



# foot scape

Newsletter

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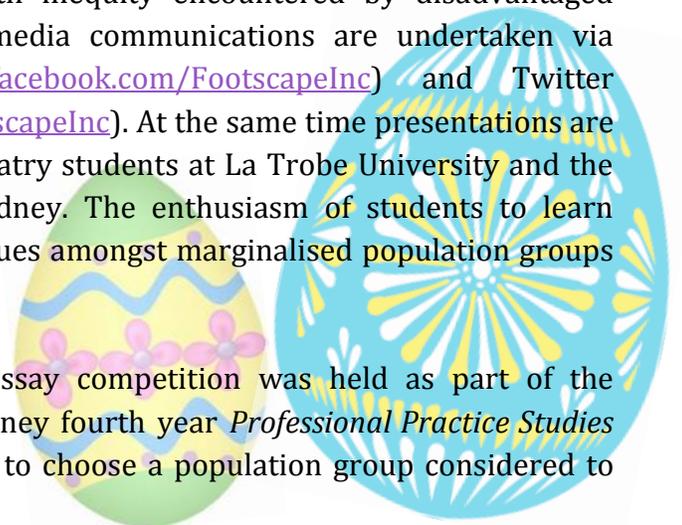
Happy Easter to all Footscape members and supporters. The arrival of this festive period has concurrently brought a fresh and revitalised Footscape website. I invite readers to browse through our updated website content which outlines current committee and project details. Supporters are presented with methods summarising how they may actively get involved, including the new option allowing individuals to apply for membership online. I encourage readers to now complete this simple task and become members of our growing charity. Thanks to Daniel Bryant for his tremendous efforts in developing the latest website edition.



From the  
President

Engaging the community through such projects as developing a modern website continues to be a high priority for our governing committee. Indeed Footscape endeavours to inform, educate and motivate Podiatrists, other health professionals and the greater community in regards to the foot health inequity encountered by disadvantaged persons. Regular social media communications are undertaken via Facebook (<https://web.facebook.com/FootscapeInc>) and Twitter (<https://twitter.com/FootscapeInc>). At the same time presentations are delivered annually to Podiatry students at La Trobe University and the University of Western Sydney. The enthusiasm of students to learn more about foot health issues amongst marginalised population groups is very pleasing.

During 2015 a student essay competition was held as part of the University of Western Sydney fourth year *Professional Practice Studies* unit. Students were asked to choose a population group considered to



## From the President

(continued)

experience social and health inequity then conduct a systematic search and critical review of the literature detailing the influence of social determinants of health upon foot pathology in that group. Many fine essays were received, including such topics as:

- Diabetic foot education for the Aboriginal population
- Understanding the need for Podiatry care in homeless populations
- Podiatry service provision and access for people of non-English speaking backgrounds.

The University Podiatry Department and Footscape Committee have selected a winning essay. Congratulations to Patrick Chung who will be presented with a \$250 cash prize. Patrick's unedited essay pertaining to Foot Care service provision for people with HIV is now presented in this newsletter.

*Anthony Lewis  
President*



*Anthony Lewis responding to follow up questions with University of Western Sydney Podiatry students in July, 2015.*



*Committee Member Chalerm Tuantab addressing the La Trobe University Podiatry students during November, 2015*

## **Self-care behaviours, quality of life and factors affecting provision of health care to people living with HIV: A literature review.**

### **Abstract**

The introduction of anti-retroviral therapy has increased the life-expectancy of people living with HIV (PLWH) however toxicity of antiretroviral treatment and increasing HIV incubation has led to an increased prevalence of HIV-affected individuals suffering from peripheral neuropathy. As HIV-infection moves from acute infection to long-term management, health practitioners, including podiatrists, have a greater role in management of HIV-related peripheral neuropathy. The purpose of this review was to examine quality of life in PLWH with HIV-related neuropathy, coping strategies of these individuals and factors affecting provision of health care to these individuals so that this information may be used to improve podiatric practice in the treatment of PLWH. An online search was conducted for peer-reviewed articles and published texts and 5 articles were identified for review. Increasing age and HIV-related stigma was found to be negatively associated with quality of life, while increased income and support networks were positively associated with quality of life. PLWH with peripheral neuropathy report decreased lower limb function and quality of life. Substance use and alternative therapies were identified to be in common use for self-management of peripheral neuropathy. Satisfaction with HIV-related care was associated with decrease in pain. Holistic treatment of PLWH must address concerns relating to HIV-disclosure, HIV- stigma, education, the availability support networks and diminution of substance use. Further longitudinal studies are necessary to identify causative factors that affect access to care and quality of life in PLWH.

### **Introduction**

There is currently no cure or prophylactic vaccine for HIV infection. HIV continues to place a large economic and social burden worldwide. An estimated 25000 to 30000 people are living with HIV in Australia. The rate of HIV infection has remained steady with approximately 1000 new cases of HIV infection diagnosed each year. (The Kirby Institute, 2015).

At the outbreak of the HIV-AIDS epidemic in the United States in the 1980s, an individual diagnosed with AIDS had a life expectancy of no more than 20 months. (Nakagawa, May & Phillips, 2013). This statistic has greatly improved due to introduction of HIV-testing, antiretroviral therapy and education programs. Without antiretroviral treatment, the time-frame from HIV infection to death is estimated to be approximately 10 years. With antiretroviral treatment, a person living with HIV (PWLH) is considered to have almost the same life expectancy as a person living without HIV given early diagnosis, access to HIV-care and treatment compliance (Nakagawa, May & Phillips, 2013). Thus, in developed countries where HIV testing and treatment is readily available, HIV-infection has shifted from being an acute and fatal condition to a chronic disease.

There are two types of human immunodeficiency virus: HIV-1 and HIV-2. Unlike HIV-1 type infection, HIV-2 type infections have a lower transmissibility and are currently confined to the West African region (Nyamweya et al., 2013). HIV-1 infection is prevalent worldwide (Nyamweya et al., 2013) and is associated with a greater likelihood of progression to acquired immunodeficiency syndrome (AIDS) and neurological complications. Six distinct patterns of HIV-associated peripheral neuropathy exist. These include distal symmetrical polyneuropathy (DSP), inflammatory demyelinating polyneuropathy, progressive polyradiculopathy, mononeuropathy multiplex, autonomic neuropathy, and, diffuse infiltrative lymphocytosis syndrome (Wulff, Wang & Simpson, 2000). DSP is the most difficult to treat due to unresponsiveness to drugs typically prescribed to ease neuropathic symptoms.

The pathogenesis of distal symmetrical polyneuropathy is unclear however cytokine dysregulation, anti-retroviral therapy induced mitochondrial dysfunction and viral protein neurotoxicity has been implicated (Anastasi, Smolowitz & Capili, 2009). Highly active anti-retroviral therapy (HAART) and in particular, dideoxynucleoside reverse transcriptase inhibitors such as stavudine, has been associated with an increased incidence of peripheral neuropathy (Centner, Bateman & Heckmann, 2013). While stavudine use is generally no recommended as first-line treatment, it is still used to developing countries due to its low cost and high availability (Sankhyan et al., 2014). Despite the decrease in incidence in HIV-related DSP, the prevalence of DSP in PLWH is increasing due to a prolonged life-expectancy (Dal Pan & McArthur, 1996). Indeed, the prevalence of HIV-related neuropathy has been reported to occur in up to 69.4 percent of patients (Ghosh, Chandran & Jansen, 2012).

The care of PLWH and treatment of DSP falls within the scope of podiatric practice. Unfortunately there has been no literature published examining the factors affecting the provision of podiatric care to PLWH. Thus the purpose of this review was to examine quality of life in PLWH with HIV-related neuropathy, coping strategies of these individuals and factors affecting provision of health care to these individuals so that this information may be used to improve podiatric practice in the treatment of PLWH.

## Method

An online search was conducted to determine factors affecting provision of care to PLWH. Search results were limited to articles publish in or translated into English, and included articles in peer-reviewed journals and published texts. The primary search term “HIV” was combined with secondary search terms “health-seeking behaviour”, “neuropathy”, “coping”, “strategy”, and “quality of life”. Medical search headings were utilised. Electronic databases searched were:

1. MEDLINE (1950 – September 2015)
2. CINHALL (1960 – September 2015)
3. Pubmed (1950- March 2010)

Articles examining specific interventions for the treatment of HIV-related neuropathy were excluded as they were not relevant to the purpose of this review. Additionally, there already exist several reviews regarding interventions for HIV-related neuropathies. Articles were excluded if they did not provide inclusion criteria and method of subject recruitment. Descriptive qualitative studies were also excluded.

The literature was analysed according to guidelines set by the National Health and Medical Research Council (NHRMC). For prognostic and aetiological studies the NHMRC regards systematic reviews of prospective cohort studies to be the strongest level of evidence, and, cross-sectional studies and case series to be the weakest level of evidence.

## Results

8 articles were identified from the search protocol. 2 articles were excluded for review as they were descriptive studies, 1 systematic review was excluded as it focussed on coping strategies of health workers and not PLWH. After applying the inclusion and exclusion criteria, 5 articles were identified for review. These articles are listed in table 1.

**Table 1.** Studies identified for literature review

Author/s	Publication date	Study design	Sample size	Countries
Slater et al.	2015	Quantitative cross-sectional	60	U.S.
Galantino et al.	2014	Quantitative cross-sectional	92	U.S.
Krause, Butler & May	2013	Quantitative cross-sectional	1500	U.S.
Nicholas et al.	2002	Quantitative cross-sectional	422	U.S./Norway
Nicholas et al.	2007	Quantitative, cross-sectional	450	U.S., Taiwan, Colombia

### *Access to care and quality of life*

Krause, Butler and May examined the relationship between access to care and health-related quality of life for persons living with HIV/AIDS through the use of a state-wide survey. 1500 subjects were recruited for the study. The survey measured demographic information, behaviours, information relating to access to health care and services, satisfaction, unmet needs and HRQOL. The Duke Health Profile (test-retest reliability of 0.3 to 0.78) was utilised to score HRQOL. Functional scales were scored from 0 to 100, with 0 being the worst and 100 being the best. Univariate analysis of results showed increasing age to be negatively associated with health and increasing income to be associated with improved physical health, and, a decrease in anxiety and depression. Social support networks were also found to be positively associated with decreased mortality and morbidity, while satisfaction with HIV-related care received was found to be negatively associated with pain severity.

### *Peripheral neuropathy, lower limb function and quality of life*

Galantino et al. conducted a cross-sectional survey and applied predictive modelling to compare HRQOL in PLWH suffering from peripheral neuropathy and PLWH without peripheral neuropathy, and to determine to what extent lower limb function predicts HRQOL. The authors used both the lower extremity functional scale, and, the lower limb functional index (Index) to score lower limb function and quality of life. A sample of convenience was obtained as all participants in the study were patients at an infectious disease practice. The lower extremity functional scale and lower limb functional index were used to assess group differences in function and quality of life. 82 participants participated in the study of which approximately two-thirds reported symptoms suggestive of DSP. The study found DSP to be associated with increasing age and increased age with HIV infection. The study also found that PLWH suffering from DSP to report lower physical quality of life and poorer lower extremity function compared to PLWH without DSP.

### *Coping strategies and self-care management of neuropathy*

In their 2002 study, Nicholas et al. examined the prevalence of peripheral neuropathy in a sample population of PLWH and the self-care strategies and sources of information for self-care used by the sample population. 422 respondents were recruited from four sites in the USA and 1 site in Norway, and also through an Internet web-based site.

Participants completed a questionnaire that included questions about age, gender, education, income, living arrangements, CD4<sup>+</sup> T-lymphocyte count, history of injection drug use and anti-retroviral medication use. Three open-ended questions were also used to ask participants to describe a physical or psychological symptom, state what they did for the symptom, determine the source of this self-care knowledge, and determine the efficacy of the treatment. The prevalence of peripheral neuropathy in this study was found to be 11.6%. Amongst the sample population suffering from neuropathy, the most common symptoms described were in order of frequency: pain, numbness, tingling, burning and stinging. The study found 44% of participants engaged in complementary therapies to treat their neuropathic symptoms, 35% utilised medications, 16% used exercise or elevation/rest of legs and 5% resorted to substance abuse. Health care providers were more likely to suggest prescription medication for management while support groups and information obtained from classes and books were more likely to suggest complementary therapy. A summary adapted from the study is found below (Table 2). Limitations of this study include the relatively small sample size, a consequence of using the study to also measure the prevalence of peripheral neuropathy in PLWH. Future studies could possibly recruit only PLWH suffering from neuropathic symptoms, and might also include a quantitative scale to measure the magnitude of influence of difference sources on self-care behaviours.

**Table 2.** Sources of knowledge for self-care behaviours in management of peripheral neuropathy

<b>Behaviour</b>	<b>Trial and Error (6.4%)</b>	<b>Health Care Providers (44%)</b>	<b>Family/Friends (7.6%)</b>	<b>Classes/Books (12.9%)</b>	<b>Support groups (15.1%)</b>	<b>Other (3.2%)</b>
Complementary therapy	2.2%	16.1%	3.2%	12.9%	15.1%	3.2%
Medication	1%	23.7%	2.2%	0	0	0
Exercise	0%	1%	2.2%	0	0	3.2%
Rest	2.2%	3.2%	0	0	2.2%	2.2%
Substance use	1%	0%	0%	0	0	3.2%

In a later study, Nicholas et al. suggest that a greater number of HIV-affected individuals with peripheral neuropathy participate in substance use for self-management of neuropathic symptoms. In their 2007 study, a convenience sample of 1217 PLWH and suffering from peripheral neuropathy was obtained from the U.S., Puerto Rico, Colombia and Taiwan. To be included in the study subjects had to be: at least 18 years of age, receiving HIV-related care, able to provide informed consent, and English, Spanish or Chinese speaking. Subjects completed the *Revised Sign and Symptom Checklist for Persons with HIV-disease* (SSC-HIVrev), a reliable and valid tool for measuring frequency and severity of HIV symptoms. Of these subjects, 450 subjects (36.9%) indicated unhealthy self-care management strategies including cigarette smoking (30.9%), alcohol use (18%), marijuana use (14.9%) and street drug use (6.7%). Additionally patients in whom peripheral neuropathy was found to be greater than 5 in severity (on a scale from 1 to 10) indicated a significantly greater use of amphetamines and injection drug use. The advantage of this study lies in its generalisability, given the fact that the participants were recruited from multiple sites that included non-Anglophone countries.

## *Stigma and disclosure*

Slater et al. examined the experience of stigma associated with sexual orientation (homonegativity), HIV status and disclosure of HIV status, and its association with quality of life in older gay men with HIV. The study was a secondary analysis of an original study, the inclusion criteria of which were: patients identifying as gay, being 50 years or older, having HIV positive serostatus and speaking English. Patients were recruited from clinician referral and notices in HIV/AIDS clinics and organisation in Alabama, Georgia and North Carolina in the U.S. Homonegativity was measured with the Internalized Homonegativity Inventory. Regression analysis showed younger age and emotion-focused coping to be predictive of homonegativity and that homonegativity, internalised HIV-stigma and age-stigma to account for 39% in variance of quality of life.

## **Discussion**

That there has been no review in factors relating to access to care, quality of life and self-management behaviours in PLWH is not surprising given the challenges faced in sample recruitment, study design and variables for analysis. In examining a topic of this nature it is not possible to perform prospective cohort studies, and often recruitment for HIV-related studies relies heavily on convenience studies drawing from individuals with known HIV serostatus who are already seeking some form of medical treatment, and have given consent to participate in HIV-related studies. The end result is that most studies already have a heavy selection bias, although authors such as Nicholas et al. attempt to correct for this with randomisation as seen in their 2007 study. HIV-related studies are limited by cost-considerations and therefore at best, can attempt to obtain correlations between certain variables in HIV-affected individuals. Qualitative studies, which are important in understanding the context, emotions and experiences of the patient are not readily useful in obtaining meaningful quantitative data. Additionally, many HIV studies are biased towards examining men identify as homosexual, and issues relating to HIV stigma in other populations remain to be identified.

What can be drawn from this review is that factors negatively associated with quality of life include advancing age, HIV-related stigma, homonegativity and age-stigma (in gay men living with HIV), and severity of peripheral neuropathy symptoms. Factors positively associated with quality of life in PLWH include adequate income, the availability of support networks, and satisfaction in HIV-related care received. Substance use was found to be associated with the occurrence of more severe neuropathic symptoms while alternative therapies were suggested by health practitioners, family friends and support networks. Medical intervention, specifically prescription drugs were found only to be suggested by health practitioners.

Holistic treatment of PLWH must address concerns relating to HIV-disclosure, HIV- stigma, education, the availability support networks and diminution of substance use. Further longitudinal studies are necessary to identify causative factors that affect access to care and quality of life in PLWH. Additionally, valid screening tools must be constructed so that consistency across HIV-studies is obtained, and of particular interest to podiatrists, there is a need for a validated tool to assess lower extremity function in PLWH.

## **Conclusion**

There is currently no data on the provision of podiatric care to PLWH, and although there is a paucity of knowledge in this area podiatric care should aim to be holistic, identifying barriers to care in PLWH including HIV-stigma, homonegativity and lack of disclosure. While podiatrist are important in the multidisciplinary care of PLWH, they must be aware of support networks available, management strategies available and factors affecting the quality of life in PLWH, and must provide education and patient-centred evidence-based care to deal with the ageing population of PLWH.

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