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Prevalence, self-care behaviors, and self-care activities for peripheral neuropathy symptoms of HIV/AIDS

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Abstract

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

Keywords

HIV/AIDS; peripheral neuropathy; self-care; symptom management

INTRODUCTION

Recent research indicates that HIV-associated peripheral neuropathy is related to the direct effects of HIV, advanced immunosuppression, and the side-effects and toxicities of antiretroviral (ARV) medications (Schifitto et al., 2002, 2005). Studies suggest that symptoms, such as fatigue, anxiety, diarrhea, and peripheral neuropathy, exist across the spectrum of HIV and significantly impair quality of life (Holzemer, 2002). Neuropathy-related symptoms in the presence of HIV disease are common across the trajectory of HIV disease and are associated with pain, numbness, tingling, and other vexing symptoms.

Literature review

Peripheral neuropathy is the most common neurological complication of HIV disease across the trajectory from early HIV disease to AIDS and often is associated with ARV medications (Nicholas et al., 2002, 2007a; Dorsey & Morton, 2006; Ferrari et al., 2006; Gonzalez-Duarte et al., 2007). Gonzalez-Duarte et al. (2007) found that ≤ 67% of those living with HIV disease reported the symptom of neuropathy. Central or peripheral nervous system involvement is notably one of the most common and complex symptoms of HIV/AIDS (Price, 1996;Parry et al., 1997; Swanson et al., 1998; Lichtenstein et al., 2004; Schifitto et

al., 2002, 2005; Nicholas et al., 2007a,b,c). The risk factors include older age, advanced HIV disease, and the use of nucleoside-reverse transcriptase inhibitors (NRTIs) or other neurotoxic drugs (Simpson & Cikurel, 2006).

Gonzalez-Duarte et al. (2007) reported that the primary symptoms of neuropathy are slowly progressive numbness and paresthesia, with burning sensations in the feet, usually in a symmetrical pattern. The etiology of HIV-associated peripheral neuropathy, or distal sensory polyneuropathy (DSPN), is unknown, although the neurotoxic effects of cytokines, toxicity of HIV proteins, and mitochondrial damage have been implicated. The current treatment for HIV-associated DSPN is symptomatic, with pain-modifying medications including opioids, anti-inflammatory agents, antiepileptics, and antidepressants, with the tricyclic antidepressants found to be most effective (Gonzalez-Duarte et al., 2007). Other topical medications, including topical anesthetics and capsaicin, are used less frequently. Sustained virological control might improve DSPN. Novel therapies, such as acetyl-*l*-carnitine or neurotrophic factors, are being examined for the treatment of peripheral neuropathy (Chiechio et al., 2007;Youle et al., 2007).The recent study by Youle et al. (2007) suggested that these might be limited in efficacy and are often unavailable in countries where HIV is most prevalent. The literature indicates that, although neuropathy is a common problem across resource-rich and resource-limited settings, further study must focus on this complex problem.

HIV-associated peripheral neuropathy is known to be common across the trajectory of HIV disease and may exist in a variety of patterns, with DSPN as the most frequently occurring type (Wulff et al., 2000). In our previous studies, neuropathy was found to be among the most frequent symptoms experienced by patients. Antiretroviral toxic neuropathies also are described in the literature by many researchers (Pardo et al., 2001; Simpson & Cikurel, 2006). Most often, DSPN occurs in advanced HIV disease due to immunosupression or in relation to the toxic manifestations of ARV medications (Harrison & McArthur, 1995; Swanson et al., 1998; Schifitto et al., 2002, 2005; Lichtenstein et al., 2004; Verma et al., 2004; Saarto & Wiffen, 2005). The impact of mitochondrial toxicity has been explored and the influence of genetics as a possible etiology of DSPN is increasingly important (Gerschenson & Brinkman, 2004; Gonzalez-Duarte et al., 2007; Nicholas et al., 2007b). Verma et al. (2005) reported that neuropathic pain constitutes ~ 25–50% of all pain clinic visits, although not specifically limited to those with HIV/AIDS. In our study, we also examined the impact of specific ARV medication regimens in our study populations. The NRTIs and the non-NRTIs are frequently among the medications administered. The NRTIs, including stavudine (d4T) and didanosine (ddI), are linked with neuropathy symptoms (Arenas-Pinto et al., 2008). Recent literature also suggested that exposure to protease inhibitors (PIs), in the context of ARV medications, increased the risk of DSPN (Ellis et al., 2008). Gaps exist in the literature related to the complex issues of the presence of neuropathy and its relationship to medication regimens and the length of time living with HIV. Self-care management strategies also should be further investigated for the amelioration of symptoms and the education of patients living with HIV-related neuropathy.

Purpose of the study

As part of a larger study conducted by the University of California, San Francisco (UCSF) International HIV/AIDS Nursing Research Network on the efficacy of a symptom management manual for self-care symptom management in HIV disease, the purpose of the present study was to analyze the prevalence and characteristics of peripheral neuropathy in a sample of HIV-infected individuals in several countries. A descriptive quantitative design was employed for the study. Statistical Package for the Social Sciences (SPSS) for Windows Version 14.0 software (SPSS, Chicago, IL, USA) was used to analyze the descriptive data and to categorize the symptom management data. Quantitative methods were used to analyze and summarize the symptom management data related to peripheral neuropathy and to develop a model to assess the relationships in the frequency of use of the 18 self-care activities for neuropathy.

METHODS

The larger study was a randomized controlled trial, while the present study reports only baseline data related to neuropathy symptoms and self-care behaviors. The settings included university-based AIDS clinics, private practices, public and private hospitals, residential and day care facilities, community-based organizations, and home care services. Each site received appropriate institutional approval for research involving human participants. Certificates of confidentiality were obtained when requested by institutional review boards at specific sites. For the study, the inclusion criteria were that the participants had to be: (i) at least 18 years of age; (ii) receiving AIDS-related care at their respective facility; and (iii) able to provide informed consent.

Protection of the participants

The Committee on the Protection of Human Subjects at the UCSF reviewed and accepted the protocol. The study sites in each city in the USA and each country received approval from their appropriate institutional review board and/or human subjects review committee. These ethical review boards were located at: Partners Healthcare/Spaulding Rehabilitation Hospital, Boston, Massachusetts, USA; Boston Living Center, Boston, Massachusetts, USA; University of South Africa, Pretoria, South Africa; Aga Khan University, Nairobi, Kenya; School of Health Sciences, Universidad del Turabo, Gurabo, Puerto Rico; Texas A & M University Corpus Christi, Texas, USA; University of San Diego, San Diego, USA; College of Nursing, University of Utah, Salt Lake City, Utah, USA; and Medical Sciences Campus, University of Puerto Rico, San Juan, Puerto Rico. As this was a randomized controlled trial, a Data Safety and Monitoring Board was established by the UCSF's HIV Center to monitor the performance and safety of the clinical trial. The completed questionnaires with participant identification numbers were kept in locked filing cabinets. All the information was kept confidential and secure at all times, ensuring confidentiality of the participants.

After obtaining informed consent, the participants completed a comprehensive self-report assessment survey that included demographic information, illness background, adherence questions, and self-care symptom assessments related to the most commonly experienced symptoms including neuropathy. The instruments were made available in English or

Spanish. In South Africa and Kenya, the questionnaire was administered in English, which is widely spoken in these two African countries.

Measures

For these analyses, the instruments included a demographic survey, and the Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev) and the Self-care Behavior Survey (Holzemer et al., 2001).

Demographic survey—A survey booklet was used to collect information on personal and environmental characteristics including age, sex, number of years of education, whether or not the participants had an adequate income, whether or not they had children, and other variables. The level of income was self-reported by the participants as “enough”, “barely adequate”, or “totally inadequate”. In addition, data on bio-physiological factors, such as whether or not the participants had received an AIDS diagnosis or had any comorbidities, also were collected.

Revised Sign and Symptom Checklist for Persons with HIV Disease—The SCC-HIVrev is a checklist that captures the frequency and intensity of 72 common HIV signs and symptoms. The SSC-HIVrev has three parts: Part I consists of 45 HIV-related physical and psychological symptoms, clustered into eleven factor scores, along with a total score, with reliability estimates ranging from 0.76–0.91; Part II consists of 19 HIV-related symptoms that do not cluster into factor scores but might be of interest from a clinical perspective; and Part III consists of eight items related to gynecological symptoms for women. Cronbach’s alpha factor reliability scores, ranging from 0.85–0.90 for each of the factors and 0.92 for the overall 64 item instrument, excluding the gynecological factor, were obtained for this sample.

For this study, the data related to neuropathy symptoms were analyzed. The participants completed the checklist based on the signs and symptoms that they experienced on that day. The items are rated on a three-point Likert scale of 1 (mild), 2 (moderate), or 3 (severe).The reliability and validity of the instrument have been reported previously for a sample in the USA (Holzemer et al., 2001). Slightly different Spanish versions of the SSC-HIVrev were used in Texas for a predominately Mexican population, in Puerto Rico, and in Colombia. In Africa, only the English versions were used.

The study’s questions that are examined here include: What is the prevalence of peripheral neuropathy in an international sample of HIV-infected individuals in the USA, Puerto Rico, Kenya, and South Africa? Which self-care behaviors are used by this sample? Are there differences in the prevalence, symptom intensity, and self-care strategies for those individuals who are taking prescribed ARV medications and those individuals who are not? What is the reported effectiveness of these self-care behaviors? Is there a model for the trajectory of the experience of neuropathy and in the reported effectiveness of the types of self-care strategies in those taking and not taking ARV medications?

Data analysis

Responses to the questionnaires were entered into SPSS Version 14.0 software. Descriptive statistics (i.e. mean [M], standard deviation [SD], frequency, and percentage) were used to examine the demographic characteristics of the sample, and the frequency and intensity of the symptoms and self-care behaviors, while factor analyses were used to examine the relationships in the frequency of use of self-care activities related to neuropathy symptoms. Chi-squared analyses were conducted to examine the association between the symptoms of neuropathy for those on prescribed ARV medications and those not on prescribed ARV medications. The data were analyzed for comparisons of neuropathy symptoms across countries, ratings of effectiveness of self-care behaviors, and differences by sex and ethnicity.

RESULTS

The mean age for the total sample (n = 775) was 42.8 years (SD = 9.6) and 38.5% of the sample were female. The demographics of the sample were: 28% African American, 28% Hispanic, 21% Caucasian, 16% African (from Kenya or South Africa), 1% Asian, and 5% self-described as “other”. Regarding the educational level, 42% of the sample had a high school education, 29% had a grade school education, and 29% had college or posthigh school education. Sixty-two percent of those in the sample reported having at least one child living in the home. The mean number of years living with HIV was reported to be 9.1 years (SD = 6.6). Regarding HIV disease characteristics, 42% (n = 322) had an AIDS diagnosis, while 53.2% (n = 408) reported HIV disease without an AIDS diagnosis, and 4.8% (n = 37) reported having HIV, but not knowing whether or not they had AIDS. Sixty-three percent of the sample (n = 470) reported a comorbid illness. Seventy percent (n = 547) of the sample were taking prescribed ARV medications, with the mean number of years taking ARV medications reported as 6.7 years (SD = 5.2). Over 50% (n = 477) of the sample were aware of their CD4 counts and the mean CD4 count was 268 (range: 0–1200). Undetectable viral loads were reported by one-third of the sample (n = 251; 33%).

For those participants who reported neuropathy symptoms (n = 228) and self-care for neuropathy, the mean age was 44.6 years (SD = 9.8; range: 21–70 years) and 53.5% (n = 121) were male, 38.5% (n = 87) were female, and 8.0% (n = 18) were transgender. There were 25 participants from South Africa, seven participants from Kenya, and 36 participants from Puerto Rico who reported neuropathy symptoms and self-care behaviors (Table 1).

Symptom frequency of neuropathy

Neuropathy in the feet and toes was the eleventh-most common symptom in the sample (n = 339; 44%). However, only 228 participants reported that they engaged in self-care behaviors to limit their neuropathy symptoms. Fatigue, depression, muscle aches, general weakness, thirst, worry, concentration difficulties, memory loss, dry mouth, and insomnia were the most frequently reported symptoms. Table 2 displays the comparison of baseline neuropathy by site and Table 3 illustrates the frequencies, percentages, and mean scores in relation to neuropathy, number of days that neuropathy was present each week, intensity of neuropathy, impact of neuropathy, and self-ratings of the physical condition, psychological condition,

and social support. The percentage of those reporting neuropathy varied with the study sites, ranging from 1.4% (Salt Lake City, Utah, USA) to 52.1% (South Africa), although the sample in both sites was small.

For both those participants who reported taking ARV medications and those not taking ARV medications, the level of neuropathy was higher than expected in both groups, with higher-than-expected reports of moderate and severe symptom intensity ($\chi^2 = 4.62$; d.f. = 1; $P = 0.03$). There were significant differences across the study sites, countries, and continents in relation to the percentage of neuropathy reported, the number of days per week that neuropathy was experienced, the impact of neuropathy, and self-ratings of the physical condition, psychological condition, and social support. The mean neuropathy intensity (on a 0–10 scale from lowest to highest) was highest in the two African samples of South Africa (M = 7.3; SD = 2.0) and Kenya (M = 7.1; SD = 2.1). There were no significant differences in the neuropathy scores related to the length of time with an HIV diagnosis or the presence of a diagnosis of AIDS. The mean score regarding the impact of neuropathy on quality of life was also highest in the South African respondents, at 7.8 (SD = 2.6). High neuropathy intensity scores also were reported in one sample in Puerto Rico (M = 7.0; SD = 2.0) and Texas (M = 7.1; SD = 2.1). There were significant differences across study sites in relation to the rating of their physical condition by the study's respondents, with the lowest ratings reported by the respondents from South Africa (M = 3.6; SD = 2.6) on a scale with 0 as the lowest rating of physical condition and 10 as the highest rating. The highest mean rating on physical condition was in the Kenyan sample (M = 8.3; SD = 1.9). The South African sample also reported the lowest mean ratings on psychological condition (M = 3.9; SD = 3.3) and social support (M = 3.8; SD = 2.8) (Tables 3 and 4).

Self-care behaviors for neuropathy symptoms

Taking a hot bath was the most frequent strategy used by those with peripheral neuropathy ($n = 135/228$; 59.0%) and received the highest overall rating of effectiveness of any self-management strategy included in this study, at 7.4 (scale of 1–10). Other self-care strategies to manage this symptom included: staying off one's feet ($n = 115/228$; 50.4%), rubbing the feet with cream ($n = 86/228$; 37.7%), elevating the feet ($n = 123/228$; 53.9%), walking ($n = 115/228$; 50.4%), prescribed anti-epileptic agent ($n = 41/228$; 18.0%), prescribed analgesics ($n = 36/228$; 15.8%), over-the-counter medications ($n = 57/228$; 25.0%), vitamin B ($n = 69/228$; 30.3%), calcium supplement ($n = 44/228$; 19.3%), magnesium ($n = 28/228$; 12.3%), massage ($n = 65/228$; 28.5%), acupuncture ($n = 36/228$; 15.8%), reflexology ($n = 12/228$; 5.3%), and meditation ($n = 46/228$; 20.2%). Several behaviors that are often deemed unhealthy were included among the strategies that were reported to alleviate peripheral neuropathy including the use of marijuana ($n = 44/228$; 19.3%), cigarette smoking ($n = 64/228$; 28.1%), drinking alcohol ($n = 29/228$; 12.7%), and street drugs ($n = 17/228$; 7.5%) (Tables 3 and 4).

A principal axis factor analysis with Promax rotation was used to assess the relationships in the frequency of use of the 18 self-care activities for neuropathy, revealing three distinct factors: (i) an interactive self-care factor consisting of the activities of taking a warm bath, staying off one's feet, elevating the feet, exercise, and walking (the Cronbach's alpha of the

six items was 0.67); (ii) a complementary medicine factor that included taking vitamins B1, B12, and B complex, taking calcium, taking magnesium, receiving a massage, receiving acupuncture, reflexology, and meditation (the Cronbach's alpha of the seven items was 0.77); and (iii) a third factor consisting of the negative health items of smoking, alcohol, and street drugs (the Cronbach's alpha of the three items was 0.60). The items that did not load clearly on any one factor were prescription medications, over-the-counter drugs, and marijuana use. Using multilevel growth modeling, the identified factors were then run, estimating the initial status and the interactions of the factors with time to assess the effect of the factors in the change in self-reported neuropathy intensity over the 3 month study period.

Combined model for individuals taking and not taking antiretroviral medications

The model combining both individuals taking and not taking ARV medications showed that the individuals taking ARV medications had a significantly higher initial intensity score compared to the individuals not taking ARV medications (6.24 vi 5.43, respectively). In the combined group, there were no differences in the mean effect of symptom management strategies in the initial status; however, Factor 1 showed a significant interaction with time, with an increase of 0.63 (standard error [SE] = 0.29) of one point in the persons using interactive self-care strategies. A significant decrease in neuropathy intensity of 0.81 (SE = 0.36) of one point over time in the individuals using complementary medicine and those using negative health behaviors for neuropathy showed an insignificant increase of 0.5 (SE = 0.29) of one point over time.

Model for individuals not currently on antiretroviral medications

The model that was run for the individuals not taking ARV medications showed an initial mean symptom intensity score of 5.7 out of 10 and a significant interaction with time, with an increase of 0.83 (SE = 0.42) of one point in the persons using interactive self-care strategies. A significant decrease in neuropathy intensity of 2.49 (SE = 0.85) points over time in the individuals using complementary medicine and those using negative health behaviors for neuropathy showed an insignificant increase of 0.51 (SE = 0.59) of one point.

Model for individuals currently on antiretroviral medications

The model that was run for the individuals taking ARV medications showed an initial mean symptom intensity score of 6.1 out of 10 and no significant interactions with time for the three factors, although the complementary medicine strategy factor showed a decline in intensity over time.

DISCUSSION

The study's results indicated that neuropathy is a prevalent symptom and remains a significant health consequence of HIV disease. In our study, self-care strategies were frequently reported by those living with HIV disease to ameliorate the symptoms of neuropathy. The results indicated that neuropathy intensity and its impact on the quality of life were highest in the African samples. Despite the prevalence and intensity of neuropathy in South Africa and Kenya, ARV regimens (including the NRTIs, including ddI and d4T) are common and might contribute to neuropathy symptoms. In our study, PI-based therapies

were associated with neuropathy symptoms, although we did not control for prior NRTI-based symptoms or advanced HIV disease. Recent literature also suggested that PI-based therapies are associated with an increased prevalence of neuropathy symptoms (Ellis et al., 2008); thus, further study is necessary to examine the relationship between ARV medications and neuropathy symptoms.

Consistent with our previous studies (Nicholas 2002, 2007a,b), we found that self-care strategies to manage neuropathy symptoms include: staying off one's feet, rubbing the feet, elevating the feet, walking, medication therapies, and complementary therapies. Some unhealthy behaviors were described by the participants including the use of marijuana, cigarette smoking, and alcohol use. Recent research has suggested that marijuana could offer positive health benefits rather than negative consequences (Fogarty et al., 2007).

The mean neuropathy intensity (on a 0–10 scale from lowest to highest) was highest in the two African samples of South Africa (M = 7.3; SD = 2.0) and Kenya (M = 7.1; SD = 2.1). However a significant decrease in neuropathy intensity of 0.81 (SE = 0.36) of one point over time in the individuals using complementary medicine and those using negative health behaviors for neuropathy showed an insignificant increase of 0.5 (SE = 0.29) of one point over time. Thus, unhealthy behaviors related to neuropathy symptoms require further investigation.

The role of social support in HIV disease and the relationship with self-care activities require further exploration. The mean level of impact of neuropathy on the physical and psychological condition, and social support was lowest in South Africa. Further examination of social support is needed as it might moderate other negative consequences of HIV disease such as quality of life and adherence to medications. Education for self-care also might occur more frequently in supportive environments and in social support groups.

It is interesting to note that both the men and the women reported self-care activities (taking a hot bath, staying off one's feet, elevating the feet, rubbing the feet); however, the men were more likely to report exercise than did the women in the sample and the women more frequently described rubbing the feet. As neuropathy can be associated with decreased sensation, the education of those with HIV-related neuropathy is critical to avoid alterations in skin integrity related to hot baths and the risk of burns. The use of marijuana and alcohol was more common among the men in the sample, but cigarette smoking was reported frequently by both the men and the women.

In the models that were developed to examine the trajectories in the experience of neuropathy and in the reported effectiveness of the types of self-care strategies used by those taking and not taking ARV medications, there were three factors that were found to affect neuropathy. The interactive self-care factor included activities (walking, warm bath, staying off one's feet, elevating the feet, and exercise), with a Cronbach's alpha of 0.67 for the six-item factor. The second factor of complementary medicine (vitamins, massage, acupuncture, reflexology, and meditation) had a higher alpha of 0.77. The third factor of unhealthy behaviors (smoking, alcohol, street drugs) yielded a Cronbach's alpha of 0.60. The model combining both individuals taking and not taking ARV medications showed that the

individuals taking medications had a significantly higher initial intensity score compared to the individuals not taking ARV medications (6.24 vs 5.43, respectively). Further research should explore these factors in the self-care activities related to neuropathy.

The present study adds to the body of research on self-care strategies for neuropathy and supports our previous work suggesting that self-care management is an important aspect of neuropathy symptom management in HIV disease. There also might be cultural, social, and educational factors that represent the under-reporting of neuropathy in some of the study's settings. For example, in Salt Lake City, USA, only 1.4% of the sample reported neuropathy, which might be related to early treatment and intervention for neuropathy symptoms. In other settings (South Africa and Kenya), where NRTI-based medications are linked with the presence of neuropathy, this symptom was reported more frequently.

CONCLUSIONS

The study offers important implications in relation to the assessment of neuropathy symptoms in resource-limited and resource-rich countries. As neuropathy is a painful condition with limited options for minimizing the symptoms, nurses must be astute in the assessment and education of patients about the available self-care and other management strategies. As peripheral neuropathy is often a chronic and debilitating condition and can be worsened by ARV therapy, focusing on the self-care strategies that improve neuropathy symptoms is essential. In addition, specific medications for HIV treatment, which are first-line medications in Africa, are prescribed often and nurses' assessment and interventions to ameliorate neuropathy symptoms are critical.

Additional research is needed regarding other self-care strategies, as well as the medications that could limit neuropathy. Many individuals living with HIV/AIDS utilize a variety of complementary therapies that should be further investigated. Nursing research in South Africa and Kenya also should focus on the wide variety of complementary therapies unique to these cultures. With this research, nursing interventions that include self-care strategies, medications, and complementary therapies might be found that improve the symptom of neuropathy.

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Table 1.

Demographic data of the participants who reported neuropathy ($n = 228$)

Variable	Range	Mean	SD	Frequency
Age	21–70 years	44.65 years	9.8	228
CD4 count (self-report)	0–1604	193	217	–
Sex: N (%)				
Male				121 (53.5)
Female				87 (38.5)
Transgender				18 (8.0)
Ethnicity: N (%)				
African American/African				92 (40.9)
Caucasian				35 (15.6)
Hispanic/Latino				80 (35.6)
Asian/Pacific Islander				5 (2.2)
Native American				2 (0.9)
Other				11 (14.9)
Risk factors: N (%)				
Sex with a man with HIV				161 (70.6)
Sharing needles				49 (21.5)
Sex with a woman with HIV				36 (15.7)
Don’t know				13 (5.7)
Blood transfusion				9 (3.9)
Other				6 (2.6)
Income: N (%)				
Enough				52 (23)
Barely adequate				105 (46.5
Current injecting drug user				69 (10.3)

SD, standard deviation.

Table 2.

Comparison of baseline neuropathy by site (n = 228)

Variable	Total sample (n = 228)	San Francisco (n = 35)	South Africa (n = 25)	Salt Lake City (n = 1)	Boston (n = 17)	Philadelphia (n = 15)	Chicago (n = 10)	Puerto Rico I (n = 30)	Puerto Rico II (n = 6)	Texas I (n = 27)	Texas II (n = 28)	Texas III (n = 21)	Kenya (n = 7)	*P*
Percentage neuropathy	29.4	40.7	52.1	1.4	24.6	14.0	62.5	42.9	21.4	44.2	50	28.8	9.9	< 0.001
Days/week	5.2 (2.1)	6.0 (1.6)	5.9 (1.6)	5.0	4.9 (2.3)	3.4 (2.2)	4.5 (2.4)	5.0 (2.1)	6.1 (0.9)	5.0 (2.1)	5.1 (2.3)	5.8 (2.1)	4.6 (2.3)	< 0.001
Neuropathy impact (scale: 0–10)	6.3 (3.3)	6.3 (3.1)	7.8 (2.6)	4.0	5.1 (3.4)	4.8 (3.5)	5.3 (3.2)	6.8 (3.1)	7.3 (1.8)	5.0 (3.4)	6.5 (3.4)	7.2 (2.2)	4.7 (2.5)	< 0.001
Neuropathy intensity (scale: 0–10)	6.4 (2.9)	6.9 (2.5)	7.3 (2.0)	4.0	5.4 (3.3)	5.4 (3.3)	5.0 (3.5)	6.7 (2.7)	7.0 (2.0)	5.7 (2.8)	6.5 (3.1)	7.1 (2.1)	4.3 (2.0)	< 0.001
Self-rating of physical condition (scale: 0–10)	6.2 (2.5)	6.3 (2.0)	3.6 (2.6)	5.0	6.2 (2.5)	7.7 (1.2)	6.0 (1.8)	7.0 (2.8)	5.2 (3.4)	6.5 (2.5)	6.3 (2.0)	6.0 (2.4)	8.3 (1.9)	< 0.001
Self-rating of psychological condition (scale: 0–10)	6.4 (2.9)	6.2 (2.8)	3.9 (3.3)	9.0	8.1 (2.9)	7.3 (2.5)	7.6 (2.9)	7.2 (2.8)	4.8 (3.2)	6.7 (2.6)	6.5 (2.2)	5.2 (2.5)	7.0 (3.3)	< 0.001
Self-rating of social support (scale: 0–10)	6.5 (2.9)	6.7 (2.2)	3.8 (2.8)	7.0	6.9 (2.2)	7.6 (1.6)	6.6 (3.1)	7.7 (2.9)	6.2 (4.1)	6.4 (2.9)	6.9 (2.9)	5.3 (3.4)	9.1 (1.6)	< 0.001

Values in parentheses refer to the standard deviation.

Table 3.

Frequency and effect of neuropathy self-management strategies for the total sample ($n = 228$)

Self-care strategy	N	%	Daily (%)	Weekly (%)	Monthly (%)	Rating of effectiveness (scale: 1–10)
Activities						
Take a hot bath	135	59.0	42.5	5.7	1.3	7.4
Stay off one's feet	115	50.4	39.0	3.5	0.4	7.2
Rub feet	86	37.7	23.2	5.3	1.3	6.9
Elevate feet	123	53.9	37.3	6.6	1.3	7.3
Exercise	64	28.1	16.7	5.3	0.9	7.2
Walk	115	50.4	36.8	5.7	0.4	7.2
Medications						
Prescribed antiepileptics	41	18.0	11.8	1.3	0.4	6.6
Prescribed analgesics	36	15.8	8.3	1.8	1.3	6.8
Over-the-counter medications	57	25.0	10.5	4.4	2.2	6.8
Vitamins B6, B12, B complex	69	30.3	18.0	3.5	3.1	6.9
Calcium	44	19.3	11.8	2.2	0.4	7.1
Magnesium	28	12.3	7.5	1.3	0.0	6.9
Massage	65	28.5	8.3	7.0	7.0	7.4
Acupuncture	36	15.8	0.4	3.9	5.7	7.1
Reflexology	12	5.3	0.9	1.3	0.9	6.6
Meditation	46	20.2	11.4	2.6	1.3	7.6
Marijuana	44	19.3	10.5	2.2	3.5	7.0
Cigarettes	64	28.1	21.5	0	0.4	6.4
Alcohol	29	12.7	2.6	2.6	3.1	6.6
Street drugs	17	7.5	3.1	0.9	0.4	6.9

Table 4.

Frequency and effectiveness of neuropathy self-management strategies by country (n = 228)

	USA (n = 147)		Puerto Rico (n = 33)		Africa (n = 25)	
Strategy	**Frequency N (%)**	**Effectiveness rating (scale: 1–10)**	**Frequency N (%)**	**Effectiveness rating (scale: 1–10)**	**Frequency N (%)**	**Effectiveness rating (scale: 1–10)**
Activities						
Take a hot bath	109 (74.1)	7.6	15 (45.5)	7.4	11 (44.0)	5.4
Stay off one's feet	91 (63.2)	7.1	17 (51.5)	8.0	7 (28.0)	5.8
Rub feet	57 (40.7)	6.9	17 (51.5)	7.5	12 (52.2)	6.1
Elevate feet	90 (60.8)	7.2	22 (66.7)	7.3	11 (45.8)	7.1
Exercise	54 (38.0)	7.1	8 (25.0)	8.4	2 (9.1)	4.0
Walk	90 (60.8)	7.3	17 (51.5)	7.8	8 (32.0)	3.8
Medications						
Prescribed antiepileptics	33 (23.1)	6.5	6 (18.2)	6.8	2 (9.1)	7.0
Prescribed analgesics	26 (18.4)	6.7	9 (27.3)	7.1	1 (4.8)	5.0
Over-the-counter medications	46 (32.6)	7.0	11 (33.3)	6.5	0 (0.0)	
Vitamins B6, B12, B complex	44 (31.4)	7.0	14 (42.4)	6.5	1142.3	7.2
Calcium	35 (25.4)	7.3	8 (24.2)	6.3	1 (4.8)	6.0
Magnesium	24 (17.4)	7.0	4 (12.1)	6.0	0 (0.0)	6.0
Massage	48 (34.3)	7.4	11 (33.3)	8.0	6 (27.3)	5.5
Acupuncture	25 (17.6)	6.8	10 (30.3)	8.0	1 (4.5)	
Reflexology	12 (8.8)	1.0	0	0.0	0 (0.0)	0.0
Meditation	38 (27.3	7.6	5 (15.2)	7.8	3 (13.6)	5.0
Marijuana	42 (30.2)	7.2	2 (6.1)	4.0	0 (0.0)	0.0
Cigarettes	51 (37.5)	6.6	13 (39.4)	5.6	0 (0.0)	0.0
Alcohol	25 (18.7)	6.6	4 (12.1)	7.0	0 (0.0)	0.0
Street drugs	12 (9.2)	6.8	5 (15.2)	7.4	0 (0.0)	0.0