# CAPTURING CASES OF DISTAL SYMMETRIC POLYNEUROPATHY IN A COMMUNITY

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Accepted 1 May 2012

ABSTRACT: Introduction: Little is known about what constitutes appropriate diagnostic testing in patients with distal symmetric polyneuropathy (DSP). Methods: Utilizing an ICD-9 screening method and medical record abstraction, we determined the number of new cases of DSP within community neurology practices in Nueces County, Texas. We then compared 2 case capture methods (ICD-9 vs. all-case review screening). Results: The ICD-9 case capture method identified 52 cases over a 3-month period. Comparing case capture methods, the ICD-9 method identified 16 of 17 cases identified by the allcase review method (94%). The ICD-9 method required screening of 84% fewer charts compared with the all-case review. Conclusions: Many new cases of DSP occur each month within Nueces County. The ICD-9 screening technique combined with medical abstraction is an efficient method to identify new DSP cases in this community. These findings are critical for future epidemiological investigations into patients with DSP.

Muscle Nerve 49:943-947, 2012

Although there are many types of peripheral neuropathy, by far the most common is distal symmetric polyneuropathy (DSP). DSP is a disorder characterized by a combination of features, including pain, numbness, paresthesias, and/or weakness, starting in the feet and progressing proximally in a stocking-glove fashion. Patients often have disabling pain and balance difficulties. Due to lack of sensation in the feet, injuries also occur that can result in ulcerations or even osteonecrosis. DSP is a common, disabling condition that has been under-studied to date.

Despite the fact that DSP is common, little is known about its causes, and uncertainty exists regarding the appropriate diagnostic evaluation. Johannsen et al. followed 198 patients with symptoms suggestive of polyneuropathy who were referred for electrodiagnostic evaluation. The investigators found that diabetes and alcohol abuse were the most common etiologies, accounting for 51% of cases. However, a quarter of the patients remained with an idiopathic diagnosis.

**Abbreviations:** DCCT, Diabetes Control and Complications Trial; DSP, distal symmetric polyneuropathy; ICD-9, ninth revision of the International Classification of Diseases

**Key words:** diagnostic testing, health policy and practice, health services research, neuroepidemiology, neuropathy

**Disclosure:** K.K. received speaker honoraria from the American Academy of Neurology and Munson Medical Center, and served as a consultant for the American Academy of Neurology; the Weinberg Group; and Estes, Ingram, Foels & Gibbs, P.A.

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Published online 5 October 2012 in Wiley Online Library (wileyonlinelibrary.com). DOI 10.1002/mus.23449

Lubec et al. reported similar results in those discharged from the hospital with a diagnosis of neuropathy.<sup>5</sup> Focusing on those without a clear diagnosis based on history and examination, Dyck et al. demonstrated that, in a single tertiary referral center, a significant proportion of patients with neuropathy likely have a genetic cause.<sup>6</sup> With regard to diagnostic tests, Fagius et al. revealed that most laboratory tests have a low yield in those patients with no clear cause of neuropathy based on clinical history.<sup>7</sup> The only tests with a yield >5% included the glucose tolerance test and serum protein electrophoresis. Similarly, Smith et al. revealed that the glucose tolerance test and serum vitamin B<sub>12</sub> level were the only tests with a higher yield than expected from the general population.8 However, all of these studies were performed in tertiary care settings, and none utilized a strict definition of neuropathy. Moreover, none of the studies investigated how often diagnostic tests change the suspected etiology and/or management of these patients. Further emphasizing the need for future studies, we have recently shown that the evaluation of DSP is highly variable and costly. 9,10

Our long-term goal is to perform a population-based study examining the causes and diagnostic evaluation of DSP. To inform future sample size calculations, we sought to determine the number of DSP cases that present within a community without an academic medical center over a defined time period. We next compared an efficient case capture method [the ninth revision of the International Classification of Diseases (ICD-9) identification with subsequent medical record abstraction] to an all-case review method followed by medical record abstraction. Finally, we investigated the validity of DSP classification by a research coordinator when compared with that by a neuromuscular specialist.

## **METHODS**

**Population.** This study was designed to capture all new patients with DSP (i.e., no previous diagnosis of DSP) seen by neurologists within Nueces County, Texas. Nueces County is on the Gulf Coast, and the vast majority of its residents live in the city of Corpus Christi. Corpus Christi is 145 miles from San Antonio and greater than 200

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**Table 1.** ICD-9 codes used to screen for cases of distal symmetric polyneuropathy.

ICD-9 code	Description	Number of cases
250.60	Diabetes with neurologic complications	2
356.1	Peroneal muscular atrophy	0
356.2	Hereditary sensory neuropathy	0
356.4	Idiopathic progressive polyneuropathy	0
356.8	Other specified idiopathic peripheral neuropathy	0
356.9	Unspecified idiopathic peripheral neuropathy	40
357.1	Polyneuropathy in collagen vascular disease	0
357.2	Polyneuropathy in diabetes	8
357.3	Polyneuropathy in malignant disease	0
357.4	Polyneuropathy in other diseases classified elsewhere	0
357.5	Alcoholic neuropathy	0
357.6	Polyneuropathy due to drugs	0
357.7	Polyneuropathy due to other toxic agents	0
357.82	Critical illness polyneuropathy	0
357.89	Other inflammatory and toxic neuropathy	0
357.9	Unspecified inflammatory and toxic neuropathies	0
729.5	Pain in limb	1
782.0	Disturbance of skin sensation	1

miles from Houston. This significant distance from nearby major cities makes Corpus Christi the regional referral center for the area. Nucces County residents are unlikely to receive their medical care from the surrounding tertiary referral centers, which makes nearly complete case capture possible. This study was approved by the institutional review board of the University of Michigan.

We contacted all 11 practicing community neurologists within the 3 neurology practices in Nueces County to solicit study participation. Nine agreed to participate. Of the remaining 2 physicians, one does not see patients with neuropathy and the other is in the process of retiring.

Neuropathy Definition. The study population included patients with a new diagnosis of DSP. We defined DSP as patients who met the Diabetes Control and Complications Trial (DCCT) definition. This requires  $\geq 2$  of the following criteria: neuropathic symptoms [self-report of pain (burning, electric, shooting), numbness, tingling in the feet and/or legs]; decreased distal sensation on neurological examination; or decreased or absent ankle jerks. We also required that the physician document neuropathy within the medical record. To eliminate patients with neuropathy subtypes other than DSP, we excluded patients with atypical features such as acute/subacute/relapsing presentation, motor predominance, asymmetry (focal, multifocal), non-length dependence, and those

with prominent autonomic dysfunction. We also excluded patients who were not from Nueces County, were seen in the hospital only, or were seen for electrodiagnostic testing only.

Case Capture Methods. We utilized and compared 2 separate methods for identifying patients with DSP. The first method was to use ICD-9 codes followed by medical record abstraction to identify possible cases. The ICD-9 codes included were 250.60, 356.1, 356.2, 356.4, 356.8, 356.9, 357.1, 357.2, 357.3, 357.4, 357.5, 357.6, 357.7, 357.82, 357.89, 357.9, 729.5, and 782.0. These codes include peripheral neuropathy codes as well as symptomatic codes for paresthesias and pain in the extremities (Table 1). This method was employed for a 3-month period from January 1, 2010 through March 31, 2010. The second method, termed all-case review, involved screening of all new patient medical records with subsequent medical record abstraction over a 1-month period from February 1, 2010 through February 28, 2010.

**Medical Record Abstraction.** Medical records for cases identified by either screening method were abstracted by a trained research coordinator. Information abstracted included demographics, clinical characteristics, each of the 3 DCCT criteria, and the 5 study exclusion criteria (Table 2). The entire outpatient medical record was reviewed, including the initial visit and any subsequent follow-up visits.

Twenty patients, randomly selected from those identified using the ICD-9 screening method, were abstracted by both the research coordinator and a neurologist with fellowship training in neuromuscular disease.

**Statistical Analysis.** Cases identified by the ICD-9 case capture method within the month of February were compared with the cases identified by the all-case review method during the same time period.

**Table 2.** Demographics of the 52 patients identified by the ICD-9 case-capture method over a 3-month time period in Nueces County, Texas.

Mean age (SD), years	64.9 (13.1)
Female	55.8%
Health insurance	
Medicare	5.8%
Medicaid	1.9%
Medicare and Medicaid	13.5%
HMO, PPO, private and Medicare	59.6%
HMO, PPO, private	19.2%
Family history of neuropathy	0%
Neuropathic pain	57.7%
Muscle weakness on examination	17.3%

HMO, health maintenance organization; PPO, preferred provider organization.

The validity of the research coordinator's classification of each of the DCCT criteria and the overall classification of DSP were assessed by comparing the research coordinator's abstraction results to the neuromuscular specialist's results (i.e., the "gold standard"), and expressed as sensitivity and specificity. All analyses were performed using SAS (version 9.2).

#### **RESULTS**

From January 1, 2010 to March 31, 2010 there were 1167 new patient visits within the 3 neurology practices. The ICD-9 screening technique identified 189 neuropathy patients (16.2%). Of these patients, 89 were excluded for the following reasons: out-of-county residence; previous diagnosis of DSP; hospital-only cases; or patients seen only for electrodiagnostic testing (Fig. 1). Of the 100 remaining patients, 52 (52%) met the DCCT clinical definition of DSP based on the medical record

Of the 52 captured DSP cases, the mean age of the population was 64.9 (SD 13.1) years, and 55.8% were women (Table 2). There was a wide range of health insurance, and 73.1% of patients received at least partial coverage with Medicare. None of the patients had a family history of neuropathy, the majority suffered from neuropathic pain (57.7%), and 17.3% had distal weakness on examination.

Comparison of Case Capture Methods. When the ICD-9 case capture method was restricted to the time period of February 1, 2010 through February 28, 2010, we found that there were 66 patients with a qualifying ICD-9 diagnosis out of a total of 404 new patient visits (16.3%). Of these 66 cases, 36 were excluded for the same reasons as listed earlier. Of the 30 remaining cases, 16 (53.3%) had DSP based on the results of the medical record abstraction.

By comparison, the second method (all-case review) identified a total of 404 new patient visits between February 1, 2010 and February 28, 2010. One hundred eighty-two of the 404 total new patient cases were excluded based on the exclusion criteria. Of the remaining 222 patients, 17 cases (7.7%) of DSP were identified based on the medical record abstraction.

Thus, the ICD-9 case capture method identified 16 of the 17 DSP cases (94%) identified by the allcase review method for the same time period (Fig. 2). The one missed case was a patient with a chief complaint unrelated to neuropathy, who was incidentally found to have DSP on further inquiry and examination.

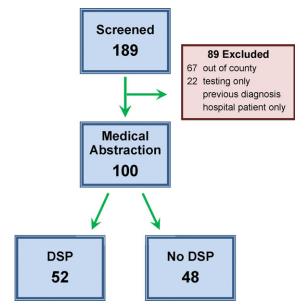


FIGURE 1. Flowchart of the ICD-9 screening method over a 3month period. DSP, distal symmetric polyneuropathy. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]

#### Validity of DSP Classification by Research Coordina-

tor. The abstraction by the research coordinator revealed a sensitivity of 100% and a specificity of 88% for the classification of patients as meeting the definition of DSP when compared with the neuromuscular specialist (Table 1). When evaluating the individual inclusion criteria, we found a sensitivity of 69% for neuropathic symptoms, 90% for sensory examination, and 100% for reflex examination. Similarly, we found a specificity of 86% for neuropathic symptoms, 100% for sensory examination, and 100% for reflex examination.

### **DISCUSSION**

Utilizing an ICD-9 case capture method, we identified 52 patients who met a strict definition of DSP over a 3-month time period within this community. The efficient ICD-9 case capture method resulted in the identification of 94% of the cases identified by a more laborious all-case review method. Further, we found high validity between a research coordinator and a neuromuscular specialist in the classification of DSP cases. These results indicate that DSP case capture can be performed in an efficient manner within community neurology practices in future epidemiological studies.

This investigation has demonstrated that the ICD-9 case capture method is an efficient screening technique. The all-case review method was labor-intensive and only identified 1 additional case (6%) meeting our criteria when compared with the ICD-9 method. In fact, 338 more charts were screened with the all-case review method to

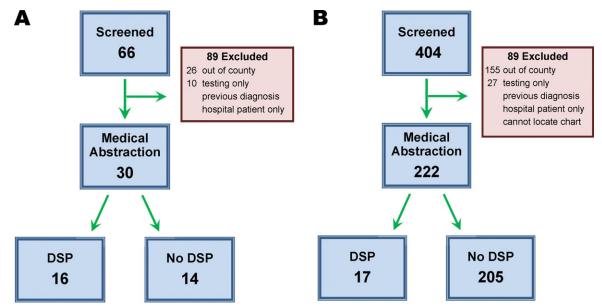


FIGURE 2. Flowchart showing the comparison of the (A) ICD-9 screening method with the (B) all-case review method over a 1-month period. DSP, distal symmetric polyneuropathy. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]

identify this one case. We also found that ICD-9 screening alone is not adequate for identifying cases, because about half of those identified by the ICD-9 code alone did not meet the DCCT criteria. Therefore, the most efficient and rigorous approach for case capture is to combine an ICD-9 screening method with medical record abstraction for the specific DCCT criteria.

By comparing the classification of a trained research coordinator to that of a neuromuscular specialist, we found that the coordinator classified cases with a high sensitivity and specificity. The criterion with the lowest sensitivity and specificity was neuropathic symptoms, but this did not significantly affect the overall classification of cases. The neurological sensory and reflex examinations both had high sensitivity and specificity. This finding is important to allow efficient medical chart abstraction by research coordinators for planned larger population-based studies of DSP.

In contrast to earlier work, we determined the optimal screening method to identify the vast majority of new cases of DSP in multiple clinics in an efficient manner. This will allow us to efficiently identify a large number of patients with DSP and to understand the population from which they were identified. Previous studies identified patients who came to their tertiary care clinic, hospital, or electrodiagnostic laboratory without attempting to capture all cases in a defined geographic area. Furthermore, our study focused on community neurology patients, whereas previous work reported on those from tertiary care centers. Because most patients with DSP are seen by

community neurologists, this population is particularly important to study and will likely yield more generalizable results. Finally, we required a systematic and rigorous definition of DSP.

Limitations to this work include the fact that some of the patients who did not meet the stringent DCCT criteria for neuropathy likely had neuropathy. Some patients with neuropathy may never fulfill the criteria, and some may have had incomplete data in the medical record to ascertain the criteria. On the other hand, physicians may overestimate neuropathy based on clinical features alone. 11 This may be in part due to limitations in the clinical criteria physicians use such as reflex assessment, especially in an older population. Furthermore, by not including electrodiagnostic studies in the definition of neuropathy, the specificity of the DSP diagnosis likely decreases. However, including these tests within the definition of neuropathy would not allow the study of the impact of these tests on the DSP evaluation nor the study of patients with DSP and a normal electrodiagnostic study. A previous systematic review recommended that a clinical definition of neuropathy can be used in epidemiologic studies.<sup>12</sup>

Another limitation is that not all patients had their medical record abstraction done by a neuro-muscular specialist, and only a small number of charts were used to assess the reliability of the research coordinator's ability to classify neuropathy. Because the trained research coordinator properly classified cases with high accuracy, this is not likely to change our results significantly. We also miss all DSP cases that are never seen by a

neurologist, and therefore this work does not pertain to this population. Our results were obtained from within Nueces County; it is unclear whether they are generalizable to other areas of the country. No cases identified had a family history of neuropathy recorded. This is surprising given the fact that inherited neuropathy is the cause of a significant proportion of DSP cases.<sup>6</sup> Potential explanations include the absence of a detailed family history or its documentation, or a lower prevalence of inherited causes of DSP in this population of patients from routine neurology practices in Texas. As a result, inherited neuropathy cannot be excluded as a potential cause of DSP in these patients.

In this study we have defined an efficient case capture method for future epidemiologic DSP research that includes an ICD-9 screening method in combination with medical abstraction. Future work will aim to enhance our understanding of the causes and diagnostic evaluations in patients with DSP.

The authors thank Dr. Frank Bonikowski, Dr. Paxton Longwell, and Dr. Juan Santos, who helped coordinate this project at their respective sites. B.C. was supported by a grant from the NIH (NIH T32) and is currently supported by an American Diabetes Association (ADA) Junior Faculty Award. B.C. and E.F. are supported by the Katherine Rayner Program and the Taubman Medical Institute. E.F. is supported by NIH R24 DK082841-01 and NIH UO1 DK076160. K.K. is supported by NIH/NCRR K23 RR024009 and AHRQ R18 HS017690. L.L. is supported by NIH/NINDS R01

NS38916, NIH/NINDS R01 NS062675, NIH/NHLBI R01 HL098065, and NIH/NINDS R01 NS070941.

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Capturing DSP Cases