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Content Analyses of *A Priori* Qualitative Phantom Limb Pain Descriptions and Emerging Categories in Mid-Southerners with Limb Loss

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Abstract

Purpose: The purposes of this descriptive study were (a) to identify the relative frequencies of *a priori* categories of phantom limb pain (PLP) quality descriptors reported by Mid-Southerners with limb loss, (b) to analyze their descriptions for emerging categories of PLP, and (c) to identify the relative frequencies of the emerging categories.

Design: This cross-sectional descriptive verbal survey assessed PLP descriptors. A content analyses determined relative frequencies of *a priori* PLP descriptors as well as emerging categories that were identified.

Findings: The most common *a priori* PLP quality descriptors reported by 52 amputees with PLP were intermittent, tingling/needles/numb, sharp, cramping, burning, and stabbing. The most common emerging categories reported were pain compared to illness/injury, electrical cyclical, and manipulated/positional.

Conclusion: The detailed descriptions of PLP provide insight into the vivid experiences of PLP.

Clinical Relevance: Rehabilitation nurses can use this information with PLP assessment, patient teaching and counseling.

Keywords: Phantom Limb Pain, Amputee, Pain Quality Description

Introduction

Rehabilitation nurses play a pivotal role and work very closely with persons recovering from amputation. Pain management is a primary role of all nurses. Nurses spend more time at the bedside than any other profession, and are an integral part of recovery after an amputation. A comprehensive knowledge of the personal experience of limb loss, especially pain associated with the missing or phantom limb (PLP) will enable nurses to provide reassurance and education about a pain that often causes anxiety by its very existence.

Phantom limb pain is pain that feels as though it is coming from a limb that has been amputated (R. Sherman, 1997). The prevalence of phantom limb pain was reported to be 72%-85% (Ehde et al, 2000; Ketz, 2008; Sherman R. & Sherman C., 1985; van der Schans et al, 2001). There is much variability in PLP intensity, and it can have a high intensity at times. Limb loss affects about 1 in 190 persons in the United States and could double within the next 30 years (Ziegler-Graham, MacKenzie, Ephraim, Trivison, & Brookmeyer, 2008).

Background and Significance

Several studies have reported on the severity of PLP intensity and report that a person with limb loss may experience PLP for years after an amputation, and report PLP is chronic and varies in intensity (Ehde et al., 2000; Gallagher, Allen, & Maclachlan, 2001; Jensen, Smith, Ehde, & Robinsin, 2001; Smith et al., 1999). Many studies have documented the presence or intensity of PLP but another dimension of PLP is the quality of pain or pain quality

descriptors. Pain quality descriptors describe the unique sensation or feeling of the pain experience (R. Sherman, 2004). Common PLP quality descriptors include hot/burning, cramping, shocking/shooting, tiring, squeezing or tight band around the arm or leg, and abnormal position (Dubuisson & Melzack, 1976; Ehde, et al., 2000; R. Sherman & C. Sherman, 1985). Although PLP is classified as a neuropathic pain, PLP quality descriptors are important to study and document because different descriptions of PLP have been linked to specific etiologies (R. Sherman & Bruno, 1987; R. Sherman, Griffin, Evans, & Grana, 1992). Burning PLP has been linked to decreased blood flow to the residual limb and cramping PLP has been linked to an increase in muscle tension. Although the prevalence of PLP quality descriptors may give great insight to common etiologies and experiences, there have only been a few that have reported the relative frequencies of PLP quality descriptors across patients.

The most recent study conducted on PLP pain quality descriptors, is almost a decade old, and does not report relative frequencies (Mortimer, Steedman, McMillan, Martin, & Ravey, 2002). However, qualitative descriptions of the PLP experience are reported. Data were gathered with a focus group methodology to assess perceptions related to the PLP experience and health education needs in persons from Scotland, not solely on the PLP lived experience.

Crawford (2009) wrote a position paper PLP and the McGill Pain Questionnaire (MPQ) and how it articulated PLP quality descriptors through providing assessment of specific descriptions of pain, therefore providing the authenticity to PLP. There are a limited number of studies that reported open ended questioning of PLP qualitative descriptors and most are old. There are numerous nursing articles focused on the overall care of persons after limb loss (Ellis, 2002; Fieldson, 2011, & Richardson, 2008). However, there were no articles discovered specifically reporting PLP quality descriptors in nursing journals. Since nurses work most closely with persons in pain, and have a greater role working with persons after an amputation, nurses will benefit from a comprehensive understanding of PLP quality descriptors from the patient perspective.

The understanding of quality descriptors is also important for different geographic regions since certain subgroups of the population rely on their own vernacular phrases to describe health conditions. Colloquial expressions are particularly important in the Southern United States where there are long traditions of ethnic customs traceable to original immigrant groups (Lobov, Ash, & Boberg, 2006). The unique Southern dialect gives a personal voice to the subjective experience of PLP.

The paucity in narrative reports of the PLP experience suggests that there should be further qualitative investigations of the subjective pain experience. A common and well validated pain assessment tool, the McGill Pain Inventory, introduced the use of pain quality descriptors that are single words (Melzack, 1975). Although this instrument is widely used for many different pain situations, PLP is unique because the area of pain is not physically present. A full description of the pain experience that is not limited to a single word may provide a more comprehensive understanding of both the individual experience and possible etiologies.

It is a reasonable assumption that more detailed descriptions could provide a more comprehensive understanding that rehabilitation nurses can apply to patient teaching and counseling. Phantom limb pain can be quite distressing to patients who can be reluctant to discuss this with clinicians (Whyte & Niven, 2004). Nurses who understand the detailed description associated with PLP are very important for counseling patients to re-assure them that this phenomenon is real and has been documented previously in the scientific literature.

The Mid-Southern United States (Alabama, Arkansas, Kentucky, Mississippi, and Tennessee) is an area that has a population with many risk factors for limb loss. These states include the highest rates of diabetes (Trust for America's Health, 2008) obesity, smoking, and concentrated poverty (Bishaw, 2005) in the United States. Although this population is at risk, there were no studies discovered that specifically report PLP quality descriptors in Mid-Southerners living with limb loss. The purposes of this descriptive study were (a) to identify the relative frequencies of a priori categories of PLP quality descriptors reported by Mid-Southerners with limb loss, (b) to analyze their descriptions for emerging categories of PLP, and (c) to identify the relative frequencies of the emerging categories.

Materials and Methods

Study Design

This study includes data that were obtained from the interviews that were part of the University of Tennessee Limb Loss Study. The study was approved by the University of Tennessee Health Science Center Institutional Review Board (UTHSC IRB). This descriptive cross-sectional study was conducted using an interviewer-administered structured questionnaire with persons living with limb loss living in the Mid-Southern United States (Alabama, Arkansas, Kentucky, Mississippi, and Tennessee). Participants were interviewed once, and the interviews were conducted either face-to-face or over the telephone. Interviews were conducted using a verbal survey because it was anticipated that some participants might have low literacy skills (National Institute for Literacy, 1998). The responses to the survey were recorded in writing.

Site

Participants were interviewed either by phone or face-to-face at a location of their choosing.

Sample

A purposive, convenience sampling method was used to recruit participants from the Mid-Southern United States. Participants were recruited through various sources including 1) limb loss support groups; 2) direct traditional mailing from an amputee advocacy group; 3) prosthetic practices; 4) physical or occupational therapists; 5) individual health care providers; and 6) electronic and print media.

Inclusion criteria for the study included 1) community-dwelling persons; 2) limb loss at a higher level than a finger or toe; 3) residency in the Mid-South area; 4) age 18 years or older; 5) at least six months post-operation from the last amputation or revision; 6) ability to understand spoken English; 7) ability to communicate verbally; and 8) positive report of PLP.

The Mid-South was chosen because the demographics and health status characteristics of Mid-Southerners contribute an increased risk for amputation, and Mid-Southerners are under-represented in PLP studies. The states within the Mid-South share a common culture and a common southern dialect that may influence the language of a subjective response. All participants answered for themselves to capture the unique subjective experience.

Instrument

All interviews were conducted by the PI. To begin the interview, the PI introduced herself to the participant and provided a verbal, detailed description of the research study that included a UTHSC IRB approved verbal consent statement. No written consent was required by the UTHSC IRB because participation in a verbal survey is considered minimal risk, with no procedures for which written consent outside of the research context would be required. (UTHSC IRB, 2004) The telephone interview was conducted identically to the face-to-face interview. All participants were sent a thank you letter for their participation at the end of the study.

The entire survey asked questions about demographics, function and pain and lasted about an hour. Only the open-ended responses to the phantom limb pain quality descriptor question are reported here to remain consistent with the conceptual framework of this report's study objectives and analyses. To measure demographics, participants were verbally asked to self-report age, recorded in years, gender, race/ethnicity, and education in years of school completed. The greater study had a total of 62 participants that were given a comprehensive pain assessment using the pain map from the MPQ to assess for all pain locations. Pain that felt as though it originated distal to the level of amputation was defined as phantom limb pain. Only participants that reported positive pain in this area were included in this analysis. A detailed assessment was conducted of the phantom limb sensations. To assess for pain quality descriptors specifically, all participants were asked, "Tell me what your PLP feels like." The participant's response was recorded in writing. Responses were recorded in writing because it was thought that this vulnerable population might have better trust with the interviewer if there were no recording devices. The assessment was administered without any prompts from the interviewer that might influence how the respondent answered this question.

Analyses

A content analyses was performed with *a priori* categories. The categories chosen were from previous studies that report PLP relative frequencies described above (R. Sherman & C. Sherman, 1985, Dubuisson & Melzack, 1976). These studies were chosen because they were original research articles that gathered data on qualitative descriptors and reported the relative frequencies of the PLP quality descriptors. The presence of PLP qualitative descriptors was also reported by Mortimer (2002) and these categories are reported as this was the most recent study discovered that described PLP quality descriptors. Responses that were consistent with the *a priori* categories were summed and the relative frequencies were calculated using the methods described by Krippendorff (Krippendorff, 1980).

To conceptualize the new emerging categories, a qualitative analysis of the existing data was guided by grounded theory methodology as described by Glaser and Strauss (1967). Two researchers separately analyzed these qualitative data for emerging categories. Both reviewers then came together and triangulated their results by comparing which categories emerged, and how they defined which responses fit in each category. To increase the truthfulness of the data, the reviewers discussed the rationale for their choices if their choices were not consistent and came to a mutual agreement. Then, the reviewers consulted with a content expert to further increase the credibility of the qualitative analyses. A content analyses was performed on the newly emerged categories to determine the relative frequencies consistent with the Krippendorff methods described with the *a priori* categories (Krippendorff, 1980).

Results

Demographics

The University of Tennessee Limb Loss Study had a sample of 62 participants. For this analyses, only the participants (n=52) that were in pain, and able to answer the specific question to assess pain quality were included. The sample demographics are located in table 1.

Phantom limb pain quality descriptors *a priori* categories

The results of the *a priori* PLP quality descriptors are located in Table 2. The most common *a priori* PLP quality descriptors were intermittent, tingling/needles/numb, sharp, cramping, burning, and stabbing. The PLP quality descriptors that participants reported were categorized in these anticipated categories showed greater detail. These descriptors were sometimes reported as a standalone term, but were also reported or described within a detailed descriptive phrase.

Intermittent. The temporal pain quality descriptor intermittent was described in many ways-and although intermittent is the term used in healthcare, no study participants used this term. Intermittent pain was described as, “pulsates/stabs real quick,” “instantaneous zingers,” “most are oscillating or shooting 3 seconds to 2 minutes apart,” “can last for 30 seconds or couple hours,” and “not a steady pain, but in waves.”

Tingling/needles/numb. The descriptions in this category are consistent with paresthesias. Paresthesias are associated with neuropathic pain syndromes (Devor, 1991). Since PLP is classified as a neuropathic type of pain, it should be assumed that these would be a common experience with persons who have PLP. Exemplars of qualitative descriptors reported were, “like when foot asleep wakes up only much worse,” “tingling,” and “numb swirly.”

Sharp. Sharp is a descriptor that has been reported in the literature and was used by the study participants. The detail of the sensations were described in these exemplars, “sharp needles,” “so sharp it just stops in tracks; sharp, like a real bad sting,” and “like a sharp cramp; starts like a wasp sting, real sharp, for a few seconds/sometimes for several hours before subsides – sharp stinging.”

Manipulated or Positional. This category is similar to the *a priori* category abnormal position. The descriptions suggest that the limb or pain of a limb is being manipulated by an external object or being pressed against the floor. This manipulation may feel like someone or something is squeezing the missing limb. Sherman and Sherman describe an abnormal position which is very similar to this description (R. Sherman & C. Sherman, 1985). Hunter et al described similar reports of upper extremities being manipulated into a position for example a digit being pushed into other digits or that the phantom limb was reported to be stuck in a painful position (Hunter, Katz, & Davis, 2008).

This has not been reported previously as a category, but is consistent with a qualitative description by Mortimer et al (2002) who reported PLP was like having one's toes in a vice. Exemplars of the qualitative descriptors reported were, "toe and foot feel like it is cramped up, drawn up," "feel feet on the floor," and "Feels like someone is squeezing foot-tying rope around big toes."

Cramping. The term cramping was specifically used by participants, and the descriptions suggest that the intensity can vary. Exemplars of the qualitative descriptors of cramping were, "cramp - like a dull pain," "Strong cramp," and "(calf muscle) like a cramp from when I was playing sports." **Stabbing.** There were some participants that described stabbing as a descriptor of pain without elaborating. Exemplars of this description were "when bad - sharp stabbing," "Stabbing," and "Pulsates/stabs real quick." There were also participants that described being stabbed by a foreign object. The graphic descriptions of being a stabbed in the phantom limb were very detailed, and provide more insight to the term "stabbing". The objects reported to stab the phantom limb were either sharp or hot. This is consistent with a qualitative description by Mortimer et al (2002) who reported PLP was like having a needle in their leg. Exemplars of the qualitative descriptors reported were, "gauging foot with a sharp object, like a nail or ice pick," "Hot Poker," and "Pin prick then ice pick."

Dull. Dull is a sensory descriptor included in the MPQ (Melzack, 1975). Mortimer et al (2002) reported dull by one respondent in their qualitative report. However, no previous quantitative studies that included dull as a PLP quality descriptor, which is why we classified dull as an emerging category. Exemplars of qualitative descriptors reported were, "dull throb," and "cramp - like a dull pain."

Findings of Emerging Categories

The following emerging categories are consistent and not in disagreement with one-word pain quality descriptors (Dubuisson & Melzack, 1976; Ehde, et al., 2000; R. Sherman & C. Sherman, 1985). However, this data includes thick, rich data describing details that are consistent for most participants which add to the understanding of PLP.

Compare to injury or illness. The Selective code that emerged to drive the analyses was that PLP descriptions were described in metaphor to previous or imagined painful injuries or illness. This may have been an effort to communicate how real and personal the suffering is for persons with limb loss. This descriptor was not reported in quantitative studies, but was reported in a qualitative focus group study where PLP was compared to a previous wound (Mortimer, et al., 2002). The comparisons included descriptions such as, "just feel like you do when you have a bad case of the arthritis," "body ache like playing football" and "Numb like a frostbite."

Electrical Cycles. This category could represent the pain experience reported in the literature as shocking or shooting (R. Sherman & C. Sherman, 1985). However, in this sample population the word electrical was overwhelmingly used in place of the term shock or shooting. The data suggest an experience very similar to that which would be experienced if one received an electric shock that lasts a short period of time and then repeats. This cyclic repetition is why the term "cycles" was added to increase the veracity of this category title. Exemplars of qualitative descriptors reported were, "like an electric fence when it is real bad electric/tingling cycle get hit stop will hit again so you anticipate it because you know another one is coming," and "electrical impulse and right leg jumps this happens often."

Deal with it. There were study participants that reported how they felt about their pain as a way of describing it. This category illustrates the emotional response to pain. The affective response may have also been given to try to explain what others have told them about their pain, or to express the human element of suffering of the pain, not just a concrete explanation about the experience. Exemplars of qualitative descriptors reported were, "don't want it there, but you deal with it," "just pains so it gets so you can't hardly take it."

Itch. The category of itch describes a feeling that may not be bothersome to one who is able to scratch an itch. However, persons with limb loss describe having an itch that can't be scratched as an uncomfortable or painful experience as there is not relief. Exemplars of qualitative descriptors reported were, "ankle itches or hurts a little bit," and "throbbing, itching kind of thing."

Want to do an activity. Participants reported that they wanted to do something about the pain. This can be manipulating the residual limb or other self-care measures to relieve the pain. It can also include wanting to manipulate the missing limb but being unable to do that. Exemplars of the qualitative descriptors reported were, “feels like I want to rub it, but it is not there,” and “Toe cramp - often times hits - look for pressure points to calm down sensation.”

Pressure. This term was used to describe pressure and included greater detail than the single word pressure. For example pressure was used to describe a sensation of an internal pressure pushing outward. Exemplars of qualitative descriptors reported were, “burning, pressure,” “fine pressure,” and “Internal pressure pushing outward – about to explode.”

Hard. The term hard may be descriptive of the intensity or an affective term as well as a sensory descriptor. The term hard has been used in the lay literature and in Blues music lyrics to indicate a struggle or suffering. This may be an example of a southern cultural description of pain and suffering rather than a classic PLP descriptor. However, it may be an important term to assess the affective response to pain for persons who share the Mid-South culture. Exemplars of qualitative descriptors reported were, “kind of hard – just feels like pain,” and “just a hard hurt.”

Content analyses of emerging categories

The relative frequencies of the emerging categories are listed in Table 3. The most common were compared to previous injury or illness including electrical cycles, deal with it (affective response), and itch.

Discussion

There were *a priori* categories that clearly were consistent with previously reported literature. This demonstrates that the sensory pain quality descriptors assessed in this study were consistent with previous descriptors reported from persons not given specific prompts. The thick pain quality descriptions added richness to what has been reported by using only one single term to describe pain quality. The contribution of this study is that the exemplars cited provide information that is rich and detailed for clinicians and researchers to understand the personal experience of PLP that is not captured by single word pain quality descriptors. These descriptors provide insight to this population at risk for limb loss and their unique language of pain, relatively consistent with classic reports. This information can be used as part of patient education to re-assure persons with limb loss who are unaware that anyone else has ever had these sensations.

The emerging categories from the vivid descriptions that participants used to express PLP provide insight into this experience more vividly than a standardized single word descriptor. The detailed descriptions reveal a deeper understanding of PLP personal experience than information gathered using a numeric intensity rating, or standardized pain quality descriptors. Specific details that were frequently repeated within this cohort of participants demonstrated that these personal experiences are common in persons with limb loss who report PLP. These sensations can be anticipated in persons with limb loss, although all pain is subjective and personal and PLP is not reported by all persons with limb loss. Comparing pain to a situation shows a level of sensation that is more than a nuisance, but a graphic and real sensation.

The content analyses of emerging categories showed that the most common category was the use of metaphors to describe PLP by comparing it to an illness or injury. This information shows us that although PLP is unique in that the sensation coming from a missing limb, the participants very much wanted to emphasize the reality of his or her experience with PLP. The descriptions of the quality of PLP revealed a comparison to a situation or experience, rather than a single word descriptor. These vivid descriptions were repeated within this sample, suggesting that although these experiences are not universal among persons with limb loss, they are common. Since the study participants described situations in detail, perhaps qualitative assessment of PLP should not consist only of single word descriptors common to most assessment instruments, but should include more descriptive phenomenon.

Conclusion

Directions for future nursing research of phantom limb pain might include the details included in the emerging categories as prompts for PLP quality assessment. These descriptions may also provide a link to the physiological etiology that contributes to PLP. The development of a PLP quality assessment tool and its evaluation would be provide valuable information into how these study results can translate into practice. The development and evaluation of a patient teaching tool would be beneficial to PLP management.

Rehabilitation nurses work very closely with patients during recovery from an amputation, and have the opportunity to educate and reassure patients who suffer not only from pain but the fear and anxiety of horrific sensations that are not externally witnessed. An amputation is a seminal event that increases pain and decreases function. Phantom limb pain can cause human suffering from both the pain itself as well as the confusion about the experience. Phantom limb pain is not frequently discussed by persons with limb loss with health care providers (Whyte & Niven, 2004). Rehabilitation nurses can encourage patients to discuss their pain experiences with reassurances that PLP is experienced by most persons with limb loss and that specific pain quality descriptors are common. A comprehensive nursing assessment of pain quality descriptors might include open ended items of questioning, followed with PLP pain quality descriptor from both the *a priori* quality descriptors and the emerging categories. Furthermore, these categories can guide patient teaching as well.

Rehabilitation nurses have the opportunity to alleviate fears regarding the phantom limb pain experience. Knowledge of the details that are common experiences reported by persons with limb loss allows the rehabilitation nurse to provide comprehensive patient teaching. The paucity of original nursing research of PLP descriptors suggests that there is a knowledge gap in all nurses in this area, and this study can be put to use in both PLP assessment and education. Rehabilitation nurses can provide comfort and reassurance that these specific sensations are actually commonly described in persons with limb loss.

Limitations

This study sample included participants recruited from only the Mid-South. This limits the transferability of the data results because persons of other cultural backgrounds may use different words to describe a similar sensation. Another limitation is that there is much diversity regarding the reason for limb loss, the time since amputation, the amputation location, and amputation level. The responses were all recorded in writing using the study participants own words. Since the survey was not recorded there is a chance that the statements may not be complete.

Diversity of factors contributing to amputation and the recovery process is difficult to control because each subject has a unique limb loss experience. The very similar descriptions and relative frequencies suggest that these pain quality descriptors are very common. Since the data was not a classic qualitative study, but part of a larger study, saturation was not a factor in how many subjects were in the study.

Lincoln and Guba (1985) have proposed that trustworthiness of qualitative data is maintained through credibility, transferability, dependability, and confirmability. Credibility was demonstrated through the commonalities of the PLP pain quality descriptors. Credibility may be compromised since this is a cross-sectional study without prolonged engagement. There may be limited transferability since the population was from one geographic area. However, many PLP quality descriptors were consistent with *a priori* categories. Dependability was increased through inclusion of two researchers that separately analyzed the data then triangulated it and was further demonstrated with consultation with a content expert. The content expert was in agreement with both the *a priori* and emerging categories and was instrumental in reinforcing the intermittent or cyclical nature of the electrical sensations. One analyzer was very familiar with PLP and one was a novice, agreement between these analyzers demonstrates that there was confirmability in the data.

Findings from this qualitative study on PLP provide personal and vivid detail on this pain syndrome. These findings show descriptors consistent with previous literature as well as full descriptions that capture the pain quality experience unique to the Mid-Southern culture. This information can guide PLP assessment of all pain domains as well as serve as a resource for rehabilitation nurses to provide reassurance and comfort to persons with limb loss through patient teaching about common experiences.

References

- Bishaw, A. (2005). Areas With Concentrated Poverty: 1999, *Census 2000 Special Reports*, Retrieved from <http://www.census.gov/prod/2005pubs/censr-16.pdf>
- Devor, M. (1991). Neuropathic pain and injured nerve: peripheral mechanisms. *British Medical Bulletin*, 47(3), 619-630.
- Dubuisson, D., & Melzack, R. (1976). Classification of clinical pain descriptions by multiple group discriminant analysis. *Experimental Neurology*, 51(2), 480-487.
- Ehde, D. M., Czerniecki, J. M., Smith, D. G., Campbell, K. M., Edwards, W. T., Jensen, M. P., et al. (2000). Chronic phantom sensations, phantom pain, residual limb pain, and other regional pain after lower limb amputation. *Archives of Physical Medicine & Rehabilitation*, 81(8), 1039-1044.
- Ellis, K. (2002). A review of amputation, phantom pain and nursing responsibilities. *British Journal of Nursing*, 11(3), 14-27.
- Fieldsen, D., & Wood, S. (2011). Dealing with phantom limb pain after amputation. *Nursing Times*, 107(1), 11-17.
- Gallagher, P., Allen, D., & Maclachlan, M. (2001). Phantom limb pain and residual limb pain following lower limb amputation: a descriptive analysis. *Disability & Rehabilitation*, 23(12), 522-530.
- Glaser BG, & Strauss, A. L. (1967) *The Discovery of Grounded Theory; Strategies for Qualitative Research*. Hawthorne, NY: Aldine Publishing Company.
- Hunter, J. P., Katz, J., & Davis, K. D. (2008). Stability of phantom limb phenomena after upper limb amputation: A longitudinal study. *Neuroscience*, 156(4), 939-949.
- Jensen, M. P., Smith, D. G., Ehde, D. M., & Robinsin, L. R. (2001). Pain site and the effects of amputation pain: further clarification of the meaning of mild, moderate, and severe pain. *Pain*, 91(3), 317-322.
- Ketz AK. (2008) The experience of phantom limb pain in patients with combat-related traumatic amputations. *Archives of Physical Medicine & Rehabilitation*. 89, 1127-1132.
- Krippendorff, K. (1980). *Content Analyses; An Introduction to its Methodology*. Beverly Hills: Sage Publications.
- National Institute for Literacy, (1998). *The State of Literacy in America: Estimates at the local, state, and national levels*. Retrieved from <http://www.nifl.gov>.
- Lincoln, YS. & Guba, EG. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Lobov, W., Ash, S., & Boberg, C. (2006). *The Atlas of North American English*. Berlin: Mouton-de Gruyter.
- Melzack, R. (1975). The McGill Pain Questionnaire: major properties and scoring methods. *Pain*, 1(3), 277-299.
- Mortimer, C. M., Steedman, W. M., McMillan, I. R., Martin, D. J., & Ravey, J. (2002). Patient information on phantom limb pain: a focus group study of patient experiences, perceptions and opinions. *Health Education Research*, 17(3), 291-304.
- Richardson, C. (2008). Nursing aspects of phantom limb pain following amputation. *British Journal of Nursing*, 17, 7, 10-23.
- Sherman, R. A. (2004). *Pain Assessment and Intervention from a Psychophysiological Perspective*. Wheat Ridge, CO: Association for Applied Psychophysiology and Biofeedback.
- Sherman, R. A. (1997). *Phantom Pain*. New York: Plenum Press.
- Sherman, R. A., & Bruno, G. M. (1987). Concurrent variation of burning phantom limb and stump pain with near surface blood flow in the stump. *Orthopedics*, 10(10), 1395-1402.
- Sherman, R. A., Griffin, V. D., Evans, C. B., & Grana, A. S. (1992). Temporal relationships between changes in phantom limb pain intensity and changes in surface electromyogram of the residual limb.. *International Journal of Psychophysiology*, 13(1), 71-77.
- Sherman, R. A., & Sherman, C. J. (1985). A comparison of phantom sensations among amputees whose amputations were of civilian and military origins. *Pain*, 21(1), 91-97.
- Smith, D. G., Ehde, D. M., Legro, M. W., Reiber, G. E., del Aguila, M., & Boone, D. A. (1999). Phantom limb, residual limb, and back pain after lower extremity amputations. *Clinical Orthopaedics & Related Research*(361), 29-38.
- Trust for America's Health, (2008). *Shortchanging America's Health 2008*, Retrieved from <http://healthyamericans.org/reports/shortchanging08/>.
- University of Tennessee Health Science Center Institutional Review Board (2004). IRB 005 UTHSC IRB Informed Consent Retrieved 8-29-09, from http://www.utmem.edu/research/research_compliance/IRB/docs/sops/SOP05.pdf.
- Whyte, A., & Niven, C. A. (2004). The illusive phantom: does primary care meet patient need following limb loss? *Disability & Rehabilitation*, 26(14-15), 894-900.

- Wilkins, K. L., McGrath, P. J., Finley, G. A., & Katz, J. (2004). Prospective diary study of nonpainful and painful phantom sensations in a preselected sample of child and adolescent amputees reporting phantom limbs. *Clinical Journal of Pain, 20*(5), 293-301.
- Ziegler-Graham, K., MacKenzie, E. J., Ephraim, P. L., Travison, T. G., & Brookmeyer, R. (2008). Estimating the prevalence of limb loss in the United States: 2005 to 2050. *Archives of Physical Medicine & Rehabilitation, 89*(3), 422-429.

Table 1.	
<i>Demographics of study participants</i>	
Demographic	Mean \pm SD, Range or Percent
Race/Ethnicity	White 67.3 %
	Black/African American 23.1 %
	Other 9.6 %
Gender	Male 71.2 %
Age	52.5 \pm 14.7 Years
Lower limb loss only	88.5 %
Intact knee or elbow on affect limb	51.9 %
Mean time since amputation	7.1 Years (Range 0.5-39.0)

Table 2

Responses compared to previous studies that reported qualitative phantom limb pain descriptions

<i>A Priori</i> Category	Findings (Open Questioning)	Dubuisson & Melzack (Prompted)	Ehde et al (Prompted)	Mortimer et al (Open Questioning)	R. Sherman and C. Sherman (Open Questioning)
Inter-mittent, rhythmic or Episodic	35%	Rhythmic 63%	Episodic	Episodic	
Tingle/Tingling	(Tingle/Tingling 10%) (Tingle/Needles/ Numb 29 %)		77%	Severe Tingling Tingling Pins & Needles	13-14%
Sharp Shock/Shooting	(Sharp 25%) (Shock 6%) (Shooting 6%)	Sharp 38%	Sharp 78% Shooting 76%	Shooting	32-33%
Unusual Position	0% (Manipulated/ Positional 23 %)				4%
Cramping	19%	50%		Cramping Cramp	14-15%
Stabbing	17% (By foreign object 15 %)	50 %	72%	Stabbing	
Burning	17%	50%		Burning	
Aching	10%	38%	56%		
Dull	4%			Dull	
Throbbing	2%	38%	67%		
Constant	2%	88%		Daily/Constant	
Hot	2%				14-15%
Squeeze	2%				13-16%
Broken	2%				0.3-1.0%
Tiring	0%	50%			
Exhausting	0%	38%			
Cruel	0%	38%			
Warm	0%				3-8%
Past Wound	0%			Past wound	
Juddering	0%			Juddering	

*A priori categories were obtained from previous studies by Dubuisson and Melzack (1976), Ehde et al (2000), Mortimer et al (2002), and R. Sherman and C. Sherman (1985).

Emerging category	Relative Frequency
Compare to injury or illness	35%
Electrical Cycles	25%
Deal with it	19%
Itch	17%
Want to do activity	6%
Pressure	4%
Hard	4%