

## Peripheral neuropathy and quality of life of adults living with HIV/AIDS in the Rulindo district of Rwanda

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### Abstract

Although the life expectancy of people living with HIV/AIDS (PLWH) has increased in the past years, they could experience secondary illness such as peripheral neuropathy (PN). Therefore, they need to adapt to chronic disablement which could affect their quality of life (QoL). The research that informed this article aimed at determining the prevalence of PN among adults living with HIV/AIDS and attending the outpatients' clinic at Rutongo Hospital in the Rulindo district of Rwanda. Another aim was to determine these patients' QoL. A cross-sectional descriptive quantitative research design was used. A time-constrained method was used to sample 185 adults living with HIV/AIDS and attending the outpatients' clinic at Rutongo Hospital. The subjective PN screen and the World Health Organization Quality of Life Scale Brief Version were used to collect the data. Data were analysed using the Statistical Package for the Social Sciences. Student's *t*-test and one-way analysis of variance were performed to determine if significant differences existed between QoL scores in participants with and without PN symptoms. The results indicated that 40.5% of respondents experienced PN. QoL in participants with PN showed significantly lower scores in the physical ( $p = 0.013$ ) and psychological ( $p = 0.020$ ) domains when compared with those who did not have PN. These results indicate a high prevalence of neuropathy among PLWH attending the outpatients' clinic at Rutongo Hospital. In addition, patients with neuropathy had lower QoL scores in the physical and psychological domains than those without neuropathy symptoms. The management of PLWH should therefore include interventions to optimise QoL as well as screening for neuropathy symptoms so that sufferers can liaise with their medical providers to find medical and supportive therapies that could assist them.

**Keywords:** peripheral neuropathy, HIV/AIDS, quality of life, Rwanda, WHOQOL-BREF

### Résumé

Bien que l'espérance de vie des personnes vivant avec le VIH/ SIDA (PVVIH) a augmenté ces dernières années, ils pourraient subir une maladie secondaire comme la neuropathie périphérique (NP). Par conséquent, ils ont besoin de s'adapter à l'invalidité chronique qui pourrait affecter leur qualité de vie (QdV). La recherche qui a informé cet article vise à déterminer la prévalence de la NP chez les adultes vivant avec le VIH/SIDA et qui fréquentent la clinique externe de l'hôpital de Rutongo dans le district de Rulindo au Rwanda. Un autre objectif était de déterminer la qualité de vie de ces patients QdV. Un modèle d'étude transversale quantitative et descriptive a été utilisé. Une méthode de contrainte de temps a été utilisée pour échantillonner 185 adultes vivant avec le VIH/ SIDA qui fréquentent la clinique externe de l'hôpital de Rutongo. L'examen subjectif de NP et le WHOQOL BREF ont été utilisés pour collecter les données. Celles-ci ont été analysées en utilisant le logiciel de statistiques des sciences sociales. Le test-t et l'analyse de variance ont été effectués afin de déterminer si des différences significatives existent entre les scores de qualité de vie QdV chez les participants avec et sans symptômes NP. Les résultats indiquent que 40,5% des répondants ont eu le NP. La qualité de vie chez les participants ayant le NP a montré des scores significativement plus faibles dans les domaines physique ( $p = 0.013$ ) et psychologique ( $p = 0.020$ ) comparé à ceux qui n'ont pas eu de NP. Ces résultats indiquent une prévalence élevée de la neuropathie chez les PVVIH fréquentant une clinique externe de l'hôpital de Rutongo. En outre, les patients atteints de neuropathie avaient des scores de QdV moins élevé dans les domaines physique et psychologique que ceux qui n'avaient pas de symptômes de neuropathie. La gestion des PVVIH devraient donc inclure des interventions afin d'optimiser la qualité de vie ainsi que le dépistage des symptômes de neuropathie de telle sorte que les malades puissent assurer une liaison avec les fournisseurs de soins médicaux pour trouver des thérapies médicales de soutien qui pourraient les aider.

**Mots clés:** Neuropathie Périphérique VIH/SIDA, Qualité de vie, Rwanda, WHOQOL BREF

### Introduction

People living with HIV/AIDS (PLWHs) have a higher life expectancy than before. Thus, they are presenting with more chronic

health problems and are not only concerned with a treatment's ability to extend life but also with the quality of the life they are

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able to lead (Demmer 2001; Gale 2003). Quality of life (QoL) for patients living with HIV has become increasingly important, with the goals of therapy now including improvement of QoL in addition to the reduction of symptoms, suppression of the virus and extension of survival (Casado 2005; Globe, Hays & Cunningham 1999). QoL among HIV-infected individuals has been studied extensively, and prior research has attempted to assess QoL and determine predictors for good or poor QoL in this context (Mweemba 2008).

Peripheral neuropathy (PN) is one condition associated with functional limitations which can affect the QoL of patients. Chronic painful symptoms as experienced with PN can have a considerable impact on an individual's life and may be associated with anxiety, depression and loss of mobility and independence (Benbow, Wallmahmed & Mcfarlane 1998; Breitbart & Dibiase 2002; Pandya, Krentz, Gill & Power 2005). Thus, increased and improved surveillance for HIV-associated PN will allow earlier interventions to improve QoL and prevent severe toxicities. The ability to cope with a disease such as HIV/AIDS seems to influence certain domains of QoL (Jia, Uphold, Wu, Reid, Findley & Duncan 2004; Vosvick, Koopman, Gore-Felton, Thoresen, Krumboltz & Spiegel 2003).

It is therefore important to identify the QoL of PLWH in different population groups in order to plan and implement effective intervention programmes. Illnesses associated with HIV/AIDS have been reported to have an impact on the QoL of PLWH. To date, there has been no published study that has assessed PN and QoL of PLWH in Rwanda. This information is important as this country was identified as one of the sub-Saharan countries most severely affected by HIV/AIDS (WHO 2005). Furthermore, the 1995 genocide in Rwanda resulted in the increase of women being affected by HIV and greater instability of the health-care system. Although the management of HIV/AIDS in this country includes the provision of antiretroviral drugs (ARVs) and psychological support, it was deemed important to determine whether there are other needs of PLWHs in this country which could be addressed. Therefore, the aim of this study was to determine the prevalence of PN among adults living with HIV/AIDS and the QoL of such people attending the outpatients' clinic at Rutongo Hospital in the Rulindo district in Rwanda. Particular attention was paid to specific aspects of QoL. This included physical, psychological, social relationships and environmental domains.

## Methods

A cross-sectional descriptive design was used to collect the data. Approximately 35 adults living with HIV/AIDS attend Rutongo Hospital per week to receive medication. The study was conducted over a 6-week period. A time-constrained sample of 185 PLWH attending this hospital was recruited to participate in the study. The patients attending the outpatients' clinic included those who were receiving highly active antiretroviral therapy (HAART) and those who needed assessment of their CD4 counts but were not receiving medication. Only those patients attending the outpatients' clinic who had a confirmed diagnosis of HIV/AIDS, were over 18 years, able to provide informed

consent and fluent in Kinyarwanda (an indigenous Rwandan language) or English at the time of data collection were included in the study. Permission to conduct the study was sought from relevant committees at the University of the Western Cape as well as the relevant Rwandan authorities. Written consent was sought from the participants.

Two validated instruments were used to collect data. The subjective PN screen (SPNS) was used to screen for the presence of PN (McArthur 1998). The SPNS asks about three symptoms which cover the following: 'pain, aching or burning'; 'pins and needles' (paraesthesias) and 'numbness'. Each of these three different symptoms was rated either as never occurring or occurring. If present at the time of data collection, the severity of the symptoms was scored on a scale from 1 (mild) to 10 (most severe). The subjective neuropathy grade is determined by using the symptom with the highest score between 1 and 10. A symptom scored from 1 to 3 equalled a clinical grade of 1; a symptom scored from 4 to 6 equalled a clinical grade of 2 and if it scored from 7 to 10 it equalled a clinical grade of 3. These were then categorised into three groups. Grade of 1 illustrated a mild PN, 2 moderate and 3 severe.

The World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF) was used to assess QoL. The WHOQOL-BREF consists of 26 items. Each item uses a Likert-type five-point scale. These items are distributed in four domains. The four domains of QoL are (a) physical health and level of independence (seven items); (b) psychological well-being (eight items); (c) social relationships (three items) and (d) environment (eight items). There are also two items that were examined separately: one which asked about the individual's overall perception of QoL and the other which asked about the individual's overall perception of his or her health. Each item uses a Likert-type five-point scale. Most scores are scaled in a positive direction where higher scores denote higher QoL. Domain scores were scaled in a positive direction (higher scores denoting a higher QoL) (Hakuzimana 2005). Participants were questioned regarding their experience relating to the above domains in the 2 weeks prior to data collection.

Ethical clearance to conduct the study was provided by the University of the Western Cape. Once permission to conduct the study was obtained from the relevant parties, the researcher and trained research assistants visited the outpatients' clinic and eligible patients were approached and invited to participate in the study while waiting for the doctors to attend to them. The aims and objectives of the study were explained to each participant. All subjects who agreed to participate provided written informed consent. The researcher completed the SPNS and WHOQOL-BREF questionnaires. Demographic data, including age, gender, level of education, occupation, marital status and the length of time participants had known their HIV status was also collected from the participants.

Data entry and statistical analysis were performed using the SPSS (Statistical Package for Social Science) software, version 15.0. Descriptive statistics, such as mean and standard deviation,

were used to examine demographic characteristics of the sample and to summarise the score of the QoL. One-way analysis of variance (ANOVA) and independent sample *t*-tests were performed to determine a significant difference between QoL domain scores and demographic characteristics. The level of statistical significance was set at  $p < 0.05$ , while chi-square tests were used to demonstrate the association between demographic characteristics such as age and severity of PN.

## Results

A total of 185 participants completed the two questionnaires. The ages ranged from 19 to 73 years. The participants' mean age was  $38.7 \text{ SD} \pm 9.6$  years. Table 1 illustrates demographic characteristics of the study sample.

A total of 75 (40.5%) out of 185 participants reported at least one of the three symptoms of PN. The most commonly reported symptoms were pain, aching or burning, while the least common reported symptoms were pins and needles in feet and legs. The mean subjective PN score was 1.69, with a standard deviation of  $\pm 0.88$ . In addition, out of 75 participants who reported symptoms at the time of data collection, 44 (58.7%) were in grade 1 whereas 10 (13.3%) were in grade 2 and 21 (28%) in grade 3. Chi-square tests were used to demonstrate association between age and clinical severity grade. There was a significant association ( $p = 0.001 < 0.005$ ).

Table 2 presents the demographic information and mean scores of QoL domains and their respective mean differences. Multiple

comparisons of means were performed using Tukey's test. The results from Student's *t*-test and ANOVA showed that a significant difference existed with respect to the ages of the participants in the psychological domain ( $p = 0.028$ ). Lower scores were seen among subjects who were older than 60 years compared to those who were less than 30 years old. However, there was no significant difference in QoL in the physical, social and environmental domains among the different age groups.

In addition, the comparison of the mean raw scores of QoL in men and women showed that there was a difference in the social relationships domains ( $p = 0.033$ ), with lower scores for women in this domain. In the present study, there was no significant difference between QoL and occupation.

ANOVA was also performed to determine if there was a significant difference between the scores of the different domains and marital status. There were no differences between QoL domains and marital status. In the social relationships domain, there was, however, a statistically significant difference ( $p = 0.030$ ) for the subjects who were cohabiting when compared to those who were widowed, with subjects who were cohabiting having higher scores. Comparisons of mean scores of QoL revealed significant differences between the physical health ( $p = 0.000$ ), psychological ( $p = 0.000$ ), social relationships (0.033) and environmental domains (0.040) and level of education; lower scores were seen among subjects who did not attend school compared to those with primary, secondary and tertiary level of education. The mean scores were lower in the physical domain for

**Table 1. Demographic characteristics of the study sample (n = 185).**

Demographic variables	Characteristics	Frequency	Percentage
Age (years)	<30	35	18.9
	31–40	79	42.7
	41–50	49	26.5
	51–60	16	8.6
	>60	6	3.2
Gender	Female	131	70.8
	Male	54	29.2
Occupation	Farm workers	160	86.5
	Unemployed	12	6.5
	Public or private employed	10	5.4
	Self-employed	3	1.6
Marital status	Married	94	50.8
	Widowed	53	28.6
	Separated	24	13.0
	Single	12	6.5
	Cohabiting	2	1.1
Level of education	Primary	112	60.5
	Secondary	15	8.1
	University	3	1.6
	Not at all	55	29.3
Time elapsed since HIV diagnosis	<2 years	54	29.2
	2–4 years	110	59.5
	5–7 years	12	6.5
	8–10 years	7	3.8
	>10 years	2	1

**Table 2. Relationship between QoL scores and demographic characteristics (n = 185).**

Demographic characteristics	Mean QoL scores			
	Physical health	Psychological health	Social relationships	Environment
<i>Age (years)</i>				
<30	13.06	15.17*	13.60	12.51
31–40	13.04	14.90	13.58	12.57
41–50	12.31	14.92	13.49	12.59
51–60	12.44	14.00	12.00	12.44
>60	10.83	12.83*	12.50	13.17
<i>Gender</i>				
Male	12.59	14.74	13.91*	12.52
Female	12.78	14.84	13.18*	12.60
<i>Occupation</i>				
Public or private employed	12.90	15.10	14.00	12.70
Self-employed	13.00	15.00	15.00	13.33
Unemployed	12.17	14.42	13.92	11.58
Farming or livestock	12.75	14.82	13.28	12.63
<i>Marital status</i>				
Married	12.57	14.81	13.46	12.50
Single	13.25	14.58	13.08	12.08
Separated	12.46	14.21	12.29	12.54
Cohabiting	12.50	16.00	14.00*	12.00
Widowed	13.00	15.09	13.81*	12.85
<i>Education</i>				
Not at all	11.60*	13.87*	12.71*	12.09*
Primary	12.93*	15.13*	13.62*	12.82*
Secondary	13.21	15.60	14.07	12.40
University	14.00	16.00	14.00	13.00
<i>Time elapsed since HIV diagnosis (years)</i>				
<2	12.70	14.48	12.78*	12.26
2–4	12.69	14.96	13.78*	12.67
5–7	13.58	15.50	13.67	13.08
8–10	12.29	14.14	12.43	12.57
>10	11.50	13.50	10.00	12.50

\* $p < 0.05$ .

those who did not attend school. The variable relating to time since HIV diagnosis indicated that subjects who had known their HIV status for 2–4 years had higher mean scores in the social relationships domain when compared to those who had known their status for less than 2 years.

An independent sample *t*-test was performed to determine if significant differences existed between the QoL domains (physical, psychological, social and environmental) of participants with and without PN symptoms. QoL in participants with PN showed significantly lower scores in the physical ( $p = 0.013$ ) and psychological ( $p = 0.020$ ) domains. Table 3 shows the mean values of the QoL domain for the overall cohort, participants with and without PN symptoms.

## Discussion

The diagnosis of PN can generally be made by a health-care provider who is experienced in the treatment of HIV disease based on a history of the symptoms and a comprehensive physical examination which includes testing of the reflexes and evaluation of the sense of vibration, touch, pressure and pain in the extremities (Swanson, Zeller & Paice 1998). In the present study, a researcher established the diagnosis of PN based on the subjects' responses, using the SPNS. Pain, paraesthesias and numbness were the three symptoms that differentiated those with PN from those without.

With the use of the SPNS, the overall prevalence of PN in the participants was found to be 40.5%. The high prevalence of

**Table 3. Mean values of QoL domain for overall cohort, participants with and without PN symptoms (n = 185).**

QoL domain	Overall cohort mean values	PLWHs with PN symptom mean values	PLWHs without PN symptom mean values	p-Value
Physical	12.72	13.1*	12.2*	0.013
Psychological	14.81	15.1*	14.4*	0.020
Social	13.39	13.5	13.2	
Environmental	12.57	12.75	12.35	

\*p < 0.05.

neuropathy among patients surveyed in the current study is consistent with previous findings (Mbuya, Kwasa, Amayo, Kioy & Bhatt 1996; Nicholas, Mauceri, Slate Ciampa, Corless, Raymond, Barry, *et al.* 2007; Shurie & Deribew 2010; Skopelitis, Kikotis, Kontos, Panayiotakopoulos, Konstantinou, Kordossis, *et al.* 2006; Smyth, Affandi, McArthur, Bowtell-Harris, Mijch, Watson, *et al.* 2007). The figures from other studies that were found to conflict with the findings of this study could be due to differences in the minimum criteria for making a diagnosis, sample size and exclusion criteria. In the studies conducted in Kenya (Mbuya *et al.* 1996) and the UK (Skopelitis *et al.* 2006), objective measures were used to diagnose PN compared to the subjective measure used in the current study.

PLWH and experiencing PN may present with a number of different symptoms. Participants in this study mainly experienced pain, aching or burning followed by numbness, while the least reported symptoms were pins and needles. These findings are similar to those from previous studies (McArthur 1998; Nicholas, Kemppainen, Holzemer, Nokes, Eller & Corless, *et al.* 2002; Wadley, Cherry, Price & Kamerman 2011). However, a contradictory result was found in a previous study conducted by Konchalar and Wangphonpattanasiri (2007) where numbness was the dominant symptom in all patterns of HIV-related neuropathy. Harrison and McArthur (1995) have suggested that pain and paraesthesias could be early symptoms of the disease, whereas numbness becomes evident as the disease progresses.

Severity of PN in PLWH can range from mild discomfort to a debilitating condition, making it difficult for the individual to walk or even to stand (Herrmann, DeMarcaida & Akowah 2001; Schifitto, McDermott, McArthur, Marder, Sacktor, Epstein, *et al.* 2002). In addition, many people with early or mild PN do not experience any symptoms, with the worst symptoms generally occurring in people with more advanced immunosuppression (Simpson & Cikurel 2006). In the present study, the majority of PLWH with PN were in grade 1 compared to grades 2 and 3. This indicated that PN was mild in the majority of PLWH and attending outpatients' clinic at Rutongo Hospital who participated in the study.

## Quality of life

Living with HIV/AIDS remains a severe strain for those who are afflicted, for various reasons. These include the physical and psychological effects of HIV-related symptoms, toxicity of HAART, the difficulty of having to adhere to a rigid medication regimen, the implications of the HIV infection for the patient's relationships and sex life, stigmatisation and the fear of dying from the illness (Pierret 2000). As a result, the physical, psychological, social relationship and environmental domains of QoL of PLWH are affected.

### Physical health domain

The physical health domain assesses the impact of the disease on the activities of daily living, dependence on medical substances, a lack of energy and initiative, restricted mobility and the capacity to work (Skevington 2002). In the present study, the mean score for the physical domain fell in the intermediate level (12.72). As noted in the literature, research has shown that nearly one-third of PLWH reported problems with mobility, limitation of usual activity and pain or discomfort (Hughes, Jelsma, Maclean, Darder & Tinise 2004). These problems might also have contributed to the large number of subjects who rated lower scores in the physical domain of WHOQOL-BREF in the present study. The physical health domain of QoL deteriorates with HIV progression; in addition, the side effects of HAART may cause as much physical discomfort as the symptoms of the illness, which includes PN, nausea, vomiting, anaemia, headaches, skin rashes, neutropenia, diarrhoea and abdominal discomfort (Liu, Ostrow, Detels, Hu, Johnson, Kingsley, *et al.* 2006; Maenza & Flexner 1998).

Furthermore, a factor found to have a significant effect on the physical health domain was the level of education. In the present study, lower scores were seen among subjects who did not attend school compared to those with primary education. These results support the findings of a study by Dos Santos, Junior and Lopes (2007), where lower scores were seen among subjects who did not attend school or only completed middle school education compared to those with higher education. The results of the present study observed no significant difference between QoL domains and different occupations of the respondents. This could have been caused by the homogeneity of the sample regarding occupation, since 86.5% of the participants were farm workers. Skilled workers and business persons reported better physical health domain scores when compared to others (Wig, Lekshmi, Pal, Ahuja, Mittal & Agarwal 2006).

### Psychological domain

The psychological domain assesses the patient's own thoughts about body image and appearance, negative feelings, positive feelings, self-esteem and personal beliefs (Skevington 2002). In the current study, the participants' QoL scores in the psychological domain were close to the high level (between 15 and 20). This positive result could be due to the fact that the management of HIV/AIDS in Rwanda includes the provision of psychological support. In the study conducted by Uwimana and Struthers (2007), 50% of the participants reported having received psychological support. This support could assist the individuals in

accepting their illness. When people start accepting their disease, they take control over their lives and exercise self-determination and autonomy (Murphy & Melby 1999). This approach could result in high self-esteem and positive feelings about themselves.

### Social domain

The social domain assesses the individual's personal relationships, social support and sexual activity (Skevington 2002). In the present study, the mean score of the participants in the social relationships domain of QoL fell into the intermediate level (13.39). The fact that the participants reported that they were experiencing challenges in this area could be as a result of their communities' attitudes towards them. PLWH are still being stigmatised by the communities in which they live (Herek, Capitano & Widaman 2002). In this study, females scored statistically lower in the social domain than men. This result is in agreement with a previous study where women with HIV/AIDS had lower QoL scores as opposed to men despite having less-advanced disease; they were also found to be likely to face a chronic disabling condition that is progressive (Hader, Smith, Moore & Holmberg 2001; Nirmal, Divya, Dorairaj & Venkateswaran 2008). Moreover, women often face more severe discrimination than men if they are known to be HIV positive, and they are more likely to sacrifice their own health for the welfare of their family and postpone treatment. Disclosing their HIV status could lead to physical abuse by their partners and a loss of economic stability if their partners were to leave them.

### Environmental domain

The environmental domain assesses how QoL is influenced by factors such as financial resources, the work environment, accessibility to health and social care, freedom, security and opportunities for participation in leisure activities. The mean score of the participants in the environmental domain of QoL fell into the intermediate level (12.57). This domain had the lowest mean score in the present study. This finding could have resulted from a number of factors, including the geographical setting of the study, the financial status of the participants and a lack of family support. The study was conducted in a rural area where the condition of the roads hampers access to health facilities. Although the study sample included only those who attended ARV clinic, patients could find it difficult to access the clinic due to the condition of the roads. The financial situation of the participants could also have resulted in the low score reported for this domain. The majority (86.5%) of the participants were farm workers who often do not receive large salaries. Uwimana and Struthers (2007) also reported that financial support was one of the greatest needs identified by PLWH in Rwanda. Family support and occupation significantly affect the environmental domain of QoL in PLWH (Wig *et al.* 2006). The family is usually the most important component of the immediate environment of the patient (Wig *et al.* 2006). The family could provide financial support and a sense of safety and security, resulting in a good and supportive home environment which can help a patient feel better. Although this is the case, there is extreme poverty in Rwanda and it is therefore questionable whether the families who might need support themselves would be able to provide support to the family members who are suffering from HIV/AIDS.

### Limitations of the study

There were a number of limitations to this study. No medical investigations or assessment tools for identifying PN were used. The presence of PN was therefore based on self-report, which could have been exaggerated. In the present study, the critical indicators of disease progression, such as CD4 count and viral load, as well as data on antiretroviral tuberculosis (TB) medication were not assessed. Thus, an association between the progression of the disease and the presence and severity of PN could not be determined. The study population was biased in that it only included those who were actively seeking routine medical care. Those who did not schedule or keep regular clinic visits were not included; consequently, the results of this study cannot be generalised to all HIV patients in the Rulindo district. With regard to the environmental domain of QoL, it is impossible to know how much of the environmental problems experienced were due to the condition of the participants or due to living in an impoverished area. A comparison of the results with the (WHOQOL-BREF) scores for the general population would therefore have been very useful.

### Conclusion

The results provided in this article indicate a high prevalence of neuropathy among PLWH and attending an outpatients' clinic at Rutongo Hospital in the Rulindo district of Rwanda. In addition, patients with neuropathy had lower QoL scores in the physical and psychological domains than those without neuropathy symptoms. The management of PLWH should therefore include interventions to optimise QoL and screening for neuropathy symptoms so that sufferers can liaise with their medical providers to find medical and supportive therapies that could assist them.

For further research, an investigation into CD4, viral load, antiretroviral and TB medication history would be advantageous for a more in-depth analysis of PN in PLWH. In the present study, the researcher established the diagnosis of PN based on the subjects' responses using the SPNS. In future research, objective confirmation of PN, such as nerve conduction studies and grading of severity, may benefit patient management.

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