RUNNING HEAD: UPPER LIMB DEFICIENCIES AND UPPER EXTREMITY AMPUTATIONS AND THE LIVED EXPERIENCES OF THESE INDIVIDUALS.

A phenomenological study to explore the lived experiences of individuals with congenital upper limb deficiency and acquired upper extremity amputations.

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Abstract

This study was a qualitative phenomenological research study designed to examine the lived experiences of individuals with congenital upper limb deficiencies and acquired upper extremity amputations. The purpose of this study was to better understand the lived experiences of individuals with upper extremity acquired amputations and upper limb deficiencies. The more knowledge available to practitioners will ensure more client centered interventions such as, effective use of one’s prosthetic, personal lifestyle changes, and their ability to adapt to their environment (Davidson, 2002). Through this study the intent is to give the therapists a better understanding of those who have upper limb deficiencies and those who have upper extremity acquired amputations so that the most appropriate adaptations can be made for each particular patient. Information was obtained from a non-standardized questionnaire analysis that was conducted via e-mail, phone conversations and face-to-face interviews with seven participants. Information obtained from the participants was coded by the researchers in which common themes were identified, from the responses made by the subjects. Themes that were generated included self image, adaptation, and fellowship. Each of these themes are discussed and supported by the personal experiences of the participants of the study.
A Phenomenological Study to Explore the Lived Experiences of Individuals with Upper Extremity Acquired Amputations and Upper Limb Deficiencies.

The loss of an upper extremity can result from disease, injury, or from congenital causes. Acquired amputations are defined as any surgical amputation after birth as a result of trauma or disease (Trombly & Radomski, 2002). Whereas congenital limb deficiencies are a loss of a fetal limb, usually the result of an intrinsic deficiency of embryonic tissue (Reed, 2001). Nonetheless, the lack of or the loss of a limb may challenge the individual with a multitude of intricacies such as disability in physical functioning, prosthetic use, pain, changes in employment status or occupation, and alterations in body image and self conception (Desmond & MacLachlan, 2005). The absence of an upper limb, whether congenital or acquired, may result as a traumatic life event with numerous psychological and physical challenges. The response to a loss of an upper limb is highly individualistic and may significantly affect an individual’s quality of life (Butler, Turkal, & Seidl, 1992).

Gilin (1998) stated, “the ratio of persons with upper-limb amputations to those with lower-limb amputations is 1:3.4” (p. 278). Therefore, since relatively few amputations result in upper-limb loss, only a small number of health practitioners have the opportunity to provide services for a significant number of persons with upper limb deficiencies or upper extremity amputations (Gilin, 1998). This investigation aims to further develop the therapeutic relationship that will enhance the therapist’s ability to work with upper limb deficiencies and upper extremity amputees, and also provide insight into the alternating patterns of a person’s life.
The purpose of this study was to better understand the lived experiences of individuals with acquired amputations and congenital limb deficiencies. It is the duty of occupational therapist to have some knowledge of how to treat individuals with upper limb deficiency and acquired upper extremity amputations. Increased quality in the delivery of rehabilitation services for those with upper extremity loss is needed since prosthetic wear, function, and compliance are important aspects to consider for each individual. Having a better insight of the lived experiences of these individuals, will increase the quality of care provided by the occupational therapist.

The following research questions were addressed in this phenomenological study with the objective of targeting the individuals' lived experiences. Areas in which the subjects were questioned within the investigation included: adaptation, social, leisure, vocational and familial aspects of their life

1. How do individuals with an upper limb deficiency adapt to the areas of occupation as defined by the Occupational Therapy Framework: Domain and Process (OTFDP) (AOTA, 2002)?

2. How do individuals with acquired amputations adapt to the areas of occupation defined by the OTFDP?

3. What/who has empowered you to return to previous or start new activities?

4. How do you respond to the intrinsic and extrinsic factors that affect your ability to perform according to the Occupational Therapy Framework: Domain and Process?

5. What has influenced you to use or not use your selected prosthetic device?
The qualitative information gathered will help practitioners become more informed about the lived experience of their patients who come to them with upper limb deficiencies and acquired upper extremity amputations. This insight may result in more client-centered treatment of individuals with upper extremity impairments which includes; identifying what role changes have occurred for the individual and how the person has coped with those changes are important issues to address for future clients in need of occupational therapy prosthetic services.

Literature Review

Prosthetics

It is essential for the occupational therapist to know the basics of prosthetic training in order to enable the client to become proficient in using a prosthetic. An unusually high rejection rate of upper limb prosthesis can be attributed to one or more of the following reasons; one handedness, poor comfort of the prosthesis, poorly made prosthesis, or a lack of sufficient training. The most successful outcomes in prosthetic use for individuals with unilateral and bilateral amputation can be attributed to early intervention, a team approach, and patient education (Upper Extremity Prosthetics, 2003).

Articles regarding the outcomes of individuals with amputations, limb deficiencies, and the success of prosthetics are addressed within the occupational therapy and physical therapy literature. Poole & Parkinson (1980) discussed the lived experience of a 24 year old male who acquired a bilateral shoulder disarticulation as a result of an industrial accident. To accomplish daily activities, he was given two battery powered prosthesis. Because the prosthesis had limitations in range of motion, the areas of dressing, bathing, and toileting were not completed independently. Because of this
limitation, the therapist had to design equipment to help this man achieve independence in the areas in which the prosthesis was not functional.

Davidson (2002) also performed research on how often individuals wore their prosthesis and their level of satisfaction with both their prosthesis and their functional abilities. It was found that 56% of the patients wore their limbs once in awhile or never. The amount of time amputees wore their prosthesis was moderately associated with their level of satisfaction with their prosthesis.

Adaptation to areas of occupation

Concerning treatment process with a client, the occupational therapist must encourage open discussion and instill a climate of trust and respect. Amputation affects not only physical function but also the patient’s life roles in many contexts: maintenance of self, family, and home; self-enhancement, such as engaging in leisure and community activities; and self-advancement as a worker or student (Trombley & Radomski, 2002). With an inability to fulfill the addressed areas of occupation, a person may possess feelings of helplessness, guilt, denial, bitterness, revulsion, or depression. Such stressors challenge the individual’s ability to maintain emotional well-being and may create maladaptive reactions leading to poor psychosocial adjustment (Desmond & MacLachlan, 2005). An additional role for an occupational therapist, or other health professions, involves introducing adaptations which can be made to encompass each individual to live their life to the fullest.

The stages of grieving are universal and are experienced by people from all walks of life but not everyone experiences them all or in the same order. In truth, the process of grief is not a “cut and dried” process that can be subdivided into strict categories.
Mourning occurs in response to an individual's own terminal illness or to the death of a valued being, either human or animal. There are five general stages of normal grief and by dividing the grief process into these "stages" helps the grief stricken person to understand that their experiences and emotions are perfectly normal (White, 1998). Each individual who loses a limb goes through a different process of grieving. Individuals who have upper limb deficiencies may not even experience grieving, as one participant stated “what does it feel like to have two hands”. For those who do experience grief there are five steps: denial, anger, bargaining, depression and acceptance.

Seymour (2002) explained that reactions to a loss of normal function can be divided into various stages, including; shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgment and adjustment. Being aware of these stages can help the clinicians interact appropriately with the patients. In addition, “individuals with an amputation and whom phantom limb pain persists tend to have greater adjustment problems. Conversely, those who regard their health and social support as well and have higher functional abilities and successful stress-reducing mechanisms have better psychological adjustments” (p. 64).

Profound psychological shock and disbelief are likely to accompany amputation, especially for those who experience a sudden trauma that causes amputation. Pedretti (2001) reported that “seeing the residual limb for the first time can cause shock, panic, despair, self pity, suicidal impulses, and even rage. There can be feelings of hopelessness, despondency, bitterness, and anger” (p. 927). Individuals may also mourn the possible loss of a job or the ability to participate in favorite activities as well the loss of the limb. Petretti (2001) also noted that a person may feel lonely, isolated, or an object
of pity. They have concerns about the future, responses of family and friends, employment, body image and function; all of which affect a person's emotional status.

"The person's personality, age, culture background, and psychological, social, economic, and vocational resources influence the reaction to amputation. The individual must come to terms with the consequences of limb loss and perceived diminished attractiveness" (p. 927). The individual may need to change occupations due to social discrimination from cohorts. Coping with their medical problems is an additional challenge.

The primary objective for the individual with an upper extremity amputation or with an upper limb deficiency is linking behavior and activities that can be adapted for skilled performance in their areas of occupation. In one case report, a developmental frame of reference was the basis for a treatment program for a male amputee with traumatic bilateral shoulder disarticulation. "Inherent within the evolution of skill is subcortical organization of postural and perceptual sets which become part of the self-system to be called forth for functional performance" (Garza, 1986, p. 197). The loss of an upper extremity evidently affects independence in performing activities of daily living. As occupational therapists, our aim is to restore independence in the lives of these individuals through the use of adaptation techniques.

**Empowerment to new activities**

Gilin (1998) stated, "the treatment of a person with body powered prosthetics can be very challenging and rewarding. Watching a patient regain their independence is what makes our profession rewarding" (p. 283). Treatment activities were based on a particular patient's activities of daily living evaluation. This treatment plan provided the patient with some control over the direction of treatment, since the patient chose the
particular task to work on during each session. The patient’s motivation was further increased due to this aspect of a client-centered approach.

Trombley and Radomski (2002) discussed rehabilitation as a team approach. The members of the team consist of the physician, prosthetist, occupational therapist, and patients. The occupational therapist is critical to the rehabilitation process because he or she works so closely with the patient. The pre-prosthetic period includes providing emotional support, limb shaping, and facilitating independence in activities of daily living. The therapist established an ongoing, supportive, trusting relationship with the patient and family to facilitate open discussion.

Mendelson (1986) explained how a patient with an upper extremity amputation must be assured that he or she is not alone because approximately one million other Americans have upper limb loss. They must also be made aware that their degree of disability will depend on their ability to accept and adapt to the traumatic amputation (p. 578). In Mendelson’s article (1986) Kessler stated, “these individuals experience extreme emotions when told they must lose a limb. These emotions are even more intense because the person becomes a victim without any choice” (p.581). It is essential for the therapeutic team to help the person progress to new activities. By doing so, the individual will establish a rehabilitated sense of self and feel whole within their environment.

**Intrinsic and Extrinsic Factors**

It was important when the researchers communicated with the subjects to take into consideration the emotional reaction to their trauma. Fitzpatrick discussed how patients tend to avoid the topic of their trauma because talking about it calls upon painful
memories and/or symptoms (1999). The majority of psychosocial research identified by the investigators has almost exclusively focused on the negative impacts the event has on the person’s life and well being exhibited as depression, grief, and body image disturbances. However, there is a danger of presenting a one sided picture of upper limb loss as an inevitably overwhelming negative event from which the person is unlikely to recover. Because of this bias there has recently been an attempt to readdress this balance by identifying factors that promote positive adjustment (Gallagher, 2000).

Methods

Research Design

The research investigation involved a qualitative methodology focusing on a phenomenological design. (Marshall and Rossman 1990). According to Portney and Watkins (2000), a qualitative research method is, “concerned with subjective, narrative information which typically is obtained under less structured conditions. In qualitative methodology, “measurement” is based on open ended questions, interviews and observations as the researcher attempts to capture the context of the data to better understand how phenomena are experienced by individuals” (p.15). Phenomenology is an approach to qualitative research involving the study of complex human experience as it is actually lived (Portney & Watkins, 2000, p.13).

Participants

The study consisted of 7 adult subjects (4 males and 3 females). To be included in the study, participants were required to have a diagnosis of congenital limb deficiency or acquired amputation. Subjects were between the ages of 19 and 80, and resided in the United States. There were no candidates diagnosed with any secondary condition that
could potentially result in cognitive impairment. A sample of convenience was used to congregate participants for this study. Initially there were four individuals with acquired amputations and three individuals with upper limb deficiencies. A number of new participants were added post completion of the initial data collection.

Instrumentation

A non-standardized interview form was devised to capture initial information from participants relative to the detail associated with the research questions. Aspects addressed within the initial interview were background focused questions to get a feel for the participants' lifestyle, living situation and the stage of life they are in. After obtaining the information on each participant, each investigator then came up with an individualized battery of questions for each participant. Additional pilot testing was also completed prior to the commencement of the formal investigation.

Data Collection

Researchers communicated with their subjects via e-mail, face to face interaction, and/or telephone conversations. The type of communication was decided by the participants. This determination was based on what they were most comfortable with, where they lived, and what types of possible communication techniques they had access to. Information was collected through field notes, phone conversations and transcripts from e-mails. These methods of data collection were implemented by the following; course documents, interview transcripts, and observation notes, lesson transcripts, learning diary summaries, questionnaire transcripts and additional notes from the field diary.

Data Analysis
The study utilized the lived experience of individuals with congenital limb deficiencies and acquired amputations. The collected data was combined into a single research study to compare the lived experience of upper limb deficiencies and acquired upper extremity amputations. This study applied the constant comparative method of data analysis (Creswell, 2003). A detailed analysis referred to as a “coding process” was carried out. Creswell (2003) describes coding as “the process of organizing the material into “chunks” before bringing meaning to those chunks. It involves taking text data or pictures, segmenting sentences or paragraphs or images into categories, and labeling those categories with a term, often a term based on the actual language of the participant” (p. 192).

**Trustworthiness**

According to the article by Dudgeon, Tyler, Rhodes, & Jensen (2006), Lincoln & Guba explained how it is essential to focus in on the aspect of trustworthiness due to the fact that the findings of a study can be viewed as worthy of confidence relies on this component. The criteria of credibility, transferability, dependability, and conformability are the essences of what qualitative research is supported by. Credibility was addressed in this study through the use of open-ended questions designed to elicit open discussion regarding the perceptions of the participants’ significant others. A member check was used to maximize credibility, dependability, and conformability of all the responses of the participants. Triangulation of data methods was completed through phone, e-mail, and face-to-face interviews (Earley, 2006). The researchers implemented peer examination to discuss the research process; they discussed the process of qualitative data collection with
their professors and discussed the research findings with impartial colleagues whom have experience with qualitative analysis.

Results

Results of Qualitative Data Analysis

Three themes that were generated from this phenomenological study include: a) Fellowship b) Adaptations c) Self Image. These themes are elaborated upon in the following paragraphs using direct quotes from participants' questionnaires they received from the researchers and also direct quotes the participants stated during phone conversations.

Social Support

The researchers' participants unknowingly defined social support as friends, family and other means of support throughout their lives. This was a common theme noted by the participants about how they were supported by influential people in their lives. One participant with an acquired amputation stated, “there was a girl I grew up with who had a prosthetic hand. It influenced me to wear one without reservation for what others would think about me.” Another individual with an acquired amputation stated, “Family members would help out with things and tell [me] that [I] could do it.” One of the participants who had a congenital limb deficiency made a statement about his family support, “They don’t treat me any different[ly] than any of my siblings and they always encourage me and never tell me that I [can not] do something.” A second congenital described how she is the facilitator for her friends and frequently persuades them to try new activities.

Adaptations
Learning to function independently throughout one’s environment is crucial in society today. The following quotes were gathered from individuals with upper limb deficiencies. One noteworthy statement from a participant with an upper limb deficiency about adapting to leisure activities stated, “it feels natural for me so I don’t really think about how I adapt, I just do whatever it is I’m doing and it normally works out.” A second participant said, “I have not found anything I cannot do.” A third stated, “sometimes you learn to change the ways you do things.” A fourth comment made by a participant was, “no one ever suggested a prosthetic device because they did not have them [in my generation].” A fifth participant shared their experiences with a prosthetic device:

My mother first encouraged me to try using a prosthetic around the age of 10. After using the prosthetic for a year it became my personal decision to stop wearing the device due to the following reasons: the prosthetic was heavy and uncomfortable, especially in the summer months, in which my arm would be warm and sweat with the device on. The prosthetic felt like a foreign object that was always hanging on my arm, in other words “It was not a part of my body, and it felt ‘awkward’”.

A final comment made by a participant in the area of self care was, “I wash without my prosthesis. I can reach all parts of my body from the front and I wash my bottom by putting a wash cloth between my heels.” This is just one example of how an individual can go to extraordinary lengths to adapt to their activities of daily living.

Self Image
The most significant theme that was found throughout all the participant responses concerned self image. Jacobs & Jacobs (2004) defined self image as "an internalized view a person holds of him or herself that usually varies with changing social situations over one's lifespan" (p. 210). A person's self image may be the result of interpretation of personal experiences or by rationalizing the judgments of others. When asked about wearing a prosthetic device one participant stated, "I wear my prosthesis everyday. Its part of me and I feel undressed without it. I wear it like you would shoes. No shoes on the beach...no arm, no shoes in bed...no arm." Another stated about his family, "they have always believed in me and gave me the self confidence to face whatever it was that was challenging." A third stated, "I live a good life and face my share of challenges like anybody else. But I adapt and overcome the best that I can."

When asked about how having a birth defect influenced their life socially a participant with a congenital limb deficiency stated the following:

Being born with one hand has made me the person I am today and I can honestly say I would not want to trade lives with anyone. If I were asked this question as a teenager my answer would have been the exact opposite, at that time all I wanted was to be "normal", and can remember wishing I could be anyone else but myself. I also thought at the time that no one would never fall in love with me, I would never get married and definitely not have kids because I was born with only one hand. Now I am engaged to be married and I have a two year old daughter. I will say that [my] high school or teenage years [were] the hardest time for me, it is a time that the individual strives to be accepted and being different does not
help. I have just a small group of friends then and now, but I know they are true friends.

A major theme within the “self image” category was that all the participants tried to continue activities as they always had prior to their amputation. Those patients with an upper limb deficiency invented their own way to complete tasks. One participant with an acquired amputation stated, “I try to do everything the same as I did prior to the accident. I have more confidence and I work hard to be independent.” A second stated, “If anything I am more sociable now than before my incident. I was real shy back then. Although by people asking me questions now about my amputations, it has helped me to really open up.”

Discussion

With a stable support system most individuals with an upper limb loss can overcome all of life’s obstacles. Reoccurring themes of social support, adaptation, and self image were noted in the comments of the participant’s questionnaires. Both individuals with upper limb deficiencies and acquired upper extremity amputations stated that their lived experiences were joyful; however, some participants from both groups stated that they had feelings of hopelessness and depression. In one case, a participant described how she desired to be anyone in the world other than herself during her adolescent years. It was found that all participants’ family members had an astounding affect on their positive outlooks on life.

Those individuals with upper limb deficiencies were found to need less support or adaptive equipment compared to those who acquired their amputations. Those who are
born with a limb deficiency know no other way of life, which was a mentality supported by the participants.

This study has some apparent limitations. First, the demographic make-up of the participants sample was Caucasian and therefore it was not representative of diverse ethnic groups. Second, the study was limited to 7 subjects which led to limited understanding of the lived experiences of the entire population of acquired amputees and congenital limb deficient individuals. New information was added post completion of the research due to the addition of new participants, which is a limitation due to the inability to exhaust the resources.

Conclusions

The comparison verified the need for more research in this branch of occupational therapy in the lived experience of the participants who have a congenital limb deficiency compared to those with an acquired amputation. It was apparent that those with an acquired amputation went through a “grieving process” and several emotional issues due to the loss of part/all of an extremity, as opposed to those who were born with a congenital limb deficiency. Individual’s born with a congenital limb deficiency did not display as much emotional strife because they were born with the deficiency and do not know any other way of life. One statement from a participant supported this claim, “Often people ask me, ‘how does it feel having only one hand?’ The only response I can give is, ‘it’s fine, how is it having two hands?’”

The themes generated from both populations included the positive effects of fellowship, self image, and adaptation. These themes can be used by occupational therapists as well as other professions in helping to treat or care for individuals with
upper limb amputations and upper limb deficiencies. The themes gathered from the research further validated the necessity for occupational therapy within this population. It is crucial for occupational therapists to respect the client’s choice to wear or not wear a prosthetic device. Education on the necessary prosthetic options are vital in the intervention (i.e. no prosthesis, passive functional/cosmetic, body/powered/conventional, myoelectric/external power, hybrid, and adaptive). The therapist can prepare the client during the preprosthetic phase by showing prostheses that are appropriate to the amputation level. Training to use the residual limb to adapt to his or her environment, if the individual chooses not to wear a prosthesis, is also a decisive element to the therapeutic process. “A collaborative relationship between therapist and patient instills a sense of control in the patient” (Trombly & Radomski, 2002, p. 1047). The clinician must also assist in the psychological adjustment to limb loss. The client’s performance in daily living skills can be further enhanced in the therapeutic process by centering goals on purposeful, meaningful, functional activities.

The analysis of the questionnaires obtained from the participants confirmed an evident pattern. Individuals who have an acquired amputation will do whatever it takes to return to previous activities while living a satisfying, meaningful, and purposeful life. Their amputation becomes a part of them but does not dominate nor prohibit them from achieving their dreams and aspirations. Individuals with upper limb deficiencies adapt from birth because they know no other way of living.

Recommendations for further research: (a) expand the study to a larger population including a diverse ethnic group and age range; (b) increase the amount of face to face contact between the researcher and subjects and also include group
collaboration if feasible; (c) researchers should expand their relationship with other supporting health professions to increase the clinician’s knowledge on acquired amputees and congenital limb deficient individuals, including but not limited to, prosthestists, spouses, family members, occupational therapists, physical therapists, social workers, and psychologists.
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