and etiology of pain prior to using a TENS unit
- Recommended establishing physician referral prior to using a TENS unit
- Do not complete desensitization techniques if other medical implications may impede safety of the client

Certification or Licensure:
- No certification or licensure required to complete desensitization techniques
- If using a TENS unit, refer to national and state regulations regarding physical agent modalities certification prior to use regarding if certification or licensure is required

Occupation-Based Application Ideas:

It is recommended prior to completing desensitization techniques, that a discussion with the client is completed to ensure client-centered practices are taken and that the client is motivated to participate in treatment. It is important to note that intervention methods will differ depending upon the level of amputation. Possible occupation-based interventions that incorporate desensitization techniques include grooming pets, washing dishes, folding laundry, making the bed, typing on a computer, mixing food with hands instead of utensils, washing hair, dusting with a rag, leisure activities such as gardening and swimming. These intervention techniques will vary depending on the goals of the clients and roles which they partake in within their daily lives. These activities will increase overall client satisfaction and functional performance in daily tasks.
Module Five: Home Program and Outcomes Measurement
**Home Program:**

The purpose of a home program for the intended use of this manual is to provide continued treatment of clients with an amputation while they are in their natural environment or context. This home program will be dispersed by the occupational therapist to the client as a means for tracking their progress upon returning to their home environment. Depending on the frequency of therapy sessions, it is recommended the client returns the program once a week where a follow up discussion with the occupational therapist will determine client perspective outcome measures.

This program will be a tracking tool for the therapists and will be returned to the client so they may have a record of their progress and a tool to present to their physician if necessary to discuss any concerns regarding phantom limb pain. The home program will provide feedback to the client as a means to increase motivation and participation in intervention activities while in their home environment.

This sample home program has been developed as a guide. Please feel free to adapt the worksheet to your client's needs.
Sample Home Program:

Name: ________________________________________________

Activities to be completed:
____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________

To be accomplished _______ times per day / week for _______ minutes per session.

☐ Mirror Therapy ______________________________________

☐ Phantom Limb Exercises
  o Stretching ________________________________________
  o Strengthening _____________________________________

☐ Occupation-Based Activities ___________________________

☐ Progressive Muscle Relaxation _________________________

☐ Desensitization ______________________________________

__________________________  __________
Signature of Client          Date

__________________________  __________
Signature of Therapist      Date
Sample: Weeks 1-4 Follow-Up Worksheet

Name: _______________________________  Date: __________________

Activities that cause me discomfort: ____________________________________________

__________________________________________________________________________

__________________________________________________________________________

Activities I can do without pain this week that previously caused me pain: ______

__________________________________________________________________________

__________________________________________________________________________

Important activities that I want to do without pain: ____________________________

__________________________________________________________________________

__________________________________________________________________________

Things to tell my doctor and or therapist: _________________________________

__________________________________________________________________________

__________________________________________________________________________

Signature of Client: ________________

Date: ___________________________
Sample Outcomes Measure of Progress

**Directions:** After initial evaluations are completed, therapists can re-evaluate and measure the progress made by each client. Using this form, therapists are able to record performance progress from baseline information to discharge.

**Client Name:** ________________________________

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Initial Evaluation</th>
<th>Discharge from In-patient</th>
<th>Out-patient Follow Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model of Human Occupation Screening Tool (MOHOST)</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
</tr>
<tr>
<td>Disability of the Arm, Shoulder and Hand (DASH)</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
</tr>
<tr>
<td>Beck's Depression Inventory</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
</tr>
<tr>
<td>Dallas Pain Scale</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
</tr>
<tr>
<td>Functional Independent Measure (FIM)</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
<td>Date: Results:</td>
</tr>
</tbody>
</table>

Additional Comments: ________________________________________________________________

__________________________________________________________________________________

Therapist Signature: ________________________________________________________________

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disabilities of the arm, shoulder and hand outcome measure in different regions of the upper extremity. *Journal of Hand Therapy, 14*, 128-146.

CHAPTER V

SUMMARY

The purpose of this manual is to provide occupational therapists with a comprehensive guide to the intervention process when working with an individual with an upper extremity amputation who is experiencing phantom limb phenomena. The manual consists of five modules. Module one provides general knowledge of what phantom phenomena is comprised of as well as additional integral information for client and family education. Module two is an overview of the occupational therapy intervention process as guided by The Model of Human Occupation. Module three describes possible psychosocial concerns resulting from an upper extremity amputation and available assessment tools to evaluate the client’s needs. Physical restoration interventions are described in module four in which purposeful, preparatory, and occupation-based activities are promoted. A sample home treatment program is presented in module five as a tool for therapists to provide their clients for tracking progress made outside of the clinical setting.

The clinical practice strengths of this product include a comprehensive review of the literature for phantom phenomena representing best practice and providing
intervention general information in a user-friendly format. The product is easily transferable and applicable to several age ranges and settings; however it is primarily intended for adults.

One limitation of this educational manual is that it is unable to provide all possible intervention methods that may be effective when working with individuals with an upper extremity amputation as each patient presents with different strengths and weaknesses. Limitations also include the lack of available research in which the authors had access to. Of the available treatment options which are currently being utilized by occupational therapists, there are several that have limited research regarding their effectiveness. Also, due to a lack of knowledge regarding the cause of phantom limb phenomena, it is difficult to determine consistent and effective treatment methods for all individuals who experience this condition.

Anticipated road blocks to implementation of the manual include the cost of production and distribution of the manual, specifically in large quantities. Also, it may be difficult to achieve well known statue, as well as the perception of the manual as being a reputable source of available intervention methods for phantom phenomena. This will be addressed through the authors’ initial distribution of the manual and spreading awareness of the information to healthcare facilities. These issues may require a period of time to address but it is the authors’ intentions to disperse the information throughout the region over a time period of one year.

Further improvement of the product may be necessary to include periodic review and analysis of the literature as well as seeking and performing additional
research regarding the application of intervention methods by occupational therapists within the region.

Potential for further scholarly study of the application of this product includes providing a manual to facilities where the authors become employed. This will increase awareness of intervention methods for therapists who work at the facility. Long term goals for the application of this product include providing educational in-services which the manual is dispersed among occupational therapists and therefore advocating for increased exposure and research of this important topic.

In conclusion, it is recommended that further research be conducted to increase the quality of care clients receive post amputation as well as to increase knowledge regarding the psychosocial impact of phantom limb phenomena. Due to an increase in the number of veterans returning from war with amputations, the authors project that the prevalence of phantom phenomena will increase and therapists will continue to require further information in regards to best intervention methods.
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