PAIN CONTROL METHODS IN USE BY PATIENTS WITH EHLERS-DANLOS SYNDROME AND PAIN CONTROL EFFECTIVENESS

A Thesis
by
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Abstract

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The purpose of this study is to assess the pain control methods in use by patients who have Ehlers-Danlos Syndrome, a group of connective tissue disorders. This descriptive study involved 1179 adults diagnosed with Ehlers-Danlos Syndrome who completed an anonymous on-line survey. The survey consisted of demographics information, the PROMIS Pain-Behavior, Pain-Interference, and Satisfaction with Social Roles and Activities scales, as well as a modified version of the Pain Management Strategies Survey (PMSS). Among the treatment modalities participants reported in this study, the most helpful for acute pain control were opioids, surgical interventions, splints and braces, heat therapy, nerve blocks, and physical therapy. Chronic pain was treated most effectively with opioids, heat therapy, splints or braces, and surgical interventions. Knowledge of pain management practices and perceptions of benefit is important for understanding how to support individuals with Ehlers-Danlos Syndrome. Increasing knowledge in this area could help clinicians better advise individuals who experience persistent pain as to pain management strategies most likely to be considered beneficial by the patient.

Dedication

I would like to dedicate this work to the participants, without whom this would never have been possible. For my fellow Zebras, may we continue to make history. Thank you for contributing to this dream and working to take our search for treatments, comfort, and a good life in our own flexible skins to the next level.

Acknowledgments

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Table of Contents

Chapter 1: Introduction

Ehlers-Danlos Syndrome (EDS) is a group of inherited connective tissue disorders associated with defective production of collagen (Berglund, Anne-Cathrine, & Randers, 2010; Rombaut, Malfait, Cools, De Paepe, & Calders, 2010; Voermans, Knoop, Bleijenberg, & van Engelen, 2010). The disorder has been categorized into six sub-types based on the symptoms exhibited by each category of patient. Of these types, Hypermobility Type (EDS-HT) is the most severe with respect to chronic pain, and the most commonly occurring. Other types of EDS can be equally debilitating, causing not only pain and fatigue but also profound disability or deformities to EDS patient's joints. The musculoskeletal functioning of the patients inflicted with this condition can be dramatically affected and reduced by patient symptoms of joint laxity and frequent dislocations, eventually leading to disability (Rombaut et al., 2010). With recent estimates suggesting that EDS may be as common as 1:5000 (Berglund et al., 2010; Rombaut et al., 2010) and dramatically under-diagnosed, there is clearly a need for research on the most effective methods to manage the chronic pain present in patients with EDS and to prevent the disability that is common with EDS.

Pain that is poorly controlled in EDS-HT patients can lead to disability, depression, anxiety, and other mental and physical health concerns that interfere with daily functioning. A cycle can develop in which the patient becomes tired, develops more pain, withdraws from social situations, sleeps poorly, and becomes depressed. This leads to increased poor sleep and increased pain (Tinkle, 2008). The current study was conducted to determine how satisfied individuals are with their current levels of social involvement and their current satisfaction with their pain level. This should demonstrate the degree to which the respondents feel their pain is well controlled.

Purpose of the Study

This project expands the work of other researchers of Ehlers-Danlos Syndrome by exploring patients' preferred pain control methods. By completing this research, I hope that suggestions can be made to patients seeking treatment as well as provide information to healthcare professionals. Results of this study reveal pain control methods that are effective among patients and alleviate some of the frustration experienced by physicians when treating a condition that will not improve over time (Berglund, Anne-Cathrine, & Randers, 2010).

Research Questions

EDS sufferers obtain many suggestions for pain control from a variety of sources, including experts in the field (Tinkle, 2008). The goal of this study was to assess the kinds of pain control treatment methods EDS patients are using and whether these methods demonstrate effectiveness as reported by the patient. Research questions for the study are:

1. What pain control methods are people with EDS using?
2. What is the impact of pain experienced by EDS participants on their daily life?
3. What methods do participants perceive as effective for different types of pain (e.g., acute, chronic, or both)?

Chapter 2: Review of Literature

EDS Quality of Life

In a study of EDS (Hypermobility Sub-Type – EDS-HT) patients and quality of life, Rombaut et al. (2010) found that the most debilitating complaints reported from the EDS-HT participants were chronic pain and repeated dislocations. Due to the joint hypermobility, dislocations, and high levels of pain, EDS-HT patients may not be able to engage in physical activity. Over time these patients are likely to experience disability due to the condition (Rombaut et al., 2010; Voermans et al., 2010). Current methods of managing pain, such as surgical interventions in an attempt to stop dislocations, may cause more pain from injury to the surrounding nerve tissue caused by scarring (Voermans et al., 2010). With high levels of pain, it is no surprise that EDS-HT patients frequently experience challenges to their quality of life physically, socially, and emotionally (Voermans et al., 2010).

The Classical subtype of EDS (EDS-C) is seen in approximately 1:20,000 people, and includes symptoms of painful, loose joints, hyper-elastic skin, and atrophic scarring. EDS-C is a new term that includes what used to be known as Type I & II (Ehlers-Danlos National Foundation, 2014). Vascular EDS (EDS-VT) is associated with fragility of blood vessels, like arteries. EDS-VT is also associated with spontaneous rupture of organs and arteries, making it important to manage correctly. Kyphoscoliosis is very rare and involves fragility in the eyes and arteries with progressive scoliosis and hypotonia (weak muscle tone) from birth. The subtype Arthrochalasia is described as “very rare,” and is seen with severe joint hypermobility, congenital hip dislocation, tissue fragility, and skin hyperextensibility (Ehlers-Danlos National Foundation, 2014). Finally, the Dermatosparaxis subtype of EDS is known for severe skin fragility and widespread bruising. Ehlers Danlos National Foundation (2014) indicates that the skin of a patient with EDS-Dermatosparaxis is doughy, with sagging extra skin visible.

Chronic Pain Management

While there is limited research on the management of chronic pain specific to EDS, there is a large literature base devoted to chronic pain management related to other disease processes. Chronic pain is altogether too common in western societies at approximately 20-30% of the population (Turk, Swanson, & Tunks, 2008). This has led to a plethora of research on chronic pain of various causes. Creating a comprehensive list of all the methods of pain control is beyond the scope of this study, but the variety of the research conducted thus far demonstrates the diverse and numerous suggestions EDS patients may encounter when seeking suggestions for pain control.

From the studies on the painful nature of this condition it is clear that a new way of thinking about the patient's pain needs to be further developed. In several studies regarding other forms of chronic pain, a wide variety of other pain control methods were suggested. A comprehensive method of pain control using multiple methods and pain control techniques may engage the patient's attention, thus distracting from the pain and providing physical and emotional relief (Tinkle, 2008). As individuals learn to think about the pain in different ways that allow them to see themselves as capable of managing it, the distress of being in pain is lessened and severe lifestyle limiting pain may be improved. As such, this study suggestively aligns itself with the ideas of gate control theory, cognitive restructuring, and attention management (Morley, Shapiro, & Biggs, 2004).

Cognitive Behavioral Therapy (CBT). Cognitive Behavioral Therapy (CBT) is a popular method of controlling pain in both group and individual therapy settings. CBT is a counseling theory that uses a number of techniques to increase the coping skills necessary to live with a chronic pain condition and engage in attention management. "Attention Management is the limitation of the impact of pain either by switching attention to another stimulus or returning attention of the pain to that aspects are attended to which are less distressing and interruptive" (Morley et al., 2004, p. 2). In their 2004 study, Morley et al. explained that attention management must be used gently with patients suffering from chronic pain due to the risk of making the individual feel trivialized. However, used appropriately with clients, CBT and attention management can facilitate sufferers' learning to be the master of their own pain (Turk et al., 2008) and can address a patients suffering physically, mentally, and emotionally (Dysvik & Stephens, 2010). CBT typically includes lessons on stress management, problem solving, assertiveness, and cognitive restructuring, among others (Dysvik & Stephens, 2010; Morley et al., 2004; Turk et al., 2008). Turk et al. (2008) and Buenaver, McGuire, and Haythorthwaite (2006) point out that CBT is a great management method for motivated clients who may benefit from at home development of skills after physician or other helping professional interventions have ended.

Dysvik and Stephens (2010) explored the use of CBT in a group setting, and addressed unique characteristics of groups that may allow pain sufferers to improve their lives. Groups are unique in that they allow the individual to come in contact with people who may be sharing some similar experiences, and with these peers new coping skills can be experimented with and put into practice. Skilled facilitators can heighten the group's effectiveness by increasing their own self-awareness, pursuing training in CBT techniques, and by seeking supervision. Coupling these techniques with a willingness to engage themselves in group development, CBT groups can assist members in changing negative thought patterns, learning to express needs clearly, and encouraging participants to see themselves as capable of maintaining some control over their condition.

A different approach to CBT is through a self-help model. Although not without its unique challenges, self-help CBT programs can be maintained long term after professional interventions have ended. Buenaver et al. (2006) discuss a Minimal Contact Treatment (MCT) method during which participants are taught the techniques with a professional's supervision.

After learning the techniques the participants were given resources such as handouts, tapes, and videos to use at home and practice what they had learned. Participants who were more educated and more motivated were generally more successful with this program, suggesting that careful screening for reading comprehension and commitment to the treatment would be needed on the part of the practitioner prior to the patient beginning this treatment.

In another study of CBT methods used for treating chronic pain, Turk et al. (2008) point out that psychological approaches like CBT might give chronic pain patients the tools necessary to manage the side effects of their condition. The study addressed maintenance pain behavior reinforcement, which is an approach that could be used with chronic pain sufferers such as EDS patients where the patient is encouraged by the result of a preventative activity. For example, a patient who uses ice to reduce inflammation may notice less pain and may be encouraged to use ice more regularly. According to the study, this is congruent with other goals of CBT, which focus on changing patient thought patterns about their condition. Addressing CBT techniques of biofeedback, relaxation, and meditation for chronic pain maintenance, Turk et al. (2008) discuss some of the positive and negative attributes of each technique. Overall, they describe them as effective in treating chronic pain. In a separate review using biofeedback to treat low back pain, researchers found evidence to support the effectiveness of biofeedback in improving symptoms of low back pain (Sousa, Orfale, Meireles, Leite, & Natour, 2009).

Pain treatment facilities. Pain treatment facilities are another common way that patients can seek care for their pain, and not all are medication-based. Fishbain (2000) describes four different kinds of pain treatment facilities. Pain treatment facilities began to develop as the population, researchers, and physicians began to realize that chronic pain is a very common occurrence. The common consensus was that people should be able to live their lives free of pain, which in western culture is seen somewhat as an enemy to be conquered (Brennan & Cousins, 2004). Following the Second World War, physicians observed that a large number of soldiers wounded in the fighting would suffer from chronic pain due to their injuries.

During the 1970s pain clinics demonstrated that patients with some conditions did not improve from traditional medical treatment. Multidisciplinary pain control was born. Fishbain (2000) reviewed multiple studies on the efficacy of four types of pain treatment facilities. Due to the enormous variations in treatment philosophies at these facilities it is difficult to describe what treatments work best. However, Fishbain proposes a description of an ideal treatment facility as one that provides a mix of over-the-counter and prescription medications, physical therapy, CBT and educational therapies, and other treatments as needed by the individual patient. This unique meta-analysis again addresses the need for comprehensive chronic pain treatment, rather than band-aid stopgaps that address only a single facet of the pain.

Chronic pain stemming from spinal cord injury is the attention of Heutink, Post, Wollaars, and van Asbeck (2011). Examining the forms of pain control that the patients in the study were using, researchers discovered that a more varied approach was taken when the patient was experiencing multiple types of pain. Therefore, Heutink et al. suggest that multiple pain control methods be used together for more complete results. Respondents in their study indicated that acupuncture and cannabis were the most common forms of pain control used by their population, and these methods were followed by medications such as opioids, gabapentin and other anti-convulsants.

Transcutaneous electrical nerve stimulation (TENS). Transcutaneous electrical nerve stimulation, or TENS, is another suggested method of pain control. Designed to confuse the body and brain, electrical signals are sent into the skin from electrodes placed strategically over painful areas. "Transcutaneous electrical nerve stimulation is based on the gate control theory of pain . . . which means that the alternative stimulation of the nervous system through transcutaneous electrodes can alter the perception of pain" (Jarzem, Harvey, Arcaro, & Kaczorowski, 2005, p. 4). The body is tricked into thinking it is feeling numbness instead of pain while the machine is on, but as Jarzem et al. indicate, the efficacy of TENS as reported in multiple studies has been inconsistent, and it is difficult to say how effective this treatment may be for chronic pain sufferers.

Complementary and alternative medicine (CAM). Complementary and alternative medicine (CAM) was explored as a chronic pain treatment method. CAM can include herbal remedies and eastern health practices such as acupuncture. A meta-analysis on many herbal CAM treatment methods assessed the appropriateness of CAM treatments for chronic pain (Wirth, Hudgins, & Paice, 2005). The study also discussed a lack of physician training in CAM techniques of treatment, which can be dangerous if CAMs and western medicine mix and cause bad interactions. The authors indicated that some herbal CAMs may cause medications to be absorbed improperly (either they are absorbed too slowly, not absorbed enough, or absorbed too quickly), which can result in patients receiving too much or too little of their medication. The study lists CAM treatments and the efficacy, positives, and negatives of each alternative medicine (or herb). Interactions with common drugs and cautions of using the herbs are also listed in the study. Overall, few of the CAMs studied could conclusively be demonstrated to have an analgesic affect for chronic pain.

Finally, CAMs were reviewed in Ndao-Brumblay and Green (2010) as an increasingly popular chronic pain treatment. Researchers indicated that education, marital status, and past experiences with medical care are indicators for seeking medical care and for interest in trying CAM medicine. The most common CAMs in use are alternative medical systems (i.e., Chinese medicine), manipulation, and mind-body techniques (e.g., relaxation and biofeedback). Utilizing CAM techniques may be limited due to insurance companies failing to cover such alternative techniques. The relief reported in the study from patients indicates that these techniques warrant more study for efficacy (Ndao-Brumblay & Green, 2010).

This is by no means an exhaustive list of chronic pain treatment methods, but it is indicative of the interest and willingness of patients to pursue techniques beyond the limitations of traditional western medicine. Chronic pain sufferers are unique groups that require long-term care by physicians and other professionals in helping professions. This study attempted to reveal the current methods in use by EDS patients. This study also attempted to show the effects that each participant gains from their own pain control methods.

Chapter 3: Methods

Participants

Participants for this study were adults who have been diagnosed with EDS. Potential participants were recruited from a number of sources after approval was received from the Appalachian State University Institutional Review Board for the study procedures. Several organizations that were contacted at the Ehlers-Danlos National Foundation (EDNF) conference in 2012 agreed to supply advertising for the survey project. The EDNF agreed to post news of the study on the foundation website. Dr. Tinkle, one of the leading world experts on EDS, sent an announcement in 2012 to members of his mailing lists requesting participation, and posted an announcement on his website. An online support community that helps people with EDS to set up virtual and in-person support groups called edsawareness.com emailed the link to the study to everyone on their online mailing list that indicated interest in EDS related news and announcements.

Later in the study, EDSCanada, a new organization serving EDS patients across Canada, asked if it could lend its support to the project. Finally, EURORDIS, a rare inherited disease organization for patients in Europe, asked if it, too, could advertise the survey. As a result, the survey was left open longer than originally planned to allow EDS Canada and the EURORDIS groups time to recruit more participants. In addition to these online options, a business card directing potential participants to the online survey was distributed at the EDNF conference in August 2013. Lastly, flyers with more information about the study were distributed at the EDNF August 2013 conference.

Participant protection was paramount. No identifying information was collected, and the survey was completely anonymous. Even participant's birthdates were not collected so the participants could not possibly be identified from their birthdate and EDS diagnosis. The informed consent document explained that participants may leave the survey at any time without penalty. Psychdata, the hosting site for the survey, collected Interpersonal (IP) addresses for the sole purpose of finding and eliminating duplicate responses. IP addresses were then removed from the dataset to protect the identity of the participants. Survey data are stored on a password protected computer.

Instruments

Demographics. Participants provided demographic information on their age, gender identification, medical diagnoses, and the type of physician that diagnosed them.

Pain Management Strategies Survey (PMSS). The Pain Management Strategies Survey was developed by Kemp, Ersek, and Turner (2005) to assess the use and perceived effectiveness of 42 medical, complementary, and self-care strategies used by older adults managing chronic pain. Their instrument was adapted from the work of Warms, Turner, Marshall, and Cardenas (2002). Original face validity was determined through use of items reported by Warms et al.'s spinal cord injury patients. The PMSS was modified for specific use with the pain management strategies that have been recommended for EDS patients. The Ehlers-Danlos National Foundation (2014) website contains documents for patient care, including several regarding pain. A variety of treatment modalities are addressed through the foundation's website. Due to the rare nature of this condition, it is reasonable to believe that patients and physicians may seek information on the EDNF (2014) website. Respondents had the opportunity to specify whether the pain treatment modality was used for acute pain, chronic pain, or both acute and chronic pain. EDS has unpredictable symptom expression experienced with wide levels of pain and/or musculoskeletal dysfunction, so it was expected that multiple pain control modalities could be used by the same respondent for different types of pain.

Pain interference with quality of life. The Pain Interference scale (PROMIS-PI) from The Patient Reported Outcomes Measurement Information System (PROMIS) sponsored by the National Institutes of Health measures the self-reported consequences of pain on relevant aspects of one's life (Amtmann et al., 2010). Pain interference (also known as "pain impact") refers to the degree to which pain limits or interferes with individuals' physical, mental and social activities. The Pain Interference scale has six items answered on a Likert scale. Cronbach's alpha was reported by Amtmann et al. (2010) as .96-.99. Evidence for concurrent and construct validity for the instrument is strong using responses from large national samples (Amtmann et al., 2010). Raw scores are converted to T-scores through use of scoring tables included in the scoring manual (PROMIS Health Organization and PROMIS Cooperative Group, 2008-2013a).

Satisfaction in social functioning. The Adult Satisfaction with Social Roles and Activities of the Quality of Life in Neurological Disorders (Neuro-QOL) (SSRA) is an eight item survey using a Likert scale that measures satisfaction in social functioning (Cella et al., 2012; Salsman, et al., 2013). Raw scores are converted to T-scores with a mean of 50 and standard deviation of 10. Initial norms were established using a national sample *(n = 3,123)* from the United States. Cronbach's alpha was .96. Preliminary evidence of validity was established by Cella et al. (2012) by demonstrating that the scale could discriminate between groups that were healthy and those that had significant health problems.

Pain behavior. There are several ways that individuals in pain (whether it is acute or chronic) can communicate to others that are in pain and that pain is interfering with how they would like to be (Revicki, et al., 2009; Rothrock et al., 2010). The Adult Pain Behavior Scale from PROMIS (PROMIS-APB) assesses the ways that people in pain are communicating their pain to others, and can detect whether those communication methods are adaptive or not. The comparative fit index from the factor analysis conducted by Revicki et al. (2009) was 0.94. The Pain Behavior Scale has reliability scores of .90 and higher. The evidence for concurrent validity was moderate (-.48; Revicki et al, 2009). The PROMIS-APB scores were totaled and transformed into T-scores using the scoring tables included in the scoring manual (PROMIS Health Organization and PROMIS Cooperative Group, 2008-2013b).

Design

The current study is a descriptive study of the methods for pain control used by EDS patients which included medications, CAMs, therapy techniques, exercise, physical therapy, and other alternative therapies. Each method was assessed for effectiveness and compared to the others being used by the individual respondent. The goal was to identify generally accessible and effective techniques that can be suggested to the EDS patient and physician community. Descriptive statistics were used to summarize the demographic characteristics of the sample, the strategies used, and their perceived effectiveness. For each participant, ratings of helpfulness of strategies used were averaged to create a single mean strategy helpfulness score. Pearson's correlation and chi-square analyses were used to examine associations between participant strategies used and perceived effectiveness, age, and gender.

Pearson correlations were also used to investigate the relationships between pain behavior, pain interference, and satisfaction with social roles and activities.

Procedure

Potential participants were directed to an on-line survey. The first page of the survey contained the informed consent information and explained participants' anonymity. The on-line survey was hosted by PsychData using a secure website. PsychData is a professionally developed and maintained web presence utilizing state-of-the art technology that combines parent-level, centralized database architecture with strict security policies and procedures so that these services exceed industry standards.

Prior to distributing any survey information, approval was secured from the Institutional Review Board at Appalachian State University. This process confirmed that proper HIPPA regulations were followed, and confidentiality and anonymity were ensured to the highest degree possible. No serious harm was expected for study participants, although there was a risk of psychological discomfort when responding to questions regarding chronic pain, long-term health diagnoses, and disability resulting from EDS. There was also a risk of elevating the pain level by answering questions about pain. This potential risk was no more than would be expected while talking to a physician, a concerned friend, or a family member. The benefit of the study was the satisfaction of contributing to the knowledge base on EDS, possibly making it a little easier to get treatment in the future.

Prior to beginning the survey, respondents were provided with informed consent about the survey and the risks and benefits of participating in the study. IRB approval was explained, and consent to the survey was implied if respondents continued on to complete the on-line survey. Respondents were asked to identify their diagnosis or diagnoses. After data collection was complete, the data were analyzed with SPSS and the results formatted for the final presentation of the study.

As discussed earlier, the EDNF, Dr. Tinkle, edsawareness.com, EDSCanada, and EURORDIS advertised the study. A limitation of this method is that it would interfere with generalized the study from being generalized to the larger EDS population, as it can be assumed that respondents who seek out information on EDS websites and choose to take the survey may differ somehow from a randomly generated set of participants.

Announcements about the survey were distributed at the 2013 EDNF Living Learning Conference. These announcements listed the website where the survey was available. Business cards with my contact information were available on the general information table and at several vendor tables during the conference. The cards included the web address for the survey. Small posters (8.5 x 11 inches) were left on socializing tables around the convention center. These posters included a study description, the web address for the survey, and my contact information. At the end of the conference, approximately 200 business cards were distributed and 50 of the small posters were distributed.

Statistical Analysis

The online survey closed on January 10, 2014. Prior to screening the data, 1283 participants responded to the survey. Data screening revealed 42 incomplete datasets connected to a duplicate complete dataset with the same IP address. Duplicate IP addresses were carefully screened, and 13 repeated IP addresses were found to be distinct datasets and retained. Forty-three incomplete datasets with unique IP addresses were found and deleted. A dataset was considered incomplete if the participant did not complete all 26 of the required questions. Nineteen responses were deleted because the participants were less than 18 years of age. After screening, data analysis proceeded with 1179 participant responses.

Descriptive statistics summarized demographic characteristics of the sample, the strategies used, and their perceived effectiveness. On the SSRA four items were reverse scored before adding the items for a total score. Total Scores for the Pain Behavior and Pain Interference scales were created by adding the responses for each item. Tables from the PROMIS user manuals for the Pain Behavior and Pain interference scales were used to convert raw scores to T-scores. Tables from the National Institute of Neurological Disorders and Stroke (NINDS, 2010) manual were used to convert raw scores on the SSRA to T-scores.

Descriptive statistics summarized whether a particular method was used to manage acute, chronic, or both pain types. A variable called “Ever Used” for each method was created by consolidating responses across the acute, chronic, or both responses to determine whether an approach was ever used by participants. The total number of approaches ever used by a participant was determined by summing the “Ever Used” responses for each modality. Pearson correlations were used to assess the relationship between age, pain behavior, pain interference, satisfaction with social roles, and the total number of pain methods ever used.

Chapter 4: Results

Sample Characteristics

The mean age was 37.78 years with a standard deviation of 12.21. The range was 18-82 years old. The participant sample was 93.9% female (*N*=1107), with 60 males in the analyzed dataset. Nine participants marked an "Other" category for their sex, and 3 marked "Prefer not to answer." This is consistent with the literature, which states that the vast majority of patients diagnosed with EDS are female.

The prevalence of the primary EDS diagnostic type was as follows: Hypermobility Type (75.1%, n = 885), Classical Type (14.2%, n = 167), Vascular Type (3.0%, n = 35), Arthrochalasia (0.3%, n = 4), Kyphoscoliosis (0.3%, n = 3), and Dermatosparaxis (0.1%, n = 1). Participants also selected "I don't know my EDS diagnosis" or "Other, please specify." In the "other" field, participants wrote in that they are diagnosed with multiple types, or that their case has recently changed to involve symptoms of another type, causing other testing to call their original EDS diagnosis into question.

There were 84 respondents who reported that they either did not know their subtype, they were awaiting an appointment with a specialist to clarify the subtype, or had a variant form of EDS that contains many subtypes. Fifty-seven respondents reported clinical diagnosis of multiple subtypes (variant EDS) of Ehlers Danlos Syndrome. Those with the variant diagnosis reported that several specialists (geneticists, mostly) had given them the variant diagnosis, leaving them without a single subtype. Six participants reported clinical confirmation of three subtypes, and one participant reported clinical confirmation of four coexisting subtypes.

Participants reported being diagnosed with EDS by multiple physicians, and were invited to choose all that applied for them. Of the options, 653 respondents reported being diagnosed by a Geneticist, followed by Rheumatologists (*n* = 636), General Practitioners (*n* = 465), Orthopedic Surgeons (*n* = 301), and Other Healthcare Providers (*n* = 318). Many participants responded with other physicians who had confirmed their diagnosis. The maximum number of physicians a participant reported being confirmed by was 14 (*n*=1). Participants reported that for many, one physician had confirmed their diagnosis (n=443). Others listed 2 physicians (*n*=356), 3 physicians (*n*=231), or 4 physicians (*n*=106).

Participants also recorded other diagnoses that relate to, or exacerbate, their EDS diagnosis. These were recoded numerically for this study into how many other diagnoses were reported. The range was 49 (0-49). However, the descriptive statistics were skewed because the higher rates were reported by only one or two participants. The top 4 most common responses were 0 other diagnoses (*n*=163), 3 others (*n*= 142), 2 others (*n*=137), and 1 other (n=130).

What Pain Control Methods Were Reported?

Acute pain. Pain control methods reported by participants are summarized in Tables 1-3. For acute pain only, participants reported that in the past 6 months, they had most commonly used ice therapy (*n*= 237), creams or ointments (*n* = 149), acetaminophen (*n* = 147), and Non-Steroidal Anti-Inflammatory Drugs, also known as NSAIDs (*n* = 135) to control acute pain. In the past month, the participants reported most frequently using ice therapy (*n* = 184), creams and ointments (*n* = 114), heat therapy (*n* = 114), and NSAIDs (*n* = 103) to manage acute pain. See Table 1 in Appendix A for more information about how participants reported controlling acute pain only.

Chronic Pain. Participants responded differently to treating chronic pain only. In the past 6 months, the top methods utilized for chronic pain control were regular exercise (*n* = 227), diet management (*n* = 125), anti-seizure medications such as Neurontin (*n* = 109), and counseling or psychotherapy (*n* = 91). In the past month, the most commonly used methods for chronic pain control were regular exercise (*n* = 185), diet management (*n* = 117), herbal remedies (*n* = 83), and anti-seizure medications (*n* = 82). Table 2 in Appendix A contains more information about managing chronic pain only.

Acute and chronic pain. The majority of participants reported using pain control modalities to assist with acute and chronic pain. In the past 6 months, they reported using avoiding potentially damaging activities (*n* = 710), heat therapy (*n* = 480), splints or braces (*n* = 457), and physical therapy (*n* = 412) most frequently to control for chronic and acute pains. In the past month, the participants reported using avoiding potentially damaging activities (*n* = 710), heat therapy (*n* = 452), splints or braces (*n* = 419), and opioids (*n* = 367) to control acute and chronic pain. Table 3 in Appendix A shows more about these participants' responses.

What is the Impact of Pain?

For Pain Behavior (mean = 5.7, *SD* = 5.1), the SD was just less than 1 *SD* above the mean. People with EDS behave similarly to other people with other types of pain, although they do evidence more pain behavior than national norms. For Pain Interference, the mean is 67.77, which is 1.7 *SD* above the mean. People with EDS have higher than average pain interference in their lives. In the Satisfaction with Social Roles, the mean is 41.82, 1 *SD* below the mean. People with EDS have lower than average satisfaction with their social roles and activities.

No relationship was discovered between age and pain behavior (*r* = -.03, p = .275), pain interference (*r* = -.02, *p* = .508), or social role satisfaction (*r* = .001, *p* = .976). Greater pain interference is associated with increased pain behavior (*r* = .61, *p* = .000). Greater satisfaction with social roles is associated with lower pain interference (*r* = -.70, *p* = .000) and lower pain behavior (*r* = -.48, *p* = .000). Greater role satisfaction was associated with lower number of methods ever used (*r* = -.18, *p* = .000).

Effectiveness of Pain Management Modalities

Despite the most commonly utilized pain control modalities, the scores for the helpfulness of the treatment of acute pain were different. The top modalities for helpfulness in relieving acute pain were Opioids (mean = 3.6), surgical interventions (mean = 3.3), splints and braces (mean = 3.0), and heat therapy, nerve blocks, and physical therapy all with a mean score of 2.9. The modalities reported as the least effective for acute pain include a spinal pump (mean = 1), herbal remedies (mean = 1.1), and chronic illness classes (mean = 1.6).

Helpfulness was again different from what participants reported using for chronic pain. Opioids were rated the most effective (mean = 3.3), followed by heat therapy, splints or braces, and surgical interventions, all with a mean score of 3.1. The least effective for chronic pain were reported as herbal remedies (mean = 1.1), chronic illness classes (mean = 1.4), acetaminophen (mean = 1.8), and homeopathy (mean = 1.8).

For both acute and chronic pain, Opioids were still rated the most effective (mean = 3.6), followed by massage therapies (mean = 3.4), and heat therapy and splints and braces (both with a mean = 3.2). The least effective methods for managing both acute and chronic pain were herbal remedies (mean = 1.1), spinal cord stimulation (mean = 1.1), a spinal pump (mean = 1.3), and special jewelry (e.g., copper or magnetic bracelets or necklaces) with a mean of 1.7.

A total of 206 participants did not report using any of the strategies listed.

A Pearson product-moment correlation coefficient was used to determine the relationship(s) between the total number of pain control methods ever used by the participants and the scores for pain behavior, pain interference, and satisfaction with social roles and activities. I found that the more the pain interferes, the more methods the participants try ($r = .175$, $p = .000$, $n = 973$). The more they try, the more likely they are to find something that works for them and they are more satisfied with social roles ($r = .113$, $p = .000$, $n = 973$).

Chapter 5: Discussion

Characteristics of EDS

The sample for this survey is mostly female. The research indicates that women are much more likely to be diagnosed with EDS (Tinkle, 2008). This study did not collect information such as race, ethnicity, birthplace, or country of origin. The literature on EDS indicates it is a genetic disorder passed autosomal dominantly. In most cases, other family members will have EDS or a related disorder (Berglund et al., 2010; Rombaut et al., 2010; Tinkle, 2008).

Physician confirmation of EDS diagnosis. The survey respondents indicated having to seek out confirmation of their EDS diagnosis with multiple physicians, which implies the difficulty many people with EDS face when trying to gain access to appropriate treatment. Many physicians do not feel qualified to diagnose EDS, and a large portion of those physicians have never heard of the condition or have only been exposed to it in passing during medical school or residency (Selong, personal communication, August 15, 2012). Several of the subtypes of EDS have had genetic markers identified, so a trip to a geneticist may be all that is needed to confirm a diagnoses, but the hypermobility subtype (the most common kind of EDS) has not had markers identified. Ehlers-Danlos Syndrome can be limited to one subtype diagnosis or several subtypes. The percentages of EDS diagnoses reported by the research participants are similar to that reported by other researchers (Tinkle, 2008). Seeing the lengths to which patients must go to be validated suggests that there is a need for physicians to be more extensively educated about EDS. Clinicians who are not knowledgeable about EDS may miss the symptoms until after a very serious injury or may misdiagnose the patient with another kind of connective tissue disorder.

A misdiagnosis may be difficult to get away from. Doctors in medical school are sometimes told to look for the most obvious choice first with the saying, "If you hear hoof-beats, look for horses." EDS Researchers, patient advocates, and patients seeking treatment say, "If you hear hoof-beats, look for horses, but check for zebras." The EDNF and many patients with EDS diagnoses use a zebra as a mascot, including clothing, ribbons, hats, and much more with zebra print. Physician education continues to improve as knowledge of EDS and the subtypes of the condition spread and research makes testing for the condition easier (Grahame, 2012).

At the 2013 EDNF Living-Learning Conference, Levy answered questions about related health conditions for the attendees. A common misconception is that the other physical problems are not related to EDS. From research, we know that there are many physical and mental illnesses that are associated with chronic pain and disability. There are also many physical complications of having a collagen synthesis disorder (Tinkle, 2008), and this is reflected in participants' reports of multiple other diagnoses in the current study. Another reflection the speaker had was that just because people with EDS have a bad genetic disorder, they are not protected from other major or life-threatening illnesses or injuries. The whole room groaned collectively, and some of the conference participants stated that they believe what the presenter had said (Anonymous, personal communication, August 2, 2013). Levy's presentation lends weight to the idea that EDS is a life-long condition with no cure full of "what ifs," "what nexts," and "what nows" (Levy, 2013). The vast majority of the other conditions that the respondents reported are related to the faulty collagen synthesis that EDS causes, or the other conditions exacerbated the participant's EDS symptoms (Tinkle, 2008).

Pain Control Methods Used

All 34 of the pain control modalities were in use by at least one participant, pointing to the desires of EDS patients to gain some control over the condition by trying almost everything. I (Arthur) received many emails about other pain control modalities and management symptoms from participants who stated that they wanted to make sure I was aware about other treatments, such as Prolotherapy, an injection-based treatment (Alderman, 2008). The survey assessed medical, psychological, and complementary and alternative medicines.

Acute pain. The acute pain management responses were low in number, partially because acute pain is usually associated with an injury or emergency, not an opportunity for regular pain management. When the individual is feeling acute pain, there may be some kind of injury. Many of the self-care pain control modalities become inappropriate and the individual may be forced to see a physician or other healthcare professional to find relief (Tinkle, 2008). This is reflected in the top answers for control of acute pain: Ice therapy is recommended for EDS patients because it helps to bring down inflammation and reduce pain. Creams and ointments can encourage people to ask for touch, which can be beneficial for neurotransmitter release which makes people feel better. Heat therapy is also recommended for patients with EDS (Tinkle, 2008). Acetaminophen and NSAIDs were reported highly, but both come with warnings about long-term use due to the potential for organ trouble, such as stomach ulcers, liver problems, and kidney problems (United States Food and Drug Administration, 2014).

Chronic Pain. Participants reported using different modalities to control for chronic pain. Regular exercise was the top selected answer, and can be a catch-22 for some patients. People have to discuss with their physician(s) what activity level is feasible so that the exercise will not worsen the EDS symptoms (Tinkle, 2008). Diet management, the next most prevalent answer, has become somewhat of a fad in recent years with developments such as the Paleodiet (http://www.thepaleodiet.com, 2014) and the Anti-Inflammatory Diet (http://www.drweil.com, 2014). At the same time, the pairing of exercise and diet management might be useful for some EDS participants because it can allow a sense of control and control over one's weight. Excessive weight wears on everyone's joints (Paans, 2013), and can exacerbate EDS symptoms, leading to more pain (Tinkle, 2008). Next, participants reported using anti-seizure medications (e.g, Neurontin) for chronic pain relief. This class of medication slows rapid-firing nerves to dull sensation slightly (United States Food and Drug

Administration, 2013). Study respondents also reported using counseling or psychotherapy and herbal remedies, despite the herbal remedies having a low helpfulness score. Counseling can support patients through the many emotions experienced during chronic illness. Chronic illness can cause losses of favorite activities, changes in mobility, and loss of independence (temporarily or permanently). There may also be increases in medications, leading to side effects. The grieving process during chronic illnesses like EDS can be dealt with in individual, family, or group therapies (Ahlstrom, 2007).

Acute and chronic pain. To manage both acute and chronic pain, participants indicated that their first defense is to try and avoid potentially damaging activities. Doctors usually advise EDS patients to restrict the amount of high-impact activity they are engaging in, which lessens the likelihood of injury. High-impact activities include things with sudden, jarring movements (e.g., running, jumping, throwing; Tinkle, 2008). Heat therapy was again a popular choice for pain management, as were splints, braces, and physical therapy. The splits and braces often give the joint more time to heal, which can take longer in EDS patients. Physical therapy can be used to strengthen the muscles around the weakest joints to prevent tissue damage in the ligaments and tendons (Tinkle, 2008). Finally, narcotic medications were chosen as an important method for controlling acute and chronic pain. Narcotics are reserved for those that would not be able to function without them. The smallest dose possibly is used to help prevent dependence on the drug, and patients are carefully monitored to make sure that they are taking the medication properly (Selong, personal communication, August 15, 2012).

Impact of Pain in EDS

Pain behavior. People with EDS are in pain more frequently than the average population, which means that even though they behave in similar ways to other people in pain, they have to respond to pain more often. In studies about the types of pain that EDS patients must endure, there is evidence for major joint pain in several areas on a regular basis. This may include areas such as the shoulders, hips, knees, and back. Instead of experiencing the pain and having it resolve, those with EDS must endure for days, months, or years at a time (Voermans et al. 2010).

Pain interference. People with EDS have clinically significantly more than average pain interference in their daily lives with pain interference scores at 1.7 SD higher than national norms. This is related to their pain behavior above, and may result in anxiety or depression from not being capable of participating in their lives as they would like to (Tinkle, 2008). Pain can interfere with things as simple as standing at the sink to wash the dishes, or as complex as house repairs, going shopping for food or supplies, or working an otherwise loved job (Rombaut et al. 2010; Voermans et al. 2010). In a society that sees pain as an enemy to be conquered, chronic pain interference may be poorly understood and may not be tolerated in a work setting or by family or friends (Glucklich, 2001).

Satisfaction with social roles and activities. In this study lower pain behavior and interference are associated with greater satisfaction with social roles and activities. When in less pain, people with EDS are capable of doing more of the activities they prefer to do. This includes activities with family members, friends, employers, coworkers, and more. Pain is exhausting, so when having less pain interference, people with EDS may be able to enjoy their lives without working so hard to compensate for pain behaviors they exhibit. Higher satisfaction with social roles was associated with fewer pain control methods ever used. If their condition is not as severe, participants may not try more pain control methods.

Pain Control Method Helpfulness

Acute pain helpfulness. Combining the above, it is not difficult to understand that patients with EDS have obstacles that must be overcome by managing the discomfort and limitations of their condition(s). People must find their own combinations of effective treatments, which are combinations of psychological, social, physical, emotional, and medical techniques. Among the treatment modalities participants reported in this study, the most helpful for acute pain control were opioids, surgical interventions, splints and braces, heat therapy, nerve blocks, and physical therapy. It is interesting to note that the most highly rated effective pain control modalities are not always the most frequently used. For example, only 33 participants listed having surgery in the past 6 months, and only 18 had surgery in the past month. This may be due in part to the riskiness of the top two rated modalities in helpfulness. Opioids, although effective at managing acute pain, carry risks for dependency or addiction. Also, EDS patients, who already have difficulty healing from injury, might be warned against or hesitant to have surgery until the pain is no longer bearable, which might mean waiting until the pain has become chronic (Selong, personal communication, August 15, 2012; Tinkle, 2008).

Nerve blocks were listed as one of the most helpful treatments available for acute pain, but may be few and far between, as they are used for some surgical procedures and only extreme cases. Effective for about 12-18 hours, a nerve block is done by injecting numbing agents into the body to surround and eliminate pain signals from particular nerves (Healthwise Staff, 2011).

Chronic pain helpfulness. Chronic pain was treated most effectively with opioids, heat therapy, splints or braces, and surgical interventions. Again, these differ from the most prevalent methods of coping with chronic pain. Splints and braces, however effective, are usually somewhat uncomfortable. If patients are lucky enough to find one that works with their unique body shape, it might limit their ability to move in the ways they want to while the braces keep the joint safe. Anti-seizure medications (e.g., Neurontin) were listed among the most popularly used modalities for chronic pain control, but only scored moderately in helpfulness. Why do people continue to take medications and use modalities that are only sometimes effective? One explanation is that it feels better to try something rather than not trying anything to keep pain under control.

Acute and chronic pain helpfulness. Lastly, the participants in the study reported that for the management of acute and chronic pain, opioids, massage therapies, heat therapy and splints and braces were the most effective pain control modalities. This is fairly consistent with the methods being used for both acute and chronic pain control. Other commonly used pain control methods are avoiding potentially damaging activities and physical therapy. Avoiding potentially damaging activities involves attempting not to participate in impact-heavy exercise, avoiding lifting heavy objects, avoiding situations where the person might fall, and more. This method is rated highly for effectiveness, but was not in the top-scoring group of pain control modalities. For adults who live on their own, it is not a viable option to not engage in strenuous activities. Physical therapy was rated slightly lower in helpfulness than avoiding dangerous activities, but can help to keep the muscles strong. If the patient must go on to have surgery, physical therapy before and after the surgical intervention might help to encourage a quicker healing time and may help to prevent additional surgery in the future (Tinkle, 2008).

Limitations

Men made up only (5.1%) of the survey. Despite consistency with data that confirms that women are more often diagnosed with EDS (Rombaut et al., 2010; Voermans et al., 2010), this imbalance may have an effect on the types of pain control modalities chosen.

Respondents were located through advertising through conference attendees and on-line organizations. This may lead to a lack of generalizability of results because conference attendees are likely to be different from people with EDS who do not attend the national EDS conference. Due to the difficulties of attending a conference for those who are disabled, it is possible that the results would be skewed to the less disabled of those with EDS. Additionally, because the conference is held in the US, there may be a lack of participation from international people with EDS.

The participation of multiple supporting organizations and people helped to get a broader sample population, but there may still be some limitations in finding people who have EDS but are unaware or uninterested in joining a supportive organization. The study organization assumes that people with EDS have some online presence through an email address. The sample population must be people of are comfortable enough with computer technology to navigate to the website and complete the questions on the survey.

Future research is needed to find effective methods of managing chronic pain and disability in EDS patients. Physician knowledge of EDS may be lacking, and future research is needed on effective methods of educating physicians about diagnosing and treating patients with EDS symptoms. More research is also needed on variant forms of EDS and possible differences in pain management strategies for the variant forms. Additional research on the co-occurring diagnoses with EDS may also help health care providers and patients find comprehensive ways of managing pain and disability in these conditions.

Conclusion

This project has left interesting points to ponder. The most effective methods of managing pain, acute and/or chronic, are not always the ones in use. Additionally, none of the means for the effectiveness of the modality were reported at a 4 or 5 score, which would have indicated that the pain control modality was effective “most of the time” or “always.” This reflects the difficulty for patients seeking treatment in finding a pain control modality that controls their pain the majority of the time.

In conclusion, I hope that this study will assist physicians who are treating patients with EDS by suggesting treatment methods that may not be otherwise considered. Treating a life-long condition like EDS can be frustrating for both the patient and the physician. There is no cure for EDS, and not always a clear understanding of what genes or what type of collagen may be responsible for the patient’s suffering. By exploring what pain control modalities are in use and helpful to others with EDS, we can begin to provide more suggestions to new patients who navigate the uncertainty, disappointment, and frustration of a new and continuing diagnosis.

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APPENDIX A

Table 1

Treatments Used by Participants for Acute Pain (*N* = 1179) and Perceived Helpfulness

Strategy	Reported use (past 6 months)		Reported use (current)		Helpfulness	
	n	%	n	%	Mean	(SD)
Acetaminophen	147	12.47	97	8.23	2.1	0.923
Acupuncture	27	2.29	5	0.42	2.2	0.97
Anti-Seizure Medications	12	1.02	5	0.42	2.3	0.914
Aromatherapy	23	1.95	21	1.78	2.2	0.577
Avoiding potentially dangerous activities	94	7.97	87	7.38	2	1.023
Chiropractic Care	40	3.39	28	2.37	2.7	0.957
Chronic Illness Classes	3	0.25	2	0.17	1.6	0.505
Counseling or	2	0.17	5	0.42	2	0.577
Creams or Ointments	149	12.64	114	9.67	2.4	0.876
Diet Management	30	2.54	26	2.21	2.6	0.807
Energy Healing	12	1.02	7	0.59	2.2	0.862
Heat Therapy	133	11.28	114	9.67	2.9	0.904
Herbal Remedies	24	2.04	22	1.87	1.1	0.272
Homeopathy	24	2.04	16	1.36	2.6	0.857
Ice Therapy	237	20.10	184	15.61	2.8	0.896
Massage Therapies	45	3.82	24	2.04	2.6	0.89
Nerve Blocks	22	1.87	10	0.85	2.9	1.306
NSAIDs	135	11.45	103	8.74	2.7	0.865
Occupational Therapy	10	0.85	7	0.59	2.2	0.718
Opioids	127	10.77	95	8.06	3.6	1.016
Other Medication(s)	39	3.31	34	2.88	2.8	1.056
Pain Medication Delivered	52	4.41	33	2.80	2.64	0.996
Physical Therapy	39	3.31	26	2.21	2.9	1.171
Regular Exercise	10	0.85	8	0.68	2.7	1.191
Relaxation Training	38	3.22	32	2.71	2.6	0.885
Self-Help Groups	3	0.25	3	0.25	2	1.225
Special Jewelry (Copper Bracelet, Magnets)	11	0.93	9	0.76	2.1	0.738
Spinal Cord Stimulation	1	0.08	1	0.08	2	
Spinal Pump	1	0.08	1	0.08	1	
Spiritual or Religious	8	0.68	7	0.59	2.3	0.823
Splints or Braces	132	11.20	100	8.48	3	0.776
Steroid Injections	66	5.60	26	2.21	2.8	1.212
Surgical Interventions	33	2.80	18	1.53	3.3	1.108
TENS Unit or Interferential Stimulation	107	9.08	62	5.26	2.5	0.984

Table 2

Treatments Used by Participants for Chronic Pain (*N* = 1179) and Perceived Helpfulness

Strategy	Reported use (past 6 months)		Reported use (current)		Helpfulness	
	n	%	n	%	Mean	(SD)
Acetaminophen	19	1.61	16	1.36	1.8	0.834
Acupuncture	25	2.12	8	0.68	2.2	1.118
Anti-Seizure Medications	109	9.25	82	6.96	2.7	1.285
Aromatherapy	28	2.37	23	1.95	2.2	0.644
Avoiding potentially dangerous activities	58	4.92	53	4.50	2.8	0.985
Chiropractic Care	11	0.93	5	0.42	2.1	0.909
Chronic Illness Classes	33	2.80	22	1.87	1.4	0.483
Counseling or	91	7.72	55	4.66	2.5	1.077
Creams or Ointments	26	2.21	20	1.70	2.3	0.62
Diet Management	125	10.60	117	9.92	2.5	0.933
Energy Healing	11	0.93	6	0.51	2.1	0.725
Heat Therapy	77	6.53	65	5.51	3.1	0.894
Herbal Remedies	24	2.04	83	7.04	1.1	0.341
Homeopathy	29	2.46	26	2.21	1.8	0.594
Ice Therapy	11	0.93	11	0.93	3	1.044
Massage Therapies	53	4.50	31	2.63	2.8	0.891
Nerve Blocks	26	2.21	17	1.44	2.5	1.222
NSAIDs	53	4.50	41	3.48	2.5	0.978
Occupational Therapy	34	2.88	26	2.21	2.8	1.209
Opioids	43	3.65	34	2.88	3.3	1.086
Other Medication(s)	81	6.87	74	6.28	2.9	1.099
Pain Medication Delivered	36	3.05	19	1.61	3	1.177
Physical Therapy	76	6.45	53	4.50	2.5	1.129
Regular Exercise	227	19.25	185	15.69	2.8	0.947
Relaxation Training	52	4.41	45	3.82	2.6	0.776
Self-Help Groups	32	2.71	22	1.87	2.6	0.987
Special Jewelry (Copper Bracelet, Magnets)	22	1.87	13	1.10	2.1	1.237
Spinal Cord Stimulation	4	0.34	3	0.25	3	1.265
Spinal Pump	1	0.08	1	0.08	2.5	2.121
Spiritual or Religious	29	2.46	24	2.04	2.6	0.979
Splints or Braces	70	5.94	63	5.34	3.1	0.887
Steroid Injections	45	3.82	20	1.70	2.4	1.267
Surgical Interventions	37	3.14	26	2.21	3.1	1.147
TENS Unit or Interferential Stimulation	42	3.56	23	1.95	2.2	0.915

Table 3

Treatments Used by Participants for Acute and Chronic Pain (N = 1179) and Perceived Helpfulness

Strategy	Reported use (past 6 months)		Reported use (current)		Helpfulness	
	n	%	n	%	Mean	(SD)
Acetaminophen	279	23.66	237	20.10	2.3	1.001
Acupuncture	114	9.67	57	4.83	2.3	1.289
Anti-Seizure Medications	125	10.60	95	8.06	2.3	1.269
Aromatherapy	93	7.89	84	7.12	2.2	1.143
Avoiding potentially dangerous activities	710	60.22	710	60.22	3.1	1.04
Chiropractic Care	156	13.23	111	9.41	2.8	1.307
Chronic Illness Classes	44	3.73	46	3.90	1.7	0.493
Counseling or	180	15.27	122	10.35	2.6	1.207
Creams or Ointments	264	22.39	221	18.74	2.4	1.003
Diet Management	321	27.23	296	25.11	2.8	1.11
Energy Healing	86	7.29	68	5.77	2.6	1.308
Heat Therapy	480	40.71	452	38.34	3.2	0.994
Herbal Remedies	189	16.03	145	12.30	1.1	0.306
Homeopathy	99	8.40	81	6.87	2.1	1.047
Ice Therapy	282	23.92	252	21.37	2.9	1.064
Massage Therapies	334	28.33	276	23.41	3.4	1.144
Nerve Blocks	68	5.77	47	3.99	2.6	1.369
NSAIDs	390	33.08	336	28.50	2.7	1.067
Occupational Therapy	140	11.87	104	8.82	2.7	1.24
Opioids	402	34.10	367	31.13	3.6	1.007
Other Medication(s)	333	28.24	318	26.97	3	1.083
Pain Medication Delivered	114	9.67	73	6.19	2.5	1.278
Physical Therapy	412	34.94	309	26.21	2.8	1.173
Regular Exercise	345	29.26	313	26.55	2.7	1.131
Relaxation Training	306	25.95	268	22.73	2.6	1.013
Self-Help Groups	176	14.93	157	13.32	2.7	1.151
Special Jewelry (Copper Bracelet, Magnets)	49	4.16	29	2.46	1.7	1.126
Spinal Cord Stimulation	1	0.08	1	0.08	1.1	0.626
Spinal Pump	2	0.17	21	1.78	1.3	0.864
Spiritual or Religious	238	20.19	225	19.08	2.8	1.194
Splints or Braces	457	38.76	419	35.54	3.2	1.031
Steroid Injections	107	9.08	71	6.02	2.6	1.269
Surgical Interventions	110	9.33	72	6.11	3	1.236
TENS Unit or Interferential Stimulation	226	19.17	169	14.33	2.6	1.158

Vita

Karen Arthur graduated from Appalachian State University in 2009 with her bachelor's degree in Sociology and a minor in Psychology. She worked from 2009-2012 at OASIS, Inc., the domestic violence and sexual assault response center for Watauga County, North Carolina. At OASIS, Inc. Karen was introduced to Expressive Arts Therapy, and chose to pursue her Master's degree in Clinical Mental Health Counseling with a concentration in expressive arts and a certificate in expressive arts to expand her training in this growing field.

Graduating in August, 2014, Karen will be transitioning to her next adventure with her husband Shawn and their two cats. After working for a while and earning her license, Karen intends to pursue a PhD in Counselor Education and hopes to someday teach in a university setting.