Clinical Pain Research

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Health-related quality of life and pain interference in two patient cohorts with neuropathic pain: breast cancer survivors and HIV patients

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Abstract

Objectives: Persistent pain is common in HIV patients and breast cancer (BC) survivors. The aim of this study was to compare two patient groups with neuropathic pain (NP) regarding several psychological variables and Health-related Quality of Life. Although, treatment of pain is always planned individually, the knowledge of the differences and similarities between the patient groups may help us to understand more precisely the targets of the interventions for pain.

Methods: Eighty nine BC and 73 HIV patients with symptoms of neuropathic pain (patients with ≥3/7 in the Douleur Neuropathique four interview part (DN4i)) participated in a cross-sectional study. Patients completed questionnaires about mood (HADS), symptoms of insomnia (ISI), pain catastrophizing (PCS), personality (TIPI), Mental and Physical Health-related Quality of Life (M/PHrQoL, RAND/SF-36), and pain intensity and interference (BPI). Analyses were applied by using t-tests and linear regression to assess associations between the studied factors.

Results: HIV patients reported higher anxiety ($p<0.001$), depressive symptoms ($p<0.001$), pain catastrophizing ($p<0.001$) and pain interference ($p<0.001$), poorer sleep ($p<0.001$), and lower HrQoL in all dimensions compared with BC survivors. There were significant differences in personality traits extraversion, emotional stability, and agreeableness between the two patient groups. In HIV patients, pain interference ($\beta=-0.344$, $p<0.001$) and mood ($\beta=-0.580$, $p<0.001$) and in the BC group, mood ($\beta=-0.591$, $p<0.001$), extraversion ($\beta=0.229$, $p=0.005$) and sleep ($\beta=-0.154$, $p=0.042$) associated with MHrQoL. Pain interference (HIV $\beta=-0.645$, $p<0.001$, BC $\beta=-0.491$, $p<0.001$) and age (HIV $\beta=-0.016$, $p=0.042$ and BC $\beta=-0.018$, $p=0.019$) associated with PHrQoL in both groups, and catastrophizing in the BC group ($\beta=-0.303$, $p<0.001$).

Conclusions: HIV patients and BC survivors with neuropathic pain, measured with DN4i, have significant differences in various health-related variables and Health-related Quality of Life with both patient groups reporting low HrQoL. The differences in low HrQoL may reflect the fundamental differences between these diseases, BC survivors in remission and HIV patients living with a chronic disease that is under control. This study brings information about the diversity of different patient populations with symptoms of neuropathic pain, and how neuropathic pain associates with wide range of health-related factors. Interventions to support better coping with the symptoms of neuropathic pain could be tailored more individually if the background disease is taken into account.

Keywords: breast cancer; health-related quality of life; HIV; mood; pain interference; personality.

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Introduction

Chronic pain is one of the leading causes of years living with disability among the working-age population, especially in Western countries [1]. It is well established that pain associates with a wide range of comorbidities, like

mood and sleep disorders, that decrease the quality of life even further.

Pain intensity is a common outcome to evaluate treatment benefits or change over time. Recently, however, it has been noted that the intensity of pain is only one part of the pain experience and in many cases other variables, such as pain interference, may better depict the impact of pain [2, 3]. Furthermore, prior studies have shown that lowered mood and pain catastrophizing associate with higher pain interference and disability [3, 4].

Persistent pain is a common consequence after breast cancer (BC) treatments and a complication of HIV infection and its treatment. Approximations of the chronic pain prevalence vary from 14 to 60% after treatment of BC [5, 6]. Even with the increasing availability of effective antiretroviral therapy (ART), the sensory neuropathy associated with HIV (HIV-SN) is estimated to affect up to 38% of people living with HIV, of which around half report neuropathic symptoms [7]. Up to 20% report significant pain in relation to HIV-SN in the modern ART era [8, 9], yet current therapies have only limited efficacy for the management of symptoms [10, 11].

In chronic and potentially life-threatening diseases like HIV and BC, the cause of pain may be a constant threat or stigma in the patient's mind. The attribution that a patient gives to her/his pain may impact how easily pain attracts attention [12]. The extent to which pain interferes with an individual's daily life likely also reflects other aspects, not just pain intensity.

Health-related Quality of Life (HrQoL) of cancer survivors and HIV patients has become an important issue as improved treatments increase survival [13]. HrQoL is a broad measure of a person's evaluation of his/her health. A Finnish study with tertiary pain clinic patients showed the HrQoL in pain patients to be dramatically lower than that of the general population, and that lower HrQoL associates strongly with psychosocial factors [14]. Personality traits are seen as quite stable in middle-age, although results are conflicting. For example, in chronic pain patients, personality scores have been shown to improve with successful pain treatment [15]. Whereas the model of person-environment transaction highlights the influence of norms, major life-events and social roles in the process of personality changes [16]. Personality features have been suggested to be associated with different health-related outcomes e.g. poor sleep [17]. They also influence how a person copes with different adversities, such as pain, in her/his life [18]. The most frequent finding has been that lower emotional stability (neuroticism) associates with negative mood, unfavorable coping, greater avoidance behavior and less acceptance of pain [18, 19].

A multidisciplinary approach is the gold standard in pain management. The treatment effects from psychological interventions vary from small to moderate on pain and disability [20]. However, rather little is known about how different etiologies of the pain problem influence how a person adapts her/his life. Also, to the best of our knowledge there are no studies that would have addressed the question whether psychological treatments for pain should be tailored differently for different patient groups.

The main aim of the present study was to compare two patient groups with neuropathic pain (NP) having different etiologies, breast cancer survivors with postsurgical NP and HIV-SN patients. The aim was to study Health-related Quality of Life and whether there are different patterns in personality, mood, or pain-related catastrophizing in these two groups.

The second aim was to study whether the psychological factors accounting for health-related quality of life and pain interference are different between these groups. These outcomes were chosen to analyze how patients adapt in their lives when being challenged by different diseases. By understanding the differences or similarities behind unfavorable coping we may be able to design more suitable interventions for these patient groups in the future.

Methods

This study is a sub-study from NeuroPain research collaboration (European Union Seventh Framework Programme (FP7) under grant agreement no 602891). This is a secondary post hoc combination of two datasets.

Breast cancer cohort

The patients for the breast cancer cohort were recruited from a previous study of 1,000 women (aged 18–75 years) operated for breast cancer (BC) at the Helsinki University Hospital during 2006–2010. The patient selection and study procedures of the original cohort have previously been described in detail [21]. The initial current patient cohort consisted of 402 women who were invited for a follow-up research visit to assess factors associating with surgical nerve injury and neuropathic pain 4–9 years later. The protocol for the cohort has been described earlier in detail [2, 22]. To the present study we included a subgroup of women who scored ≥3/7 in the Douleur Neuropathique four interview part (DN4i) [23]. Given that DN4i has proven to be a valid tool in screening components of neuropathic

pain (NP) [24, 25], it was chosen as an inclusion criterion to identify as comparable subgroups as possible from the two patient cohorts (BC and HIV). A second inclusion criterion for BC patients was a surgeon-defined intercostobrachial nerve (ICBN) lesion during breast cancer surgery. Subjects were required to be aged 18–75 years. The study was approved by the Coordinating Ethics Board of the Helsinki and Uusimaa Hospital District (149/13/03/00/14) and registered in ClinicalTrials.gov (NCT02487524). All patients gave informed written consent.

HIV cohort

Patients for the HIV cohort were recruited from HIV outpatient clinics associated with Chelsea & Westminster NHS Foundation Trust and by advertisement to national HIV charities (December 2014–August 2017). Subjects were required to be aged 18 or older and have a serological diagnosis of HIV. Full inclusion and exclusion criteria and methods for the HIV POGO study are outlined in Kemp et al. (Submitted for peer-review August 2020). In addition to DN4i score ≥3/7, only subjects displaying one sign and one symptom on the Clinical HIV-associated neuropathy tool (CHANT), as a case definition of neuropathy [26] were included. The study was approved by England's National Research Ethics Service (14/LO/1574).

Demographic factors and questionnaires

In both groups, all patients completed questionnaires about their background information: age, gender, height and weight, education, smoking, alcohol consumption, and illicit drug use.

The Douleur Neuropathique four interview part (DN4i) was administered to assess neuropathic components of pain [27]. The DN4i consists of seven items with a categorical yes-no scale. Patients are asked to describe her/his pain after two questions as follows; 'Does the pain have one or more of the following characteristics? (1) burning, (2) painful cold, (3) electric shocks'. Is the pain associated with one or more of the following symptoms in the same area? (4) tingling, (5) pins and needles, (6) numbness, (7) itching. We considered scores ≥3 for DN4i as cut-offs for suggestive NP, i.e. a positive screening outcome [27].

To evaluate the intensity and the interference of any pain during the past week we used *the Brief Pain Inventory (BPI)* long form [28]. The pain intensity variable was formed by calculating the mean of "the worst pain", "the mildest pain", "the average pain", and "pain at the moment" items. The "pain interference" variable was the mean of the last seven items from the questionnaire: How much does the pain interfere with function, mood, walking, working, relationships, sleeping, and life satisfaction. In the BC cohort the patients filled in the BPI separately for any pain and the pain in the surgical area. The highest value from either questionnaire was selected for the analyses. In the HIV cohort, the questionnaire was completed to describe any pain the patient may experience.

Hospital Anxiety and Depression Scale (HADS) [29] was used to assess both depressive symptoms and anxiety. A sum score of all items (varying from 0 to 21) was calculated, higher scores indicating higher amount of symptoms, referred in the text as "mood". *Pain Catastrophizing Scale (PCS)* sum score (varying from 0 to 52) was used to assess pain-related catastrophizing, where a higher value refers to a higher tendency for catastrophic thinking [30]. *Insomnia Severity Index (ISI)* [31] was used for assessing symptoms of insomnia (scores varying from 0 to 28) higher scores indicating more severe symptoms. *Ten Point Personality Inventory (TIPI)* [32] was used to assess personality traits. The Big-Five framework is a hierarchical model of personality traits with five broad factors suggesting that most individual differences in personality can be classified into five domains (Agreeableness, Emotional Stability, Extraversion, Openness to Experience, Conscientiousness). Scores vary from 0 to 7, where a higher score indicates a stronger profile for the factor in question.

Health-related Quality of Life (HrQoL) was assessed with the SF-36 (UK)/RAND-36 (Finland) questionnaire [33, 34]. This inventory has been developed to measure the quality of life in patients having chronic morbidities. It includes 36 items from which eight health-related dimensions are formed (physical function, role function physical, role function emotional, energy, emotional well-being, social function, painlessness, general health). A higher value indicates better performance in the dimension. Dimensions for Physical (PHrQoL) and Mental Quality (MHrQoL) of Life were formed according to the directions of the manual [33, 34] by calculating the mean value of the four dimensions. PHrQoL (physical function, role function physical, painlessness, general health) and MHrQoL (role function emotional, energy/fatigue, emotional wellbeing, social function).

Statistics

SPSS software version 22.0 for windows (SPSS Inc, Chicago, IL) was used to conduct the statistical analyses. The estimation of normality of the distributions were done by estimating skewness and kurtosis of all variables separately for both cohorts. t-tests (two-tailed) were applied to compare the variable distributions between the patient groups.

Independent variables were entered to a linear stepwise regression analysis to assess association with the outcome variables (MHrQoL, PHrQoL, and Pain interference). All models included the following independent variables: age (in years), Body Mass Index (BMI), symptoms of insomnia (ISI), Pain Catastrophizing (PCS), mood (HADS), and pain severity (BPI). Pain interference (BPI) was included as an independent variable for both HrQoL variables. The personality traits agreeableness, extraversion and emotional stability (TIPI) were included into the model since the mean differences were statistically significant between the studied groups. At each step, the variable with the highest p-value was eliminated until the remaining variables had p-values ≤0.05. Statistical tests with p≤0.05 were considered statistically significant.

Results

Eighty nine women with neuropathic pain due to BC treatments and 73 subjects with HIV sensory neuropathy (HIV-SN) (64 men, nine women) were included in this analysis. The small number of women in the HIV cohort does not allow statistical comparison between men and women with HIV.

In the BC cohort, 5.6% (n=5) had the school level education, 52.8% (n=47) foundation or honors degree, and 29.2% a postgraduate degree (n=26). There were 12.4% (n=11) missing answers. 18% (n=16) of the patients reported current smoking, 42.7% (n=38) had never smoked, 34.8% (n=31) were previous, and 3.4% (n=3) occasional smokers. None of the BC patients reported previous or current illicit drug use. 19.1% (n=17) of the patients, reported no alcohol use, 61.8% (n=55) reported <6 units per week, and 17.9% reported ≥6 doses per week.

In the HIV cohort, 37.0% (n=27) had the school level education, 15.0% (n=11) foundation degree, 27.4% (n=20) an honors degree, and 20.5% (n=15) a postgraduate degree. Of the patients, 23.3% (n=17) reported current smoking and 54.8% (n=40) were previous regular smokers. Current illicit drug use was reported by 17.8% (n=13) and previous use by 57.5% (n=42). 20.5% (n=15) of the patients, reported no alcohol use and 79.5% (n=58) reported regular alcohol use, from which 41.4% (n=24) reported at least six units per week.

Descriptive statistics and the results of univariate comparisons between groups (HIV and BC patients) for the analyzed variables are shown in Table 1 and Figures 1 and 2.

Total sum of HADS was used in regression analyses to avoid multicollinearity between depressive symptoms and anxiety subscales. Distributions for both depressive symptoms and anxiety dimensions separately are shown in Table 1. HIV patients reported a significantly higher amount of depressive symptoms, anxiety, pain catastrophizing, and symptoms of insomnia (Table 1). They also scored lower in three personality traits: agreeableness, emotional stability, and extraversion (Figure 1). HIV patients reported both higher pain intensity and interference (Table 1). The mean value of the DN4i score was higher in the HIV group than in the breast cancer patient group (4.9 sd 1.2 vs. 4.1 sd 0.95 p<0.001, respectively). Analyses of covariance (ANCOVA) was performed to control pain intensity in group comparisons for each independent variable. Group differences remained significant with covariates in the model. Therefore, for clarity, the t-test results are shown in the Results section.

Table 1: Descriptive statistics and group comparisons between HIV and BC patients.

		n	Mean	SD	p-Value
Age, years	HIV	73	56.8	8.3	0.094
	BC	89	58.9	7.7	
BMI	HIV	72	24.9	4.1	0.014
	BC	89	26.5	4.3	
Symptoms of insomnia, ISI	HIV	64	15.6	6.6	<0.001
	BC	86	9.0	5.8	
Catastrophising, PCS	HIV	63	22.4	14.2	<0.001
	BC	88	10.3	10.0	
HADS, total	HIV	64	18.8	8.9	<0.001
	BC	88	9.7	6.9	
Anxiety, HADS	HIV	64	9.9	5.2	<0.001
	BC	88	5.6	3.6	
Depressive symptoms, HADS	HIV	64	9.0	4.5	<0.001
	BC	88	4.2	3.8	
Physical HrQoL	HIV	61	31.3	25.0	<0.001
	BC	82	63.5	22.9	
Mental HrQoL	HIV	60	40.8	23.1	<0.001
	BC	83	67.4	23.0	
Pain intensity, BPI	HIV	64	4.2	2.6	<0.001
	BC	89	2.4	1.9	
Pain interference, BPI	HIV	64	5.4	2.8	<0.001
	BC	89	2.1	2.2	

BC, breast cancer; BMI, body mass index; BPI, brief pain inventory; HADS, hospital anxiety and depression scale; ISI, insomnia severity index; PCS, pain catastrophizing scale; SD, standard deviation; HrQoL, health-related quality of life.

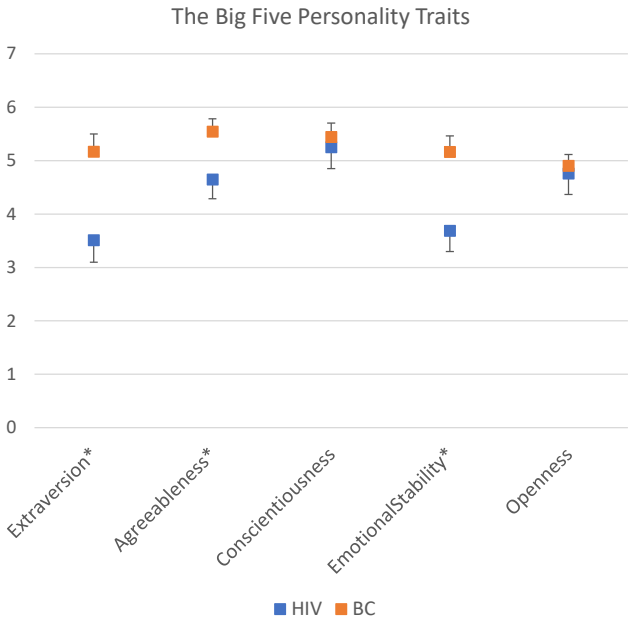

Figure 1: The distributions of the big five personality traits (TIPI) mean values and standard deviations. Asterisks denote significant group differences *p<0.001. BC, breast cancer; HIV, human immunodeficiency virus.

Means and confidence intervals (CI) for personality traits are shown in Figure 1. Figure 2 displays the mean values with 95% CI for the dimensions of quality of life in both groups. HIV patients both MHrQoL and PHrQoL were significantly lower compared with BC sample (Table 1, Figure 2).

We observed a positive correlation between anxiety and catastrophizing in the HIV group ($R^2 = 0.41$, n = 73, 95% CI 0.20–0.58) but not in the BC group ($R^2 = 0.14$, n = 89, 95% CI −0.07 to 0.34) (Figure 3).

Table 2 displays the significant variables of the final linear regression analyses for both groups and for all three outcomes. Mood (total HADS score) associated negatively with mental quality of life in both groups. Regression coefficients for HADS were approximately the same in the HIV and BC groups (β=−0.580, p<0.001 and β=−0.591, p<0.001, respectively). Lower pain interference associated with better mental quality of life in HIV patients (β=−0.344, p<0.001 of). In the BC group, higher extraversion and a lower amount of symptoms of insomnia associated with better mental quality of life (β=0.229, p=0.005 and β=−0.154, p=0.042, respectively).

Younger age (HIV β=−0.016, p=0.042 and BC β=−0.018, p=0.019) associated with better physical quality of life in both groups and better mood (β=0.334, p<0.001) in HIV patients. However, lower pain interference explained the majority of the total variance of physical quality of life in both groups (HIV β=−0.645, p<0.001, BC β=−0.491, p<0.001). Higher pain catastrophizing associated with lower physical quality of life in the BC group (β=−0.303, p<0.001).

In both groups, higher pain severity (HIV β=0.654, p<0.001 and BC β=0.766, p<0.001) and higher amount of mood disturbance (HIV β=0.271, p=0.002 and BC β=0.225, p<0.001) associated with higher pain interference. In the BC group, higher pain catastrophizing also associated with higher pain interference (β=0.103, p=0.042).

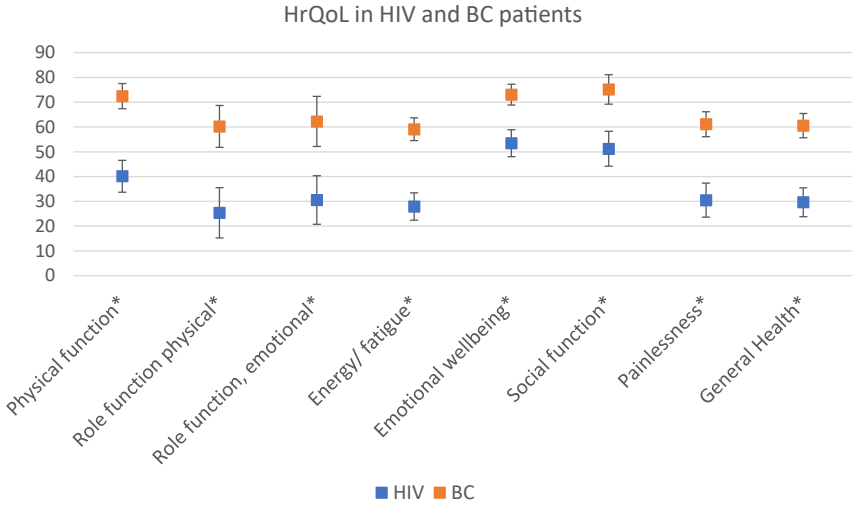

Figure 2: Mean values and 95% CIs for the dimensions of health-related quality of life (HrQoL) in HIV and breast cancer (BC) patients. HIV, human immunodeficiency virus. Asterisks denote significant group differences *p<0.001. Scale varies between 0 and 100.

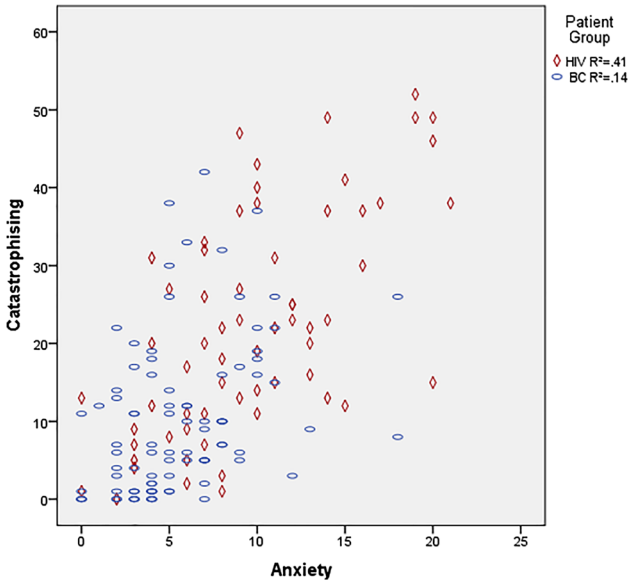

Figure 3: Association between pain catastrophising (PCS) and anxiety (HADS-A) in HIV and breast cancer (BC) patients.

The studied variables explained R^2=0.693 and R^2=0.639 of the total variance of Mental Quality of Life, R^2=0.728 and R^2=0.577 of physical Quality of Life and R^2=0.680 and R^2=0.855 of pain interference in HIV and BC patient groups, respectively.

Discussion

This study shows significant differences, but also similarities between HIV patients and breast cancer (BC) survivors with neuropathic pain. HIV patients performed much worse in all studied health-related outcomes. They reported higher anxiety, more depressive symptoms, and poorer subjective sleep quality. They reported higher pain catastrophizing and pain interference. They also reported dramatically lower Health-related Quality of Life in all dimensions. There were significant differences also in three personality traits. However, factors associating with physical and mental HrQoL and pain interference were to some extent similar in these groups.

Both HIV and breast cancer survival patients commonly present chronic pain. Of pain variables, pain interference has recently presented possibly more accurate than traditional pain intensity [2, 3]. In this study, pain-related interference was a more prominent indicator of Health-related Quality of Life (HrQoL) than pain intensity. Correlation between pain interference and intensity was expectedly high (HIV r=0.79, BC r=0.89), but only interference had a significant independent effect on both mental and physical HrQoL. In line with earlier evidence, negative effect (in this study the sum score of depressive

Table 2: Significant associations in linear regression models between the studied variables, health-related quality of life and pain interference in HIV and BC patient groups.

Mental HrQoL					
Patient group		Stand. beta	*t*	Sign.	Adj. R^2
HIV	Mood, HADS	−0.580	−6.24	<0.001	
	Pain interference, BPI	−0.344	−3.71	<0.001	0.693
BC	Mood, HADS	−0.591	−7.07	<0.001	
	Extraversion, TIPI	0.229	2.89	0.005	
	Symptoms of insomnia	−0.154	−2.07	0.042	0.639
Physical HrQoL					
		Stand. beta	*t*	Sign.	Adj. R^2
HIV	Pain interference, BPI	−0.645	−7.23	<0.001	
	Age	−0.160	−2.08	0.042	
	Mood, HADS	−0.334	−3.48	0.001	0.728
BC	Pain interference, BPI	−0.491	−5.35	<0.001	
	Age	−0.183	−2.40	0.019	
	Catastrophising, PCS	−0.303	−3.34	0.001	0.577
Pain interference					
		Stand. beta	*t*	Sign.	Adj. R^2
HIV	Pain intensity, BPI	0.654	7.64	<0.001	
	Mood, HADS	0.271	3.16	0.002	0.680
BC	Pain intensity, BPI	0.766	16.10	<0.001	
	Mood, HADS	0.225	4.78	<0.001	
	Catastrophising, PCS	0.103	2.07	0.042	0.855

The results of linear regression model. HADS, hospital anxiety and depression scale; HrQoL, health-related quality of life; BPI, brief pain inventory; TIPI, ten item personality inventory; PCS, pain catastrophizing scale; BC, breast cancer; HIV, human immunodeficiency virus.

symptoms and anxiety) was highly associated with both pain interference and HrQoL [4, 14].

Pain catastrophizing questionnaire defines negative coping responses to a pain experience. There are items of magnification, rumination, and feelings of helplessness. Pain catastrophizing has found to correlate to pain-related disability and adjustment in patients with NP [35]. In a previous review article, the authors concluded that elements of catastrophizing are very close to other variables of negative affect [36]. Rumination is an important component of both anxiety and catastrophizing [37]. In this cohort of two NP patient groups, pain catastrophizing did not remain significant in the final regression models in the HIV patient group. However, pain catastrophizing may still present an important factor behind unfavorable coping. It can be hypothesized that living with a disease which is under control but not cured (HIV), compared with the disease that is in remission (BC), generates more rumination and awareness of the symptoms of the disease. In the present study, covariance between catastrophizing and anxiety was high especially in HIV patients (Figure 3). In BC patients, in whom both mood disturbances and catastrophizing were quite modest, each of them add their share to the total variance of pain interference and physical HrQoL. On the other hand, in HIV patients the total amount of mood disturbances probably cover also some of the pain-related catastrophizing.

The results of the present study suggest that pain catastrophizing may not entirely be a within-individual quality, but also the etiology of pain may have an impact on its intensity as also suggested in a recent meta-analysis [38]. The average score of pain catastrophizing was significantly higher in HIV patients than in the BC cohort. The role of catastrophizing tendency in different pain patient populations needs to be addressed in future studies. Post-surgical NP in BC patients is quite localized in the surgical and nearby area. Although painful HIV-SN is usually located in lower extremities, multisite, and multiaetiology pain is common [39, 40]. Furthermore, HIV as a disease may hold a stigma and have an influence on how threatening a person perceives his/her pain. The nature of pain related to HIV-SN may be perceived differently than chronic postsurgical pain in BC patients.

HrQoL has previously been shown to be very low in chronic pain patients in a Finnish tertiary pain clinic population [14] and pain patients in UK population [41]. An earlier study comparing the HrQoL of HIV patients with that of patients with rheumatoid arthritis and diabetes, also showed that HIV patients had a lower mental HrQoL [42]. Here, the overall HrQoL in both studied patient cohorts was lower than in the corresponding general population [33, 43], and in patient cohorts without pain [41, 44]. Further, the HrQoL in HIV patients was dramatically lower in all dimensions compared with BC patients. Both physical and mental components of HrQoL of the present HIV population were lower even when comparing with earlier studies with HIV patients [45]. One possible explanation could be that the inclusion criteria for our current study included DN4i as a screening instrument for NP (DN4i score ≥3). This could suggest that painful HIV-SN patients have a much poorer HrQoL compared with non-painful HIV-SN. NP has been associated with lower HrQoL in earlier studies [46, 47]. The present results may also reflect social stigma in HIV, which is shown to associate with poorer HrQoL, especially mental HrQoL in HIV patients [42]. To our knowledge, there is no previous study about the experience of stigma in Finnish breast cancer patients. However, it may be hypothesized that it is not an issue among breast cancer patients.

Personality profiles differed statistically in three dimensions: The HIV cohort reported less emotional stability, agreeableness, and less extraversion. The average score differed especially in emotional stability and extraversion. Although HIV infection affects a more diverse population than in the past, still in the majority of cases, the infection is acquired through sexual contact and a small proportion occurs through use of injected illicit drugs. Over 40% of those living with HIV in the UK are gay/bisexual men and our study cohort showed a high proportion of men, although data on sexuality was not specifically collected. Although some studies have aimed to identify links between sexual orientation or risky sexual behavior and personality type, findings are often conflicting [48]. Certain patterns of substance misuse appear to be linked to certain personality types [49] and this cohort of HIV patients reported a high level of previous or current substance misuse, whereas in the BC cohort none of the women reported substance misuse. Therefore, differences found in the personality profiles may be associated in part with other potentially confounding sociodemographic factors prevalent in a higher proportion in the HIV cohort that were not accounted for in the model.

The differences in personality between the present cohorts may partly be explained by gender distributions. All BC patients were women and the majority of HIV patients were men (87.7%). In a large multicultural study looking for sex differences between personality traits, the authors found agreeableness, extraversion, and conscientiousness to be higher among women compared with men. However, in contrary to our results, women also reported higher neuroticism (lower emotional stability) across nations compared with men [50].

Although the core of personality is considered quite stable in the middle-aged populations [51] personality has also been suggested to evolve throughout the life-course [51, 52]. The model of person-environment transaction highlights the influence of norms, major life-events and social roles in the process of personality changes [16]. On the other hand, it has been suggested that personality also guides which kind of life-events a person is likely to experience e.g. neurotic (low emotional stability) individuals have a higher probability to face negative and extraverted individuals more positive life-events [53]. A large prospective study found that major life-events had no influence on personality, but personality had an effect on which kind of life-events a person faced. However, the studied life-events did not include severe disease [52].

The nature of the present study does not allow the study of causality on personality change and the disease. Our findings suggest a need for further research to find out whether experience of a severe disease (like HIV and cancer) can modify personality and whether this could have a role in the process of pain persistence and coping.

The average level of extraversion was higher in the BC group and was also associated with better mental HrQoL. Extraversion has previously been shown to relate positively with perceived social engagement [54], which has been an important factor behind various positive outcomes in breast cancer studies [55]. The role of social support for mental health has been suggested to be more pronounced in women compared with men [56]. Also, the self-rated quality of sleep associated with MHrQoL in the BC group. Sleep disturbances are common in both BC patients [57] and patients with pain [58]. Sleep is a good target for interventions to improve HrQoL [58].

Limitations

Group sizes in the present cohort are quite modest. However, the DN4i screening tool and detected nerve lesions behind the symptoms bring similarity to the selected patients from the HIV and BC cohorts and make them comparable. The results should be tested with bigger sample in future studies and also with patients with both genders.

This is a cross-sectional study and we cannot say if the primary disease or the treatments (anti-retroviral therapy for HIV and chemotherapy in BC) have changed personality (or catastrophizing tendency) in the two very different patient cohorts. Ethnicity of the patients was mixed in the HIV cohort, whereas all BC patients were Caucasian women. These differences may explain the results of this study to some extent. Gender differences in symptom burden have earlier been reported in HIV patients [59].

A questionnaire about the experiences of stigma would have brought more insight of the differences of the studied cohorts. This would be an interesting issue to address in future studies.

Conclusions

Patients with NP of two different etiologies (BC and HIV) represent two very heterogeneous groups even with the same DN4i scoring, regarding especially pain catastrophizing, sleep disturbances, and personality. HIV-SN patients had significantly lower HrQoL compared with BC patients. Pain interference and HrQoL showed similar negative associations in the groups. The burden of the disease may bring more challenge to treatment interventions. Targeted interventions to treat specific symptoms e.g. pain acceptance, sleep interventions, and active coping may be of importance.

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