Re-examining Patient- and Provider-Reported Symptoms among HIV Population

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**Background:** Symptoms are associated with health care utilization, lead the physician towards a differential diagnosis and function as prognostic factors to guide therapy. Moreover, symptoms directly impact patient’s perceived health-related quality of life and mediate medication adherence as they are a mode through which the patient commonly experiences adverse drug effects. Although it is the patient who experiences the symptoms, it is only those recognized and reported by the provider that count in many clinical and research settings. The dependence on provider report of symptoms has been justified by the assumption that providers recognize and report the *clinically important* symptoms. Previous work among patients with HIV has found that providers are not good at recognizing symptoms and that patient report correlates more closely with outcome measures (Justice et al. 397-408). This work, however, was limited as the symptom questions were not identical and patients were enrolled prior to the widespread availability of antiretroviral therapy (ARV) and its associated changes in symptom type and frequency.

**Specific Aim:** Compare the clinical importance of provider- and patient-reported symptoms using data from the Veterans Aging Cohort Study and further characterize patient symptoms in the setting of widely available ARV therapy.

**Hypothesis:** Using patient-report as the gold standard, providers will be limited in recognizing patient symptoms and patient-report will have a stronger association with clinical variables, such as health-related quality of life, survival, and previous hospitalization.

**Methods:** We relied on data from the Veterans Aging Cohort 3 Site Study (VACS 3), a longitudinal, observational study of HIV-infected veterans. Baseline survey data was collected from June 1999 through July 2000. Participants self-completed a HIV symptom index. Providers were presented exactly the same list of symptoms with the same phrasing and asked to identify the symptoms that the patient had experienced over the prior 4 weeks. To assess health-related quality of life, the SF-12 was used. Demographic data, viral load, CD4 count, and information about prescribed medications were collected through the electronic medical record. Data was further confirmed through survey data and pharmacy records as applicable. Outcomes, including hospitalization and mortality, were assessed through the providers, electronic medical record and the VA BIRLS Death File. Statistical analyses were completed using SAS, v9.1.3.

**Results:** Among the 1,038 HIV-infected veterans receiving care at the three sites, 881 (85%) of patients participated in the study. Of the 881 patients, 99% were male, a mean of 49 years old, and 54% were African American. The mean CD4 count was 331 cells/mm$^3$ and mean viral load was 714 RNA copies. Provider-reports had poor sensitivity (range 3.6 – 56.6), good specificity (range 66.8 – 98.5), moderate PPV (range 55.6 – 83.5), and poor NPV (range 39.2 – 70.4). Kappa scores for the presence or absence of a symptom ranged from 0.03 to 0.23, for hair loss or change and diarrhea, respectively. Patient symptom scores more strongly predicted HRQOL for both physical (-2 log likelihood of 5349 and 5444 for patient and provider, respectively) and mental health scores (-2 log likelihood of 5486 and 5710 for patient and provider, respectively). In contrast, provider symptom scores more strongly predicted survival (-2 log likelihood of 2811.02 and 2786.38 for patient and provider, respectively) and hospitalization (-2 log likelihood of 5771.17 and 5741.75 for patient and provider, respectively).

**Conclusions:** Providers perform poorly at reporting patient symptoms and, as expected, patient-report more strongly predicts HRQOL measures. Surprisingly, although providers report patient symptoms in a limited fashion, their report more strongly predicted survival and hospitalization. Future studies will be aimed at subgroup analysis to further characterize the patient population in the post-ARV era and to identify factors that may affect provider-patient communication.